Augmentative and Alternative Communication and Severe Disabilities: Beyond Poverty

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Contents

The purpose of this book is not to try to come to short-term solutions to the many problems facing those in developing countries, but rather to share on a more formal level the ideas on intervention and research issues in an effort to enhance discourse in the field. Hopefully the nature of the exchanges will enable interventionists and people with disabilities in developed and developing contexts to move closer together in an effort to build a more friendly global community for all.

Erna Alant
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Note

Throughout the book the terms 'low-income countries' and 'developing countries' are used interchangeably.

CHAPTER 1
Introduction

ERNA ALANT AND LYLE L. LLOYD

AAC – beyond poverty

This chapter provides a brief description of the rationale for the book and the theoretical framework used as a basis for discussions. This is followed by outlines of the chapters.

The impact of poverty and cultural issues on rehabilitation and intervention practices has been discussed increasingly in literature related to disability and implementation. These discussions largely centre on the description of the problems and challenges facing interventionists who work in areas with minimal resources. Very few publications have ventured beyond the description of the problem.

Although a fundamental understanding of challenges is needed for sound intervention, much of the rhetoric in community-based intervention in industrialized and low-income countries has become repetitive. Lack of sustainability of services, lack of infrastructure for the use of technology, inaccessibility or unavailability of services are but a few of the issues on the table (Alant and Emmett, 1995; Alant, 1999). Some innovative strategies have been developed in coping with community-based intervention programmes based on the training of parents and community people. Although these programmes have been successful to some extent, most of them reflect a tendency either to be very comprehensive, with poor focus, or very specific, with a strong focus on skill training but with limited long-term impact.

The basic underlying tension between comprehensive and selective intervention services (Rifkin and Walt, 1986) therefore is clear. How does the interventionist cope with the demands of a community-based intervention approach (which is generally more comprehensive) while ensuring that the individual's progress and achievement (which form the

main impetus of the intervention approach) are not totally de-empha-
sized? Can we really afford to put children's development, or people with
disabilities' intervention, on hold until the communities have become
more empowered to cope with intervention and rehabilitation? How does
one move beyond these and the cultural dilemmas facing intervention?
The ethical issues surrounding intervention within poverty contexts are
evident and should always remain in the foreground to ensure responsi-
ble decision-making.

The above issues and tensions are also most real in the field of severe
disabilities and augmentative and alternative communication (AAC)
implementation. Not only do AAC interventionists have to cope with the
issue of how to implement different modes of communication to impact
the individual's life; ensuring long-term support across the lifespan for
individuals and families in different cultural contexts also presents many
challenges. Apart from ongoing support for implementation, effective
communication often requires the use of light- and/or high-technological
assistive devices. Issues surrounding appropriate technology therefore
are central to AAC implementation, particularly in poverty and/or diverse
cultural contexts.

There is thus a need for the exploration of new, innovative ideas to extend
our thinking and understanding of the fields of disability and AAC to more
specifically include intervention in poverty and diverse cultural contexts.

This book therefore aims to identify and discuss issues relating to inter-
vention in the fields of severe disabilities and AAC within the context of
poverty. Why have a book specifically on poverty and AAC intervention?
This clearly is an important question to keep asking, because it is one way
in which we can deepen our understanding of the differences and simi-
larities between industrialized and low-income countries, urban and
rural, as well as diverse cultural contexts.

Inherent in this question is the assumption that one can, for example,
clearly differentiate between industrialized and low-income countries or
contexts. Obviously, this is not an uncomplicated matter; neither is the
assumption sound that countries in either group are homogeneous in any
way. However, while acknowledging differences between countries and
geographic contexts, it is important to identify commonalities to enhance
professional reflection and understanding of the impact of environments
on disability and intervention efforts.

Poverty, social inequalities, adverse health conditions and human rights
violations have all been closely associated with countries with developing
economies. Devastating pandemics like HIV/AIDS, as well as a revival of
tuberculosis, pose the most serious challenges ever to face some of these
contexts. These countries have to deal not only with different levels of
poverty, lack of education and social infrastructure but also with the
extreme trauma to individuals, families and communities induced by
HIV/AIDS.

Basic needs in terms of human survival, nutrition and shelter remain a
pivotal first phase to enable individuals to grow and develop. The prem-
ise is that only when these needs have been met can societies really
become concerned with quality-of-life issues. This notion is based on a
definition of basic needs as separate from quality of life and thus hierar-
chically basic to the development of quality of life.

The acceptance of an interrelatedness between quality of life and basic
needs therefore constitutes one of the major criticisms of the 'basic needs'
approach to community development prevalent in the 1960–70s. What is
the definition of a basic need and whose basic needs are they? If we accept
the diversity in communities (not only culturally, but also socio-economi-
cally), the concept of basic needs becomes more challenging. A more
flexible approach acknowledging the dynamic nature of the concept of
basic needs based on an interaction between quality of life and needs of
individuals within a community has become prevalent – that of focusing
on people and communities, rather than on basic needs. Burkey (1993),
in his book *People First*, emphasizes the need for community develop-
ment to be viewed on three pillars: personal, social and economic
development.

This implies that personal development of the individual is the basis for
further community development. Personal development includes the abil-
ity of individuals to rise above their context by being able to self-reflect
and gain control over their own lives. The individual therefore becomes
independent to interact and cope within the community. Should the indi-
vidual not be able to attain this level of independence, it would impact on
the family's ability to reach out and participate in community activities in
a variety of ways.

In congruence with the emerging theoretical concepts in AAC, this
book emphasizes issues related to:

- evidence-based practice, particularly in relation to issues of sustain-
  ability and quality of services and training;
- the complexities involved in understanding the association between
  disability, poverty and intervention;
- the influence of culture and socio-economic issues on communication,
  and also the use of AAC strategies to facilitate interaction in particular;
- the importance of a support-based approach to AAC intervention by
  focusing on the immediate support network of the individual, but also
  expanding the notion of intervention as a basis for community devel-
  opment by emphasizing 'the common good' and the broader impact of
  the process;

• AAC technology as an integral part of community development, as families, manufacturers, distributors and communities need to problem-solve challenges to enhance long-term use of these devices.

An overview of the chapters

Chapter 1 provides a brief background to the theoretical framework of the book, focusing on poverty and AAC intervention. The need for a book on this topic is explained by alluding to the dilemma of sustainability of services within environments with limited social support structures for intervention.

Chapter 2 sets the scene by providing an overview of issues related to intervention, and AAC intervention in particular, by describing the need for interventionists to move beyond a needs-based approach. Needs-based approaches to intervention focus on the gap between what is and what should be (deficit model) rather than addressing and extending existing resources in dealing with challenges. An asset-based or resource-based approach, on the other hand, provides interventionists with an alternative way to address and build capacity to deal with challenges by moving beyond the confines of the therapy room. A critical discussion of both a needs-based and asset-based approach to intervention culminates in a description of the basic components proposed for describing intervention, i.e. effectiveness, sustainability and versatility. These components highlight the need to look at the impact of intervention. Finally, two elements of communication are identified, namely participation and involvement, and their importance in AAC intervention is discussed.

Chapter 3 introduces the reader to the field of AAC by addressing selected aspects of AAC strategies and intervention. The purpose of AAC is highlighted as a means of supplementing existing communication of the individual. The communication model is discussed with reference to the relevance of this model for AAC users. Thereafter, different strategies that can be used to augment or supplement speech are discussed, including both aided and unaided systems. Apart from the symbols used in AAC, the technical aids that can be used to facilitate communication are briefly discussed to provide a broad overview of AAC strategies. The populations in need of AAC are considered. The communication process for a person using AAC is described, highlighting challenges and solutions. Finally, the challenges inherent in the AAC intervention process – in general and within low-income contexts – are discussed.

Chapter 4 describes the relationship between poverty and disability, in an attempt to enhance understanding of clinicians in providing intervention within poverty contexts. The link between poverty, disability and development (e.g. social, economic, educational and health) is emphasized

to provide a comprehensive background for intervention, particularly also within low-income countries. The chapter starts off by defining the concept of poverty by emphasizing the multidimensionality of the concept. Apart from income and consumption, poverty includes 'multiple interlocking dimensions' associated with human development, vulnerability and risk, isolation, powerlessness and social exclusion. After defining the concept, the relationship between poverty and disability is discussed by acknowledging that disability can be seen as both a cause and a consequence of poverty. The discussion on the movement from poverty to disability, as well as from disability to poverty, culminates in a visual representation, which aims to depict this complex set of interactions graphically. In conclusion, the implications of the links between disability and poverty are highlighted, particularly in low-income countries where poverty is so pervasive.

Chapter 5 describes cultural and socio-economic influences on communication by focusing on the process of symbolic interaction. Semiotic mediation is discussed as a background to understanding the relationship between symbols and their interpretations within context. Visual perception and comprehension are described in relation to the influence of culture on this process. More specifically, the chapter also describes pictorial comprehension as a basis for understanding the impact of cultural and socio-economic differences on the communication process.

Chapter 6 discusses selected issues in using graphic symbols in different language and social contexts, and explores different variables that might impact on first exposure and learnability of graphic symbols. Over the years, a variety of studies have been conducted on topics related to graphic symbols, their characteristics, comparative ease of recognition and learnability as well as their use in intervention (see Lloyd et al. (1997) for a comprehensive list of studies). As most of these studies were conducted within industrialized countries, this chapter aims to augment existing knowledge in graphic symbol research by discussing selected research studies conducted in different language contexts. The purpose is therefore not to present a comprehensive overview of graphic symbol learning, but rather to stimulate discussion by introducing selected studies conducted in low-income contexts. First, issues surrounding cross-cultural investigations are discussed, focusing on the issue of equivalence between the different data sets. Thereafter, the focus is on culture-specific research studies in graphic symbols conducted in India and South Africa. Discussions focus on the error analyses of the studies and explore potential reasons for participants' varied responses. The chapter concludes with the development of a clinical procedure for guiding the interventionist in understanding ways in which clients can interpret graphic symbols as a background to facilitate intervention.

Chapter 7 deals with issues related to service delivery in the broader sense as well as in AAC intervention, particularly within low-income contexts. Different levels of service provision are discussed, i.e. primary, secondary, tertiary and prevention. Service shortcomings are discussed as well as the challenges encountered in bridging specialist, primary and secondary services. A variety of strategies are outlined in meeting the challenges of service delivery in low-income countries.

Chapter 8 describes a support-based approach to AAC intervention by using an integration of the resource-based approach (Dunst et al., 1988) and the asset-based approach (Kretzmann and McNight, 1993). These two approaches are compared and used as a framework for the development of a support-based approach to AAC intervention. This approach identifies the immediate support network of the individual, as well as broader community supports, as an integral part of the AAC intervention process. The principles of the support-based AAC community intervention approach are described and case studies are used to facilitate the visualization of the intervention process. Principles of a support-based AAC intervention approach are discussed and the chapter concludes with the identification of challenges relating to the approach.

Chapter 9 deals with issues surrounding the use of assistive technology (AT), in particular AAC technology within a low-income context. It starts off by describing the problems and exploring issues relating to the integration of technology as part of development within communities, by using the model by Reidijk (1987). Some additional intervention models currently in use in the field of AAC are discussed as a background to the proposed model. The proposed model, which is based on a support-based approach to intervention (see Chapter 8: Support-based AAC intervention), focuses on the importance of sustainable infrastructure development (training and maintenance) for the use of AAC technology within a specific community, in addition to a family-centred approach towards implementation of assistive technology. A case study is used in an attempt to illustrate relevant issues to implementation within low-income countries. Challenges of assistive technology implementation in low-income countries are discussed and, in conclusion, the need for further debate and research in this field is emphasized.

Chapter 10 describes a family-centred early childhood intervention approach to intervention by describing an international as well as poverty perspective. The different roles of the family within the intervention process are described, i.e. the family as decision-makers, the family as communicative environment, the family as consumers and the family as trainers. The different roles and tasks assigned to the family, as well as the goals for intervention, are discussed in relation to the effectiveness, sustainability and versatility of communication intervention. Finally, the focus

chosen for intervention has consequences for both the desired outcome of intervention and the role assigned to the family. Accordingly, the impact of communication intervention on the family system will be dependent upon the focus for intervention and the family perception of needs for support.

Chapter 11 focuses on multiskilling as a means to equip people working in the health and educational context to function in a transdisciplinary manner when performing AAC intervention. Issues that will be discussed include defining the concept by looking at four multiskilling dimensions and the aspects that should be addressed in each of these. This is followed by a discussion of why multiskilling is regarded as critical in enhancing AAC intervention, as well as the challenges associated with multiskilling, such as quality assurance of intervention, professional registration (and associated liability and accountability issues), supervision etc. Finally two programmes developed to train nurses and teachers in how to facilitate communication and play of individuals with little or no speech will be discussed as examples of transdisciplinary training approaches.

Chapter 12 discusses the importance of peer learning and participation in AAC intervention by describing children's need for social interaction and, in particular, the need for AAC users to be involved in peer interactions. Peer training in AAC research is discussed by referring to various intervention studies. As a follow-up to this discussion, a peer programme is discussed which is aimed at training the peer group of an adolescent AAC user in communication. This programme describes pre- and post-measures and provides some data on the outcomes of the study. Challenges of peer training are discussed and research implications are highlighted.

Chapter 13 deals with practical issues in facilitating AAC implementation in the classroom by describing ways of integrating augmented language stimulation within the general classroom. An example of a project conducted within schools for children with special needs is described by explaining the objectives and training process. The training outcomes are described by focusing on two teachers who were involved in both phases of the project, i.e. the group training as well as the in-situ classroom training. The difference in perceptions of abilities between trainees and trainers on initial evaluation is discussed, together with other observations, to provide a basis for the evaluation of the training.

Chapter 14 deals with advocacy and leadership issues by describing self-representation and strategies for strengthening self-presentation of individuals with disabilities. The chapter focuses on the formation of service-user groups, either of parents who have children with disabilities or of people with disabilities themselves. The role they can play in lobbying for and providing better services to children and adults with communication disabilities is explored and ways are described in which

rehabilitation professionals can nurture and support these associations. The challenges that these associations face, especially in low-income countries, are acknowledged and described. Even so, there are some examples of self-help among parents and people with disabilities in many low-income countries that can provide hope and inspiration to others seeking to promote associations of AAC users or their families and friends.

Chapter 15, the epilogue, concludes the book by highlighting issues for future research and investigation.

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CHAPTER 2

Intervention issues

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This chapter provides an overview of issues related to intervention, and augmentative and alternative communication (AAC) intervention in particular by describing the need for interventionists to move beyond a needs-based approach. Needs-based approaches to intervention focus on the gap between what is and what should be (deficit model) rather than addressing and extending existing resources in dealing with challenges. An asset-based or resource-based approach, on the other hand, provides interventionists with an alternative way to address and build capacity to deal with challenges by moving beyond the confines of the therapy room. This discussion culminates in a description of the basic components proposed for describing intervention, namely effectiveness, sustainability and versatility. Finally, two elements of communication are identified – participation and involvement – and their relevance for AAC intervention is discussed.

It is commonly known that there is a great need for intervention in developing countries. Approximately 80 per cent of all people with disabilities are in developing countries (Lundgren-Linquist and Nordholm, 1993). The reasons for this are many but include poverty, health and social problems, lack of affordable services and, often, poor quality of available services. Although more pronounced in low-income countries, these problems are clearly not restricted to these countries as even in developed countries there have been reports of lack of quality services, particularly in relation to vulnerable groups, for example people with disabilities, rural communities, single-parent families, the elderly, migrants and the homeless. In an analysis of social welfare and financial assistance in nine different countries including both developed and developing countries, Gartner et al. (1991) concluded that common trends are: access to common or general services, growing fiscal constraints amidst

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expansion of service programmes, increased development of community-based programme designs and a growing need to support the family of the child with a disability. Since this study, critical reviews of services have become more prevalent as professionals struggle with issues surrounding what constitutes relevant service provision and personnel preparation (Winton et al., 1997).

Poor quality of services often relates to a lack of enough professionals to provide services, but also to inappropriate training and services rendered. Lack of sustainability of intervention is a challenge as professionals take the lead and devise intervention programmes for people with disabilities. The medical model in which professionals take responsibility for intervention decisions is still prevalent in many service contexts. Although institutional services might be effective, the maintenance of the intervention is less than adequate and often unsustained once professionals withdraw.

Similarly, however, the social model of disability presents us with challenges. The awareness of disability as rooted in a social context has emphasized the role of the community and family in intervention. The vulnerability of individuals with disabilities due to heightened risks for developing health, educational, social and economic problems has to be understood to ensure meaningful intervention. Community-based rehabilitation has thus been met with broad appeal as communities are assisted in developing ways of taking responsibility in accommodating their members with disabilities. Often, however, interventions are poorly directed and too comprehensive to successfully address intervention needs of the individuals with disabilities and their families. Inappropriate or lack of professional support often contributes to mediocre quality of intervention. Processes are generally slow and progress difficult to measure.

The dilemma facing service delivery is well illustrated by 'Janet's story' (Winton and McCollum, 1997) as the frustration of a speech-language pathologist is described during her first year of working in the community:

> One of the most frustrating aspects of her situation was her belief that she really wasn't prepared for the tasks that seemed to be the priority for her agency. She worked out elaborate plans for home therapy for parents to implement, but somehow the plans never seemed to get done. She sometimes found herself talking to families about problems that had nothing to do with speech and language and with absolutely no idea where to go with the conversation. Another major issue was that her team members did not seem very receptive to some of her ideas. Sometimes she believed that everyone on the team had a personal agenda ... When she consulted with child care providers and preschool teachers, she often felt unsure of her role. The teachers seem to want some ideas about how to provide therapy but never seemed to try what she suggested. (p. 4)

This quotation not only describes the powerlessness of the young professional being confronted with an unfamiliar set of work demands within an early intervention setting, but also reflects a lack of understanding of the process of change and transformation within current service models. Sadly, the outcome of this process is increasing levels of insecurity and suspicion within the team and working context. Services are becoming more community-based (Gartner et al., 1991; Lankester, 1992), family-centred (Mittler and Mittler, 1994; Dunst et al., 1988), oriented towards self-determination of people with disabilities (Powers et al., 1996) and inclusive (Guralnick, 2001) while relatively little time is dedicated to grasping basic underlying components of intervention in facilitating a sound understanding of the impact of the processes.

While the above example reflects a service situation in a developed country, the dilemma for professionals working within developing contexts is even more challenging. Intervention models and approaches have to be changed and transformed to accommodate not only an increasing number of people with disabilities, but also decreasing financial resources. The real challenge, however, seems to lie with a prevalent emphasis on intervention strategies and action-oriented implementation without a sound understanding of the complexity of intervention constructs which characterizes intervention and transformation. An example is the augmentative and alternative (AAC) interventionist who starts off with AAC implementation by using specific activity-based vocabulary on a device or communication board. Although this approach has merit and can facilitate interaction within the context, there are not necessarily any communication benefits beyond the specific activity. Parents learn to use AAC strategies in interaction with a child without necessarily internalizing the way of communication with the child to the broader, extended family context. Communication between parent and child remains focused on using vocabulary rather than developing meaning in interaction.

Needs-based approach to intervention

Professionals traditionally tended to be needs-oriented (Kretzmann and McKnight, 1993). A needs-oriented approach emphasizes the gap between the problems experienced by the individual or family and what is regarded as the desired state. The needs of the person with a disability as well as the needs of the family are described, and strategies are developed to address these needs. A comprehensive description is thus made of the needs within the individual, family and community context to provide a comprehensive understanding of the nature and extent of the problems experienced. A need is defined as 'desired or lacking but

wanted or required to achieve a goal or attain a particular end. Operationally a need is an individual's judgment of the discrepancy between actual states or conditions and what is considered normative, desired or valued from a *help seeker's and not a help giver's perspective* (Dunst et al., 1988, p. 13; authors' italics). According to these authors, therefore, a need is only a need if described as such by the help seeker.

Perhaps one of the most acknowledged dilemmas of this approach focuses on the relevance of the needs identified to the individual(s) or family involved. Often needs are identified by the professional or parents and not in collaboration with the client. This raises the critical question of whose needs are being addressed in intervention. The issue of relevance is, however, not uncomplicated, as parents and people with disabilities are influenced by increasing exposure to the multinational marketing system through globalization. A potential gap between perceived and basic needs often contributes to challenges in relation to prioritizing needs; for example, what is the definition of a basic need (Riedijk, 1987) as opposed to a created (market-driven) need?

It is also accepted that the means to satisfy a need could be very different, depending on the cultural context. The means and tools of Western countries may not be valid and relevant in the same way to clients and families in developing countries. One example is the use of AAC devices. As the support system for electronic devices is often limited within developing countries, different high- and low-technological options need to be explored to address the needs of an individual who has little or no functional speech (LNFS). The issues are, however, complex as the individual might have the same need to express a range of communication messages within different contexts and thus requires a sophisticated communication system. The question then becomes: what is an appropriate system within this context? Would it be appropriate to prescribe only a low-technological option if this could mean inhibiting the individual's access and academic development? The same dilemma might apply when comparing rural and urban contexts within Western countries. Often the infrastructure for technological support within remote rural areas is limited and thus complicates decision-making of what would be an appropriate system within the context. That the process of needs identification requires an intricate and flexible partnership between communities and interventionists is clear. It needs to be one of creative synthesis rather than based on a predefined set of constructions. As Gartner et al. (1991) point out, reality is '[that] people who live in outlying areas have the same range of life needs as others and that there are flexible and creative ways of meeting these' (p. 11), and that the myth needs to be dispelled that people in the countryside live less complicated lives and thus need less extensive services.

Critical appraisal of a needs-based approach

The implications of a needs-based approach towards intervention have, however, been met with much criticism during the past decade. In the first instance, this approach often manifests in communities being viewed as 'nearly endless lists of problems and needs' which can lead to much fragmentation of efforts to provide solutions. Communities identify different needs, without necessarily understanding the relationship between the needs identified. The approach also largely disregards basic community wisdom which regards problems as tightly intertwined.

A needs-based approach targets resources to services rather than to residents. The focus is on how to develop better access to services by the identification of common needs that can be addressed. This implies that services representing the majority needs will often get funding preference. Making resources available based on needs, however, often forces communities to highlight deficiencies and problems and ignore their strengths and capacities. It becomes beneficial to indicate a high level or incidence of needs to access ongoing funding.

This approach tends to reinforce the 'expert' model which implies that only highly qualified people from outside can succeed in providing certain services. The glue that binds together communities is thus weakened as communities tend to look at external resources to develop solutions. From the above, it is evident that the cycle of dependence is deepened as issues have to be worse than last year to attract funding.

Perhaps one of the main criticisms of the approach is the focus on the needs, and not on building capacity within the community itself. Needs of individuals and families are addressed in an isolated manner rather than focusing on creating a broader plan that can involve energies of an entire community.

Although the needs-based approach has been much more prevalent and commands vast financial and human resources, many poor countries and communities have in response to a desperate situation taken an alternative route to explore solutions. The alternative is an asset-based approach which is based on a commitment to discovering a community's capacities and assets.

An asset-based approach

This approach is based on an identification of strengths and support systems in a community to facilitate community development. The alternative path simply focuses on the development of policies and activities based on capacities, skills and assets of low-income people and their

neighbourhoods. Self-reliance of communities and their ability to develop sustainable support systems are of prime importance. 'It is increasingly futile to wait for significant help to arrive from outside the community' (Kretzmann and McKnight, 1993, p. 5).

An asset-based approach focuses on the importance of starting with a new map of a community – a guide to capacities rather than deficiencies – to allow the community to assemble its strengths into new combinations, new structures of opportunities, new sources of income and control and new possibilities for production (Kretzmann and McKnight, 1993). This approach emphasizes an analysis of existing infrastructure, services and human resources as an important first step in building infrastructure. The identification of resources, however, does not relate so much to individual organizations and memberships, but to the network surrounding a particular organization or individual.

Underlying an asset-based approach is a strong adherence to a philosophy of empowerment by building on what is available and positive within the context (Kretzmann and McKnight, 1993). Partnerships between professionals and parents develop based on mutual resources and strengths. Dependency does not build partnerships. From this it is clear that sustainability refers not only to intervention with individuals and their families, but also to services or intervention programmes. The assets referred to are inherent in the family and community while services are based in professional expertise. Intervention therefore needs to take cognizance of different kinds of supports offered to families and AAC users to ensure long-term impact of intervention.

An asset-based approach can then be characterized by a focus on:

- the individual and family strengths within a broader community context, while services are seen as professionally oriented;
- networking to build supportive relationships around the individual and family, including both formal and informal networks;
- an equalitarian relationship between professionals, clients and community, as they need to work towards a joint vision in intervention;
- the individual and family rather than on a service, to ensure that sustainable support systems develop.

The work of Dunst et al. (1994) has made a significant contribution in translating an asset-based approach (or as they refer to it a 'resource-based' approach) into practice for implementers. In their discussion of early intervention (ibid.) they point out that in addition to the intervention programmes individuals and families are exposed to, they experience additional events that influence child development and family functioning. Thus, effective intervention is determined by how support and assistance are provided, rather than the immediate effect on the child or individual.

This support for families and children should be from both formal and informal support networks that impact directly and indirectly upon parental, family and child functioning.

The resource-based intervention model includes three components – sources of support (personal social networks, association groups and community programmes), community resource mapping (to describe resources within a specific geographic area) and building community capacity (to identify strengths of community groups in building community capacity). The focus is thus on the aggregation of different kinds of assistance and service that are provided to the family and to people with disabilities by individuals and groups. Involvement in an institution-based programme is merely one kind of support, but this needs to be complemented by compassion from a friend, parent–parent support programme and so on. A striking account of the need for more support for siblings of children with autism is reflected in the following verbatim reports (from Newson and Davies, 1994, p. 247):

- 'When it comes to me doing things that I want to do, I'm "immature" then. But when it comes to looking after my brother, you know, I've got to be all responsible.'
- 'I find it hard to say things, cause they're going through a lot of pressure right now, without making it even worse.'
- 'Every time my relatives come round it's really bad, because they've got this idea that just because he's autistic he's got to be a really nice person and they treat him as if he's really nice. They say to me, "I hope you are being nice to him!"'
- 'It's best to keep to yourself, 'cause if you start telling them [friends], then they ask you questions about it that you don't know.'

Underlying this approach is the acknowledgement that change does not occur through direct intervention only – much of what is learned is acquired through informal observation, discussion and involvement in activities. Modelling, i.e. merely observing others and their ways of dealing with specific issues and problems, provides a rich context from where parents, families and people with disabilities can grow – to build capacity not only for now but also for the future.

Critical appraisal of an asset-based approach

The development of community networks is a slow, long-term process that requires much time and commitment from the family, community and facilitators or professionals. This can indeed be a frustrating approach for professionals who are trained in a medical model with an orientation towards 'fast measurable outcomes'. This approach implies a different

process of professional preparation as is stressed by Chambers (1983). The professional needs to be able to act as a facilitator to the family and individual in developing skills by collaborating with members within the existing network. This implies that the association between individual, family and professionals is characterized by an equalitarian process.

This approach is dependent on access to relevant knowledge of the community and the existing assets within the community. People involved in service delivery thus need to be familiar with both the formal and informal infrastructure in the community to facilitate the development of supportive frameworks. Skills related to asset-based profiling of a family within a community context, such as the use of ecomaps, are often not familiar to health professionals.

Understanding the infrastructure of the community, however, does not necessarily imply a sound understanding of the individual's or family's difficulties; thus an asset-based approach needs to be complemented by a description of the specific difficulties encountered. Implementers thus need to be aware of the strengths as well as pitfalls of the approach toward intervention. Focusing only on the development of a broader societal support structure for intervention does not necessarily infer a sufficient understanding of the specific problem of the individual or family. A person with little or no functional speech will need to gain access to valid assessment processes as a basis for the selection of relevant AAC strategies.

Against the above framework it becomes clear that if intervention is going to be relevant and sustainable, it needs to provide for the delicate balance between an asset-based approach while at the same time making interventionists aware of the need for collaborative description of the individual and family problems and needs. To be sustainable implies to move beyond the immediate benefit of intervention – to make the change in behaviour persistent and thus enhance the individual's or family's future capabilities of coping with challenges.

is substantially error variance. In contrast to this, however, a social system's approach assumes that, beyond the percentage of variance accounted for by the formal intervention, significant percentages of variance are attributable to other sources of support. In a study conducted by Dunst (1985) the validity of these views of intervention was investigated by assessing the degree to which parent, family and child functioning was related to various sources of support, within family, other relatives, social groups, early intervention and other professionals. Of all the dependent measures employed in the study, early intervention accounted for a significant percentage of variance in only one outcome variable. In contrast to this, informal support accounted for a significant percentage of variance in nine of the ten outcome measures. This study was replicated in a larger study of 224 parents (Dunst, 1985; Dunst and Trivette, 1987), which largely supported the previous findings.

What then should we be aiming at in intervention? In answer to this question, one should consider three concepts: effectiveness, sustainability, and versatility of intervention and training. Figure 2.1 depicts the association between these three concepts, which will now be discussed briefly.
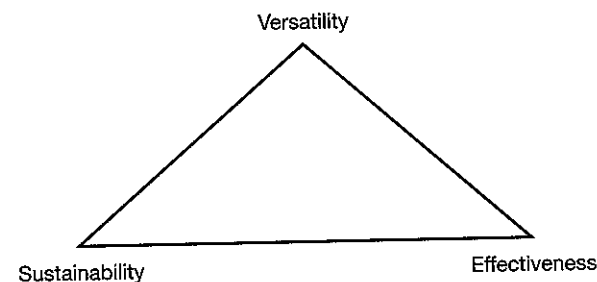

Figure 2.1 Components of intervention.

Components of intervention

The argument is for what Dunst et al. (1988) described as a broader-based definition of intervention. They described the difference between a traditional and a broader-based approach towards intervention as the percentage of variance accounted for in the treatment (intervention). According to Dunst et al. (1988), the implicit assumption of a traditional perspective of intervention is that the major percentage of the variance accounted for in the outcome is attributable to the intervention programme or its programme components, and that the remaining percentage of variance not accounted for in the programme components

Effectiveness relates to the demonstration of behaviour changes as a direct consequence of intervention (Schlosser and Braun, 1994; Schlosser, 2003). This concept focuses on the nature of the changes that are facilitated, as well as the range of daily living activities impacted by the changes. Change in this instance thus relates to the kinds of change induced by intervention within a specific context and the individual's ability to use these in other contexts as a direct result of the intervention. Objectives need to be well-defined and appropriate for the individual and family. Schumacher's (1973) concept of 'small is beautiful' is relevant, as the outcomes of intervention are outlined and delimited to ensure focused and

goal-oriented intervention. This concept thus includes the concept of maintenance of specific behaviours targeted in therapy to the outside contexts. For example, an AAC user would receive intervention to facilitate use of initiations in interaction. While in therapy, the individual uses the newly acquired skills – not only in the therapy session, but also outside of therapy. Effectiveness of therapy is thus focused on the ability of the individual to gain while intervention is still in progress. Maintenance of a specific behaviour is achieved during the time of direct intervention.

Sustainability refers to the length of time the change in behaviour of the individual or family is maintained when direct intervention is not provided, i.e. when professionals are not involved. It relates to the support system available to encourage the use and extension of the specific individual's skills when direct intervention is withdrawn. This concept includes the ability to generalize specific behaviour to other contexts over a period of time. Clearly, issues surrounding sustainability focus on the environment's capability to provide opportunities for the individual to interact while the individual maintains the motivation to participate. Mutual benefits or reciprocal gains thus maintain behaviour. In the example of the AAC user receiving therapy to facilitate the use of initiations in therapy, sustainability would relate to how long and in what contexts the individual is able to maintain this skill after therapy has been terminated. Clearly this would depend not only on the individual who uses AAC but also on the family and environment, to create the opportunities necessary to use and expand meaningfully on newly acquired skills.

The third component refers to the accumulated gains of intervention for future coping. Versatility refers to the relevance of intervention in relation to building the individual, family and community's skill in coping with transformation or change which forms an integral part of the process of growing up. *Roget's Thesaurus* (Kipfer, 1999) also uses the words changeableness and multiformity in describing versatility. It refers to the ability to manage change over time and the use of past experiences in problem-solving new or different problems. The issue of changing needs and circumstances of the individual and family over time is central to this component and relates to the ability to address changing needs (Alant, 2000). Services should be aligned for people aged from 0 to 90. Intervention thus needs to facilitate an increase in the quality of life of the individual and family beyond the specific therapy goals – to have cumulative long-term impact. Changes need to be anticipated, as people adapt to different circumstances and contexts as their social roles expand and change throughout a lifespan (Fox and Sohlberg, 2000). Needs and abilities that change require diversity in support systems and professional services. To increase the versatility of intervention thus implies that interventionists not only focus on the immediate goals and outcomes of

intervention, but also facilitate understanding of the impact of different skills acquired during intervention for future problem-solving.

In relation to the example used, versatility would refer to the individual's ability to gain from skills used during therapy not only to initiate communication in certain contexts, but also to generalize this skill to solve specific problems encountered by approaching people and initiating contact. Through intervention and sustained support, the individual is thus able to elevate gains to a higher cognitive level and become more empowered to deal with future scenarios. Clearly, this level of intervention is also dependent on a reciprocal relationship between context and individual and a strong orientation to build on skills to facilitate future success. This is an empowered stance that implies not only that people are able to acquire specific skills, but also that these skills build on generic skills. It is important to point out at this stage that although the focus of this discussion is on the association between the three components in relation to intervention, which is an individually oriented process, the use of the term sustainability is more typically used in relation to the evaluation of service programmes.

The association between the three components can be visually represented by means of a spiral moving upwards (Figure 2.2). Effectiveness is represented by a horizontal layer of the spiral, thus representing the training and outcomes within a short period of time (typically during intervention). Sustainability is represented by the maintenance of specific behaviours (different layers) over a period of time (typically after intervention was withdrawn). Versatility is represented by the induced force inside the spiral, indicating the non-tacit benefits (generic skills) of intervention over time impacting on different stages and domains of the individual or family's living cycle.
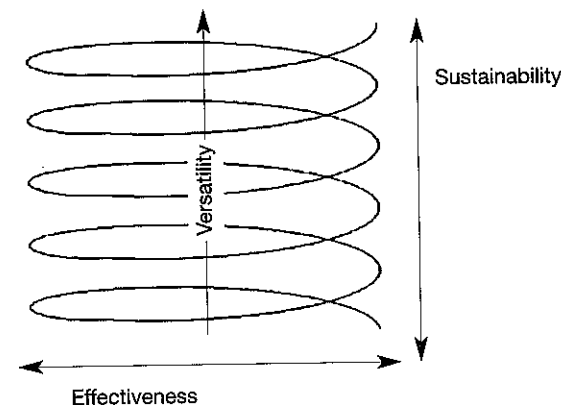

Figure 2.2 Intervention over time: the association between effectiveness, sustainability and versatility.

In all three components – effectiveness, sustainability and versatility – the motivation and involvement of the individual, as well as the environment or context, are pivotal in facilitating long-term impact. It is well recognized that people who are disempowered are less likely to apply intervention strategies in their daily life. They would remain strongly dependent on whoever provides service. Lack of generalization of intervention strategies can, however, often be attributed to the nature of the relationship between professional, individual with disabilities, family and environment.

Communication as a meaning-based process: participation and involvement

It is evident that relevant outcomes as discussed above are grounded in a sound understanding of interaction as a process of developing meaning between people. This process implies not only that the individual and family need to gain access to different communication strategies to participate in message exchanges, but also that they need to be involved or psychologically engaged in a process that focuses on the development of understanding between them. Participation or exchanging messages does not necessarily imply involvement in the process. However, for communication to become a sustained process both these components of communication are required.

It is important to differentiate clearly between an individual's involvement in communication and the overt participation in message exchanges. Figure 2.3 highlights the relationship between participation and involvement in communication interchanges.
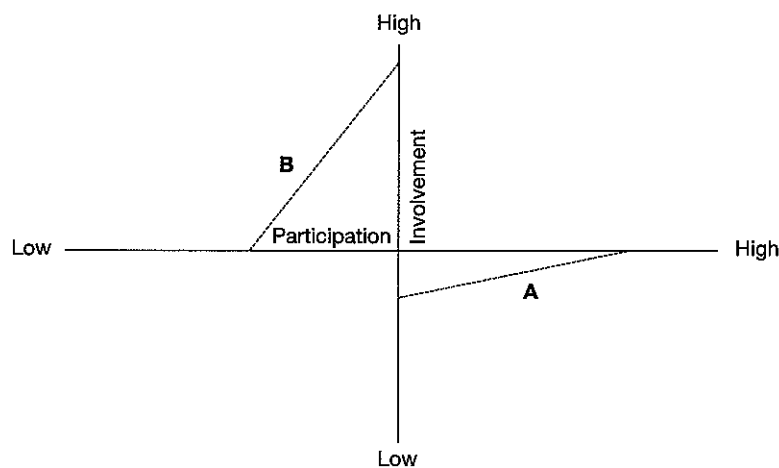

Figure 2.3 Association between involvement and participation in communication.

In this model, *participation* refers to the overt manifestation of interaction as a process of sending and receiving messages, while *involvement* refers to the level of engagement of the individual during the process. Figure 2.3 demonstrates issues surrounding participation and involvement in communication. Line A in Figure 2.3 indicates the communication of an individual who is highly participative in interaction, but has a relatively low involvement in the process. Typically, this refers to the individual who is using prerecorded messages on a voice output system and activating messages rather mechanically, without really being involved in the development of meaning in interaction. Similarly, line B indicates an individual who is relatively low on participation, thus does not interact frequently, but is engaged in the process of developing meaning in interaction. Although difficult to separate involvement from participation, an awareness of this paradigm is critical in evaluating issues relating to maintenance and sustainability of intervention.

The AAC model, effectiveness, sustainability and versatility

According to Lloyd et al. (1997) AAC refers to the supplementation or replacement of natural speech and/or writing using a combination of two kinds of symbols, these being aided (symbols that require something external to the body to represent, select or transmit messages) and/or unaided (symbols that require only the human body to produce). The term also refers to the field of clinical or educational practice focused on improving communication skills of individuals with little or no functional speech. In addition to the improvement of communication skills of individuals with little or no functional speech, the use of AAC strategies in facilitating interaction and communication of individuals with limited speech (some understandable speech) has also been acknowledged (Beukelman and Mirenda, 1998; Fristoe and Lloyd, 1979; Lloyd et al., 1997; Silverman, 1995; Von Tetzchner and Martinsen, 2000). For example, the role of AAC strategies in the facilitation of receptive language skills of individuals has been recognized increasingly, as clinicians and teachers use aided and unaided symbols to enhance their interaction with people with receptive and expressive language difficulties (Goossens' and Crain, 1986; Sevcik and Romski, 1997). This realization of different modes of communication and their roles in facilitating the development of meaning in interaction necessitates a closer look at the AAC model. To enhance understanding of issues related to AAC intervention, the interaction between specific intervention models and an AAC model is vital.

General communication models share a variety of components characteristic of the process, namely sender, message, receiver, feedback. Some of the more socially oriented models also include a reference to the communication environment (Lloyd et al., 1990). Depending on the focus of the model some of these components could be enhanced to accommodate specific needs, for example the AAC model (Fuller and Lloyd, 1997). This model acknowledges the importance of the environment and the communication partners as part of the communication process. By implication, therefore, the need for understanding the context within which the interaction occurs becomes vitally important. Understanding the infrastructure in a community or family is critical to ensure effective AAC intervention. Resources in the context with the potential to enhance communication interactions need to be understood to ensure their use to build further resources.

Apart from using specific communication strategies to exchange information and participate in interactive exchanges, the interaction patterns or styles within the family and environment need to be understood, to facilitate more sustained use of these communication strategies. For example, in some cultures, children are not expected to initiate exchanges with their parents or adults. However, they would use these skills in playing with peers. Focusing on skills of initiating conversation in this instance will thus be more relevant within peer interaction situations.

In the communication model, effectiveness of intervention relates to the success of the exchange between individuals in sending and receiving messages, which is influenced by a variety of factors, including the participants' ability to interpret and develop meaning from the symbols used in the process. The familiarity of the communication symbols used, the speed of interaction as well as the accuracy of use of the communication system will impact on the development of meaning within a specific context. All aspects relating to the message and the individual's ability to use and interpret specific symbols will, therefore, impact on effectiveness.

The development of meaning does, however, imply a variety of levels or roles of communication. AAC users, like typical communicators, use their communication abilities and strategies selectively to perform some social roles (Fox and Sohlberg, 2000). Contexts also differ in relation to intimacy and the level of meaning developed in the interaction. Being able to adapt and participate on a variety of levels and communication roles characterizes the dynamic nature of communication. Effectiveness relates not only to the nature of the interaction, but also to the range of communication contexts in which the individual can communicate effectively.

Sustainability, on the other hand, refers to the AAC individual's ability to maintain the communication skills over time. It refers to the opportunities

and barriers (Beukelman and Mirenda, 1998) the individual experiences in interaction with people in the environment after intervention is withdrawn. This component relates to issues surrounding the communication partners and the immediate environment of the individual as well as the broader social context or community the individual lives in. Fuller and Lloyd (1997) refer to this aspect as the communication environment, while other models (e.g. Johnson et al., 1996) also define this as the cultural environment of the interaction. Issues relating to communication filters (ibid.), attitudes and expectations largely contribute to sustainability of AAC interventions.

Versatility of intervention refers to the dynamic and systemic nature of communication over time. Communication intervention is not focused exclusively on present or current challenges, but also needs to have an accumulative effect in facilitating problem-solving of communication challenges over time. Training for independence implies assisting individuals to problem-solve, not just across contexts but also across the lifespans of the individual and family. This aspect of communication thus refers to the individual's development and growth over time as well as context and environmental changes that could occur throughout the years. Their communication ability needs to be flexible enough to accommodate the different needs required by society during different phases. This component, therefore, focuses on the AAC model and its effectiveness during different phases of the individual's life. Flexibility using communication systems for different purposes, as well as accommodating different environmental and cultural demands over time, is highlighted.

In conclusion, the current framework of intervention emphasizes the need to look at different elements of the AAC model as a process over contexts and time (Wasson et al., 1997). Although basic elements of interaction could be maintained, the dynamic nature of different kinds and levels of interaction necessitates that the model is sensitive towards the different manifestations of these elements over time and context. Being able to focus on the flexibility of the different elements within the communication process thus could facilitate sustainability and versatility of intervention.

Implications for AAC intervention

AAC interventionists need to take cognizance of the individual's participation and involvement in communication events. The identification and promotion of communication events, rather than the use of specific AAC strategies, form one of the core issues in intervention. Communication is about making contact with other human beings. This

is an emotional event, not a distant informational exchange. Quality thus refers to the extent to which the individual's life experiences are enhanced by the introduction of AAC strategies. AAC students or trainees need to gain an understanding of the complexities of the process to prevent them from looking at communication as a technical exchange of messages. The use of the AAC strategies needs to induce change in communication behaviour within specific situations. There needs to be an understanding that change can be induced on different levels, e.g. frequency of interaction, different functions of interaction and different roles of the individual in interaction (Fox and Sohlberg, 2000).

It needs to be accepted that service delivery has to be a balance between comprehensive and specialized services (Rifkin and Walt, 1986). We cannot ignore issues of vulnerability and poverty in families and communities by focusing exclusively on AAC intervention. We need to work to improve the broader support system and, within that, provide small steps to guide AAC intervention. Sustainability of intervention to a large extent depends on the ability of the intervention team to strengthen the involvement of the individual and family within the broader community context. Exclusively focusing on discrete or isolated goals in AAC intervention will indeed be limiting the impact of the process.

Clinicians and teachers need to understand the basis of an asset-based (Kretzmann and McKnight, 1993) *or a resource-based approach* (Dunst et al., 1988). This implies a greater sensitivity to the impact of the environmental context and broader community on the daily functioning of the individual and family. The identification of strengths in the environment is pivotal in facilitating the development of community supports for people with disabilities and their families. Sadly, very little attention has been paid to training clinicians and teachers on how to go about doing an asset-based analysis. Rather, the emphasis in training has been almost exclusively on the identification of individual needs, namely a needs-based approach. Emphasis is placed on the gap between what is and what is not rather than on extending the opportunities there are in an attempt to expand participation opportunities. Although an asset-based approach towards intervention does not exclude sensitivity towards the needs of the individual and family, it does caution against focusing on needs to the cost of assets in the intervention process. One has to understand the problems and difficulties; at the same time one needs to understand the characteristics inherent in the situation that can facilitate change.

An asset-based approach highlights the need for collective dialogue, and thus the skill to engage in dialogue as a means to develop understanding. Collective dialogue refers to the ability to engage in creative interaction with people, to create new meaning in interaction and to enhance mutual understanding. This implies the need to learn to cope with diverse opinions, often accepting chaos in discussion and interaction, to allow the participants to grow towards meaningful decision-making and participation in intervention, i.e. transformation.

Intervention needs to take cognizance of the three components of intervention, i.e. effectiveness, sustainability and versatility. Effectiveness is primarily an individual and family-oriented criterion, because it relates to the changes induced in the AAC user and the family context. This involves the strategies we teach and how they facilitate change in communication behaviour. This raises questions such as the following:

- Is communication taught as a static set of messages, or is dialogue between the AAC user and the context facilitated?
- Is the individual really using the AAC device outside of therapy or in the classroom?
- What is the level of change observed in the behaviour of the parents in interacting with the AAC user?
- Do we train what the individual needs or what we are good at?
- Whose needs are we addressing?

Sustainability is primarily a family–community-focused concept. It refers to how long newly learned communication behaviour is maintained after AAC intervention is withdrawn. The intrinsic motivation of the person who uses AAC to interact and his or her use of the different components of the communication system will reflect the value added by the system. Inherent in the focus on a value-based approach to intervention is the understanding of parents and users of AAC in relation to the use of these systems to develop closer contact and understanding between people. People generally use and maintain systems that add value to their lives. Communication is not simply a routinized exchange of messages. Although generic talk is important, sustainability depends on the motivation to maintain the process of developing meaning – for both the AAC user and the environment. If this is not achieved, the use of AAC strategies will decline because there is no further opportunity for self-expression. Training in sustainability of intervention focuses on the family and the facilitation of community networks for implementation. Traditionally the field of AAC has been sensitive to focusing on strengths rather than weaknesses of individuals and families. There is a growing awareness of including families and facilitating participation through building confidence and problem-solving strategies within the family context. Little attention has, however, been paid to assisting families in broadening their own social networks in extending support networks for themselves and their children. Poor social capital of many of these families remains a major source of isolation.

The component of versatility focuses on the integration between the individual, family and the community. It refers to the involvement of clinicians in assisting individuals and families in coping with long-term life demands. Changes in AAC systems, vocabulary and partners need to be accommodated as part of intervention. To cope with this, sufficient community networks need to be developed to assist AAC users and their families in increasing their support within the community. The challenge lies in AAC interventionists becoming more closely aware of the association between communication skills taught or acquired and the impact on lifelong coping of individuals. The need is for AAC interventionists to focus not only on immediate skills or effectiveness of intervention but also on more distant outcomes that could be facilitated by intervention. It would be important, in addition to training the individual in using a specific AAC strategy for communication, to reflect on how the newly gained skill can impact on further life activities. For example, as the individual is learning a specific skill on how to use different ways of greeting in different contexts, it would be vital also to reflect on the underlying meaning of this skill for functioning in other contexts. Attention can thus be paid to how different ways of expression can impact on people's understanding and perception of an individual. Limited research has, however, been conducted on the accumulated impact of intervention on lifespan activities of individuals with disabilities. To guide interventionists throughout this process requires an increase in AAC research focused on long-term benefits for individuals and families to facilitate the understanding of associations between skills taught and life skills acquired.

Changing a communication interaction pattern takes time and it is even more time-consuming in situations where there was very little interaction prior to implementation. Clinicians need to have a sound understanding of what is needed to facilitate a meaningful lifelong intervention scenario. The client and the family are central to this process and should be confident in their ability to access a variety of resources to problem-solve and facilitate life events in relation to AAC and severe disabilities.

It is critical for trainees to be able to reflect continually on the quality of AAC intervention in relation to these three components. We need to move from ideas relating to a 'quick fix' and accept that real impact takes time and dedication. Only in this way can we assist in building individuals', families' and communities' resilience in accommodating challenges and celebrating diversity. Quality of intervention closely links with issues relating to evidence-based practice.

Evidence-based practice (EBP) needs to be implemented. Evidence-based practice refers to the extent to which strategies and approaches used are based on fundamentals and principles supported by research. This implies an awareness of practitioners in dealing with issues, for example the social validity and reliability of intervention strategies used. It focuses on the importance of research as part of the selection and validation of strategies used as part of the intervention process.

To a large extent, issues surrounding evidence-based practice have mainly concentrated on effectiveness of intervention. Schlosser and Braun (1994) point out that to date AAC efficacy evaluation has primarily been concerned with intermediate effects, and they urge investigators to take a broader look at instrumental and ultimate effects, and thus the more long-term impact of interventions. The model described in this book emphasizes the importance of evidence-based practice as part of the intervention model. Researchers and practitioners need to ensure that they ask questions related not only to effectiveness, but also to sustainability and versatility. The highest levels of evidence available for the use of specific intervention strategies need to be considered as an integral part of practice.

Evidence relating to the sustainability of intervention strategies once the active intervention has been terminated has been limited in the literature. Although there has been an upsurge in intervention research investigating weeks of withdrawal to investigate the immediate impact of termination of intervention, issues affecting behaviour during this period have been only marginally investigated. Communication demands and opportunities can change quite substantially over time; AAC practitioners and researchers need to become more oriented toward understanding implementation of AAC strategies over time, to enhance insights into the different roles that specific strategies may play in facilitating overall communication.

The intervention component receiving least attention in AAC research relates to the versatility of intervention, and thus the impact of intervention on the development of later skills and competencies. Long-term research in AAC to investigate these processes has been severely limited – and needs to be encouraged.

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CHAPTER 3
Augmentative and alternative communication

KERSTIN M. TÖNSING, ERNA ALANT AND LYLE L. LLOYD

This chapter will aim to discuss different strategies that can be used to augment or supplement speech or communication efforts in general. How this is achieved – the challenges and solutions inherent in the process – are the subject of this chapter. First, the technicalities of the communication process are illuminated. The symbols used in augmentative and alternative communication (AAC) as well as the technical aids will be discussed. The populations in need of AAC will be considered. The communication process for a person using AAC will be described, highlighting challenges and solutions. Finally, the challenges inherent in the AAC intervention process – in general and within low-income contexts – are discussed.

A significant proportion of people with disabilities are unable to use speech and/or writing to meet their communicative needs fully. They therefore have a need to use AAC, defined by Lloyd et al. (1997b) as the supplementation or substitution of natural speech and/or writing by symbols, strategies and techniques.

However, AAC implies much more than a collection of symbols, strategies and techniques. While the terms *augmentative* and *alternative* immediately direct focus onto method, illuminating the concept *communication* is helpful to provide a basis for understanding the concept of AAC in greater depth. Communication as a physiological, psychological and social human phenomenon taking place within a physical environment is a complex process, evading complete definition and understanding. Definitions of the terms as well as models of the communication process abound, each illuminating one or more aspect(s) of communication (i.e. physical/environmental, physiological, psychological and/or social dimension) to a greater or lesser degree.

The communication process

While many more complex models of the communication process exist (e.g. Johnson et al., 1996; Lloyd et al., 1990; Sanders, 1982) the model depicted in Figure 3.1 illustrates a few of the basics, to highlight the different components of the communication process.
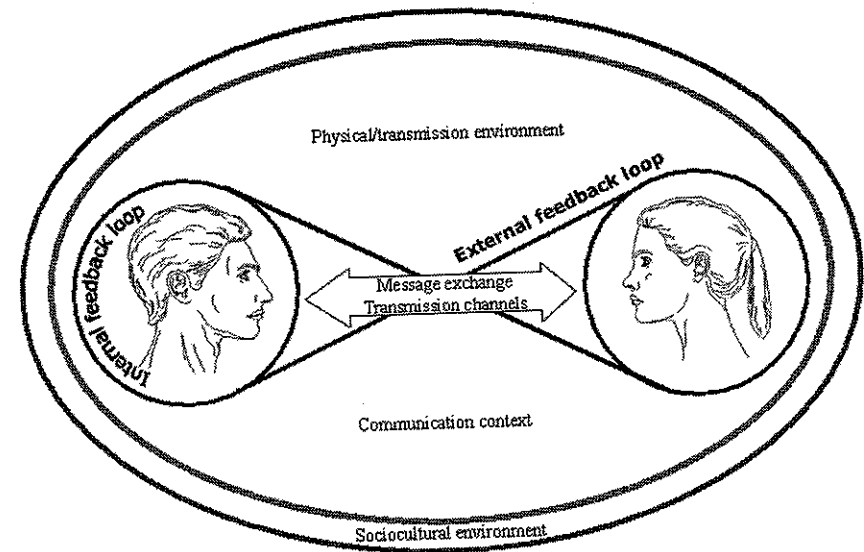

Figure 3.1 Basic elements of the human communication model. Adapted from Lloyd et al., 1997b.

From this figure, it becomes evident that communication is a continuous, non-linear process. It is characterized by the simultaneous sending and receiving of messages as two or more people engage in interaction with each other.

For the purpose of simplification, one might distinguish different degrees of intentionality within the messages that are sent and received, ranging from intentional (those messages encoded into a symbolic form for the purposes of exchanging information) to unintentional (those messages conveyed to others that are not necessarily consciously done and do not necessarily employ a symbolic code, for example facial expressions). Although it is difficult to differentiate the level of intentionality, the main concern in AAC is intentional communication – to assist people who have little or no functional speech (LNFS) to formulate a message that they want to communicate, using different strategies to enable them to put such messages across.

For sending symbolic, intentional messages, the sender needs to encode ideas into a symbolic code by generating neural impulses that drive selected muscles (be it an eye-blink or the speech muscles), which in turn produce or select a symbolic code (visual, auditory or tactile). This is transmitted through one or more transmission channels (i.e. as a form of energy such as light waves, sound waves or pressure/vibration) through the physical environment or transmission environment (characterized by variables such as lighting, noise and distance between speakers). The receiver uses his/her receptors (ears, eyes, touch receptors) to pick up the encoded message and, through a process that is mostly learnt, decodes this signal to arrive at the meaning.

While person A sends an intentional message (e.g. 'Let's go out tonight') in the form of a symbolic code, the person is at the same time receiving feedback – both internal and external. Internal feedback describes the process whereby the sender senses the message as it is produced, which helps the sender to monitor and adjust the output, such as might happen when one corrects one's own slip of the tongue. A person using AAC, for example an alphabet board, might get visual internal feedback and correct the 'slip of the finger'. External feedback is received from person B during the course of the sender's communication, such as facial expressions indicating whether the receiver is bored, interested or puzzled by the sender's message. After the message has been decoded (or failed to be decoded) by person B, further feedback might be received, such as a quizzical look or verbal message to request clarification of the message. The communication process is thus a process of feedback loops – both between and within individuals.

The process takes place within a specific context for example, a classroom, job context or an informal chat among friends. The broader framework within which these events occur, however, is accommodated within the cultural or socio-economic environment in which people live. The influence of the sociocultural environment will indeed be important in determining the rules for interaction in different interaction situations (see Chapter 5: Cultural and socio-economic influences on communication).

While the sender, receiver, message, feedback loop, context and environments constitute the main elements of the model, three components essential to understanding the AAC process will now be highlighted, these being *means to represent*, *means to select* and *means to transmit* symbols.

Components of the AAC process

As part of the communication model, three distinct components are relevant for the selection and use of AAC strategies. These are the symbols that will be used to convey messages (means to represent ideas), the way in which these symbols will be selected or identified (means to select –

such as pointing to a symbol by hand or using a scanning system to indicate a message or symbol) and finally the way the message will be conveyed (means to transmit). An example of the latter might be an individual transmitting a message by means of voice output or by means of the visual channel (letting partners read/see the message). Each of these components will now be discussed in more detail.

Means to represent

The component of *symbolization* or *means to represent* lies at the heart of all communication. This entails the use of a symbol to represent a concept or idea (referent). The ability to do so is learnt, starting in early infant–carer interactions. The reflexive cry of the typically developing infant is acted upon by the carer, and thereby interpreted as meaningful (i.e. treated as a symbol to represent hunger, discomfort etc.). In interaction with the carer, the infant learns to refine his/her symbolic code, first to differentiated crying, smiling to indicate pleasure, babbling and jargon and eventually to the use of the first spoken words. Various other cognitive processes accompany this development towards the use of spoken words as symbols. The awareness of cause and effect promotes the intentional use of symbols, whereby the sender intentionally chooses from a variety of symbols to encode a specific concept or idea to communicate. The awareness of person and object permanence is an important step in learning to transcend the here and now (world as perceived by the senses) to the abstract world of thoughts and ideas.

Use of AAC implies that the symbolic code which is used often differs from natural speech. Various types of aided and unaided symbols may be used to support the communication efforts. Unaided symbols are produced by senders using nothing except their own body, while aided symbols imply the need of an aid outside of their body. Table 3.1 provides an extensive sample of unaided and aided symbols. Some of these symbols are discussed later in this chapter. A more extensive discussion of symbols is provided by Lloyd and his colleagues (Lloyd et al., 1997a; Vanderheiden and Lloyd, 1986).

It seems that slightly different cognitive processes might be at work when making use of aided as opposed to unaided symbols. Unaided symbols need to be recalled from memory, such as retrieving the phonemes for a particular word, or the movements for a particular manual sign. Aided symbols, such as graphic or object symbols, might be recognized rather than recalled, if the person using them has all the options available in front of them. Multiple page displays, of course, put a memory load onto the user in terms of location, and the next step, namely the selection process, might therefore be more cognitively taxing.

For symbols to be used to encode meaning, they need to be understood by those in the context. Regardless of which symbolic code or AAC

Table 3.1 Overview of selected AAC symbol sets and systems

Aided	Unaided
Objects	Vocal or eye-blink message codes
Photographs	Gestures, such as cultural gestures, idiosyncratic gestures and gesture sets such as AmerInd
Picture Communication Symbols (PCS)	
Pictogram Ideogram Communication (PIC)	Key word signing
Cyber Glyphs	Natural sign languages, such as American Sign Language (ALS), British Sign Language (BSL) and South African Sign Language (SASL)
Blissymbolics	
Graphic representations of manual signs and/or gestures (e.g. HANDS, Worldsign)	
Arbitrary logographs (e.g. Yerkish lexigrams) and shapes (e.g. Premack symbols)	Manually coded languages, such as Signed English, Paget Gorman Sign System (PGSS) and Seeing Essential English (SEE-I)
Traditional orthography	
Graphic representations of fingerspelling	Four-handed signing
Synthetic fingerspelling	Fingerspelling or manual alphabet
Braille	Morse code
Electronic vibrotactile codes	Tadoma and other vibrotactile codes
Linear printing	
Digitized speech	Phonemic- or phonic-based symbols, such as hand-cued speech
Electrolarynx-generated speech	
Synthesized speech	Natural speech

Adapted from Lloyd and Fuller (1986), and Lloyd and Kangas (1994).

strategy is used, for communication to be meaningful this symbolic code needs to be shared by those involved. Should communication partners be unable to understand the symbolic code used, they need to be trained to ensure that they can meaningfully participate in the interaction.

Visual symbols, such as are often used in AAC, can be iconic, defined by Eco (as cited in Besio and Chinato, 1996) as transcribing 'the cultural properties attributed to it (an object) through graphic (or different) artifices' (p. 272). As we perceive the material world around us mainly through vision, visual symbols have a better possibility to represent at least objects and persons (and, to some extent, verbs) by symbols that visually resemble their referent (the concept being represented). Some object communication symbols can be transparent (guessable). For example, a communicator might point to a cup to indicate a wish for a drink. However, even this process needs to be agreed upon by sender and receiver of the message. Regardless of the level of iconicity or abstraction of a symbol, symbolization in itself is a learnt skill.

Means to select

If the communicator has access to symbols to convey meaning, the next step is to select the appropriate symbol for a message (*means to select*). For the purpose of this text, selection is defined as a process whereby the communicator chooses a symbol either from memory (such as retrieving the phonemes for a particular word, or the movements for a particular manual sign) or from a *selection set* which exists outside his/her memory (e.g. produced by another person or computer program as in auditory scanning, or a hard-copy communication board printed by another person or the communicator him-/herself). Thus before a communicator can encode a specific message, he/she needs to recall a symbol from memory, or recognize it from a selection set.

Selection of different types of symbols requires various cognitive and motor skills. Graphic symbol displays with multiple pictures and pages necessitate the memorization of the location of all these symbols, which can become a significant cognitive demand. Encoding techniques, such as Minspeak (semantic encoding), or the organization of vocabulary according to word class, communication function or topic are strategies used to lessen the AAC user's memory load in locating a specific concept.

In addition, the individual must be able to indicate the choice of symbol in some way. Depending on the person's motor abilities, direct or indirect selection can be used. Direct selection entails the person directly accessing the symbol, i.e. pointing to it or pushing a button. Indirect selection proceeds through scanning, either partner-assisted or electronic.

In order to produce symbols selected from memory (aided, such as writing; or unaided, such as manual sign and speech), the person is in need of certain motor skills, such as hand or arm movements to produce manual signs, or oral movements to produce speech. Symbols can be produced using only the sender's body (i.e. unaided), such as speech, manual signs and tactile Morse code, or an additional external aid (aided), such as pen and paper for writing, or an electronic communication aid for synthesized or digitized speech.

Means to transmit

Once a symbol has been selected or produced, it is transmitted as a form of energy (e.g. light waves, sound waves, pressure) through the physical environment to reach the receiver. This process can also take place by aided

or unaided means. Some produced symbols are transmitted without external aids, such as speaking without amplification, or manual signing which is directly observed by the receiver. Other produced symbols need an aid to be transmitted, such as a piece of paper with a written message, or an amplification system for a soft voice. Symbols that are externally selected are always aided symbols, and are thus transmitted by aided means. Most externally selected symbols are visual, such as graphics, objects or photographs, which are displayed by some means (e.g. communication board, wallet etc.). However, they can be auditory (e.g. partner-assisted auditory scanning of the alphabet) or tactile (e.g. tactile symbols on a communication board). Use of a voice output communication aid (VOCA) adds another step into the transmission process; while the person using the aid typically selects a graphic symbol, the VOCA 'translates' this into an acoustic symbol, which in turn reaches the receiver.

The means to transmit the message is thus important as it often determines how easy or difficult it is to receive the message in particular contexts. For example, if a child is in a classroom with other children, it is more difficult if the means to transmit the message from the child to the teacher is through paper (for example a communication board), as this requires the teacher to be close to the child to see what is being communicated. On the other hand, if the child can select the message and transmit it through the auditory channel (voice output), messages can reach the teacher over a distance. Clearly, these are considerations that need to be kept in mind as the intervention team work together to plan an appropriate AAC system for any individual.

AAC symbols

The use of a different symbolic code lies at the heart of the definition of AAC. These symbols can be described according to certain parameters (e.g. Fuller and Lloyd, 1997). Such descriptions and classifications are helpful to appreciate the possibilities and limitations of various symbolic codes, and to judge their usefulness for specific populations. Certain terms defining these parameters will now be clarified, and a brief overview will be given of some of the most commonly used symbolic codes used in the field of AAC.

Parameters describing symbols and symbolic codes

Unaided symbols consist of those which are produced by the communicator using only his/her body, such as manual signs or the production of Morse code. Manual signs refer to all those symbols performed mainly with the hands, such as sign languages or gestures.

Aided symbols are those that exist in a physical form external to the person using them. Most aided symbols are selected from a selection set at the time of the communication exchange (e.g. from communication boards or a QWERTY keyboard). When making use of drawing or writing, a user selects symbols from memory and then produces these aided symbols for communication.

As mentioned above, symbols differ regarding their degree of *iconicity*, defined as the degree of similarity between the symbol and the referent. Iconicity encompasses the terms *transparency* and *translucency*. *Transparent* symbols are guessable; Fuller and Lloyd (1991) point out that in such symbols 'the shape, motion or function of the referent is depicted to such an extent that the symbol is readily guessable in the absence of the referent' (p. 217). *Translucent* symbols do not necessarily depict a physical aspect of the referent, but there is a logical relationship between symbol and referent, which becomes obvious once the referent is known. For example, if it is stated that a circle represents a ball, and an arrow next to it means the ball goes up, it is rather logical that if the arrow goes down, this will indicate that the ball goes down. If, however, the initial symbol combination is not stated or explained, it will be more difficult to understand what a circle with an arrow pointing down means. It is important to note that both transparency and translucency are culturally bound concepts (see also Chapter 5: Cultural and socio-economic influences on communication, and Chapter 6: Issues in graphic symbol communication). If symbols are neither guessable nor based on a logical relationship between referent and symbol, they can be described as *opaque* or *arbitrary*. This means that there is no association between the symbol and its referent. Most spoken words, for example, are opaque, as there is no resemblance between the sounds or the written representation and the referent. Opaque symbols are learned within a specific context and, as stated before, if all communicators in the context do not share these symbols, the messages will be misunderstood or not understood at all.

Research (Clark, 1984; Fuller, 1988; Goossens', 1984; Hern et al., 1994; Mizuko, 1987; Nail-Chiwetalu, 1991/1992; Yovetich and Pavio, 1980) indicates that the degree of iconicity is an important factor in determining the learnability of the code, and should be considered especially if the client has some form of cognitive impairment. Other factors, however, also influence learnability, such as motivation of the AAC user to use a particular symbol, which is linked to the appropriateness of the vocabulary selected. A concept such as 'more', which might be classified as an opaque symbol in South African Sign Language (SASL), is a highly motivating and useful concept for most AAC users, and is often one of the first symbols that are acquired. Figure 3.2 illustrates the sign used for 'more' in SASL.
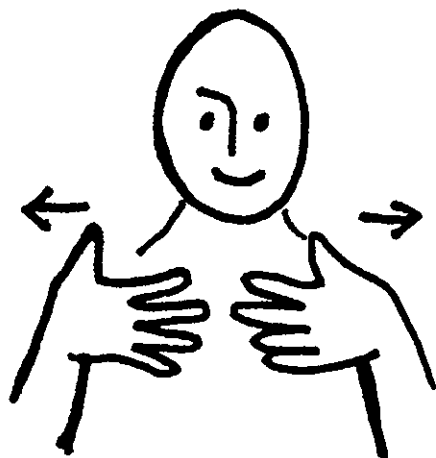
Figure 3.2 'More' in South African Sign Language (SASL).

Symbolic codes with linguistic properties mostly include opaque symbols. AAC intervention should aim at enabling a person to communicate as independently as possible in any context. The unique properties of language enable it to be generative, indicating that an unlimited number of meanings can be created. Thus supplying a person with a symbolic code that has linguistic properties is the best way of ensuring a productive, flexible system, giving access to any communication function in any context. In the trade-off between quick learnability and the need to work towards linguistic use of a symbolic code, interventionists, as so often is the case, need to maintain a long-term perspective while, at the same time, ensuring that short-term communication needs are met.

Fuller and Lloyd (1997) classify symbolic codes according to the presence or absence of internal logic and formal rules for creating new symbols – characteristics that seem to be closely related to the degree of linguistic structure inherent in this code. They differentiate between *symbol systems* and *symbol sets*. *Symbol systems* are symbolic codes that have internal rules and an internal logic for the creation of new symbols. Theoretically, symbol systems thus allow the person using them unlimited expression. Meaningful symbols can often be analysed into smaller segments, which have no meaning in themselves, or have a different meaning when standing alone than when combined into a symbol (dual patterning). Letters, for example, represent sounds, which only in combinations give meaningful units (words). Similarly, Blissymbols are composed of semantic units which, when combined, have a different meaning than when used in isolation. In order for a person to produce a symbolic code in a generative way, he/she needs to understand the internal logic of the system.

A *symbol set* comprises a delineated number of symbols, each carrying a certain meaning. Symbol sets cannot really be expanded, so that the person using them is limited to the number of symbols within the set. Typically, symbols from symbol sets do not consist of smaller units.

In terms of enabling a person to communicate as independently as possible in any context, symbol systems have definite advantages over symbol sets, provided the AAC user uses the symbol system in a generative way. With symbol systems, AAC users have the possibility to create an unlimited number of meanings, ensuring a productive, flexible system giving access to any communication function in any context. At the same time, acquisition of such a symbolic code obviously places certain cognitive demands on the AAC user.

Symbols have also been classified according to *complexity*. Blissymbolics have been researched in terms of their complexity. Fuller and Lloyd (1987) identified nine ways to define complexity of graphic symbols including both semantic elements and strokes. In this study it was found that strokes were the best correlate with perceived complexity, and semantic elements the second best. Other possible ways to classify graphic symbols include figure and ground relationship, perceptual distinctness, and amount of detail. Fuller et al. (1997) elaborate further on these aspects. Manual symbols have also been described in terms of complexity. There seem to exist basic hand shapes in sign languages, which are then changed/combined to various degrees to constitute the various signs (Loncke and Bos, 1997).

Table 3.1 (adapted from Lloyd et al., 1997) lists some examples of aided and unaided systems. Although not a comprehensive list, this table identifies most of the more commonly used symbol sets and systems.

Aided symbols

Aided symbols require a device or aid outside of the user's body. In general, such aided symbols require less motor skills, as the user selects them rather than produces the symbols with his/her body. One advantage of aided visual symbols is their permanence, which tends to reduce memory load and allows for direct prompting.

Object-based (three-dimensional) symbols

Real objects (aided set of iconic symbols)

Real objects are highly iconic and can be virtually identical to their concrete referents. This makes them suited for persons with cognitive impairments as well as for beginning communicators. Their three-dimensional nature allows for physical manipulation, which makes them suited to persons with visual impairment. Their size limits the number of

messages that can be displayed at a given time. Their representational range is also limited to mostly nouns, unless association is used (such as using a piece of chain to represent the action of swinging), which, in turn, makes the symbol less iconic.

Textured symbols (aided set of iconic and opaque symbols)

Especially suited for persons with visual impairment, these symbols use texture to represent messages. Symbols can be iconic, such as using a piece of leather to represent horseriding (leather reins), or opaque, where no logical link exists between symbol and referent.

Graphic symbols

For the purpose of this discussion, graphic symbols will refer to all visually represented symbols, including photographs, line drawings and orthographic systems.

Photographs and pictures (aided set of relatively iconic symbols)

The use of photographs and pictures is a good choice for those individuals who still find line drawings too abstract to understand. Pictures from magazines, for example, are relatively easily obtainable, while original colour photographs might be expensive. An obvious disadvantage is the limited representational range which pictures and photographs have. Most nouns and many verbs can be represented, but many concepts are not iconic in themselves (such as adverbs, adjectives or prepositions), although pictures might be used to represent them by association. However, such pictures need to be learnt by the person using them, as the connection between the picture and the concept it represents is not obvious.

Line drawings

Line drawings typically refer to sets and systems consisting of varying ranges of iconic and opaque symbols. A wide range of formalized symbol sets and systems exist, most of which were formally developed to serve for AAC. While many of these seem quite similar at first glance, there are important distinctions, which influence their suitability to various AAC users. Figure 3.3 provides examples of symbols taken from selected aided symbol sets and systems.

Picture Communication Symbols (PCS) (aided set of iconic and opaque symbols) – PCS are widely used in the USA. Designed by Roxanna Johnson (1981, 1985, 1992), this set consists of over 3000 line drawings grouped under various headings, such as food, clothing, grooming, school, health, kitchen, colours and so forth. Research confirms that PCS

	PCS	CYBER-GLYPHS	REBUS	SIG-SYMBOLS	PICSYMS	PIC	BLIS-SYMBOLS
BALL							
BED							
BOOK							
CAR							
COOKIE							
DOOR							

Figure 3.3 Examples of symbols taken from selected aided symbol sets and systems. Based on Fuller et al., 1997.

is highly iconic (Bloomberg et al., 1990; Mizuko, 1987). No rules exist for creating new symbols, which is why PCS is considered a set (Fuller et al., 1997). Symbols are obtainable in hardcopy format (Books I, II and III) as well as on software (e.g. Windows Boardmaker (Mayer-Johnson Inc.); see websites http://www.mayer-johnson.com and http://www.widgit.com). Much teaching material also exists. Reproduction of the symbols other than through photocopying, tracing or printing from the software is difficult. In low-income country contexts, both the acquisition and the reproduction of PCS are thus often too costly. In addition, brand names, logos and story characters contained within the symbol systems are only appropriate to mainstream US culture. Research into cultural appropriateness of the symbols indicates that changes need to be made to adjust for cultural appropriateness within different contexts (Haupt and Alant, 2003; see also Chapter 6: Issues in graphic symbol communication).

Pictogram Ideogram Communication (PIC) (aided set of iconic and opaque symbols) – Designed by Maharaj (1980), this symbol set consists of approximately 400 symbols (white drawings on black backgrounds). Used successfully with persons with severe/profound impairments (Leonhard and Maharaj, 1979; Reichle and Yoder, 1985), as well as individuals with autism (Reichle and Brown, 1986), these symbols seem relatively easy to learn.

Blissymbolics (aided system of iconic and opaque symbols) – Blissymbolics were originally devised by Charles Bliss (Bliss, 1949, 1965) as an international language to promote world peace. Shirley McNaughton began using them as an AAC system in 1971, while working in a team in Toronto, Canada, to promote communication among students with severe physical disabilities. Today, Blissymbols have been recognized in various countries as a powerful AAC system (Fuller et al., 1997; see web site http://home.istar.ca/~bci). Unlike PCS, Blissymbols are a system, and rules exist for the creation of new symbols. In addition, many Blissymbols contain morphological markers, indicating, for example, that a concept is an action, or an evaluation, a feeling or a past tense. Many compound symbols also exist, whereby two or more concepts combined give a new concept, e.g. *water* plus *down* becomes *rain*. This feature inherent in Blissymbolics seems to make Blissymbolics a good preparatory step towards literacy. Various hard-copy and software support materials exist. Unlike PCS, Blissymbols are also easy to draw, as they consist of relatively stylized shapes and lines.

CyberGlyphs (aided set of iconic and opaque symbols) – Similar to Blissymbolics, these symbols were designed in the early 1960s (Zavalani, 1991) to serve as a communication method for people speaking different languages. CyberGlyphs are also semantically based, and are intended to be hand-drawn. The system consists primarily of pictographs, with some ideographs and arbitrary symbols. The production and use of CyberGlyphs is governed by five basic rules. The syntax follows that of English. (See Chapter 6: Issues in graphic symbol communication, for more discussion on this system.)

Arbitrary logographs and shapes

Born out of research with nonhuman primates, these symbols were intentionally made as arbitrary as possible in order to prove that primates could learn symbols that are not iconic. The most well known of these systems are Yerkish lexigrams and Premack symbols.

Yerkish lexigrams – Designed by Ernst von Glaserfeldt in 1977, lexigrams were used to attempt teaching non-human primates the use of abstract symbols for communication. Lexigrams employ nine basic elements, which are combined to create a total of 225 symbols. Lexigrams have been used successfully with individuals with cognitive impairment (e.g. Adamson et al., 1992).

Premack symbols (aided set of opaque symbols) – Although these are technically object symbols rather than graphics, they are discussed here as these symbols were also used in research with non-human primates. Originally designed by David Premack (1971a, 1971b; Premack and Premack, 1974) as an arbitrary set of plastic shapes in different colours, this set was later adapted by Deich and Hodges (1977) to include some iconic symbols for use in communication. Premack has been used successfully with persons with a variety of disorders, specifically autism (McLean and McLean, 1974; Premack and Premack, 1974), severe cognitive impairment (Hodges and Schwerthelm, 1984; Premack and Premack, 1974) as well as global aphasia (Glass et al., 1973).

Line drawings as icons for encoding messages

Generally line drawings represented on communication boards can be combined in different ways to develop messages. These generally are used on communication boards to compose messages to be communicated. The symbol itself therefore is used to communicate different messages.

The use of line drawings as icons (for example, on Minspeak), however, is slightly different, as an icon functions as an indicator for a variety of messages that can be stored. As such the icon is not the message, but merely indicates a variety of messages associated to the icon. Although not used for the same function as other graphic symbols sets and systems, the Minspeak icons will be discussed, as they are commonly used internationally. Some research on this system is also discussed in Chapter 6.

Minspeak icons (aided system, mostly translucent and opaque associations) – Minspeak icons were devised by Baker (1986) to act as a semantic encoding technique to access stored phrases in a voice output communication aid (VOCA) or speech generating device (SGD). Over 100 coloured pictures are used to code words, phrases and sentences. The icons are purposefully ambiguous, so that different associations can be made with one picture. In the strictest sense, the icons are not the symbolic code used to transmit the message – that is done by the synthetic speech of the VOCA. However, the person using Minspeak still needs to be able to recognize the Minspeak icon in order to make a meaningful association to help him/her memorize the icon combination encoding a particular message. Today Minspeak is used extensively with devices from the Prentke Romich Company (PRC), e.g. Pathfinder.

Alphabet-based systems

Traditional orthography (TO) (aided system of opaque symbols)

While the use of traditional orthography has the powerful advantage of mimicking the spoken language of the community and of having an unlimited representational range, research shows English TO to be more

difficult to learn than other graphic symbol sets and systems (Briggs, 1983; Clark, 1977, 1981; Clark et al., 1974; Mirenda and Locke, 1989; Romski et al., 1985). Display of the alphabet on a communication board may be combined with phrases and/or common letter clusters (such as sh, ch, -ly etc.) in order to speed up the rate of communication. On an electronic communication device, the alphabet might be used in conjunction with other graphic symbols (e.g. Minspeak on devices like the Pathfinder (PRC)).

Braille (aided system of opaque symbols)

Invented by Louis Braille in 1824, Braille consists of a series of raised dots which represent the 26 letters of the Roman alphabet. Depending on the grade used, contractions, parts of words or whole words are also encoded. Braille was originally intended to help persons with visual or dual sensory impairment to 'read' English by feeling the encoded letters.

Electronically produced vibrotactile symbols

Vibrotactile codes (aided system of opaque symbols)

Electronically produced vibrotactile output may be used to encode certain messages or the alphabet, using, for example, Morse code.

Unaided symbols

The biggest advantage of unaided symbols is their availability. Nothing outside the AAC user's body is needed for communication. Most manual symbols require at least some motor control. Unaided symbols can be transmitted/perceived acoustically (for example, speech), visually (for example, sign language) or in the tactile modality (for example, Tadoma).

Vocal and eye-blink message codes (unaided set, usually mostly opaque symbols)

Persons with limited motor ability may develop a limited number of vocalizations and/or successive eye-blinks or eye movements to encode certain messages, such as a request for water (Adams, 1966).

Manual symbols

The use of manual symbols for persons with little or no functional speech (LNFS) can range from using a few gross gestures to using an extended repertoire of signs from a sign language. Often persons who are unable to communicate by speech have developed at least some movements understood by their carers to communicate some basic messages. To clarify the range of unaided systems, a brief discussion of some of the main systems will follow.

Gestures (unaided set of mostly iconic symbols)

Gestures are a non-linguistic form of communication, meaning they are not formalized into a language system. They are either cultural – meaning they are generally understood by people from the same cultural background – or idiosyncratic, meaning they have been invented by or for a specific person. Gestures alone commonly do not cover a wide range of messages. Most gestures are iconic, although some are opaque, such as the head shake to indicate 'no'.

Sign languages (unaided system of iconic and opaque symbols)

Examples of sign languages are American Sign Language (ASL), British Sign Language (BSL) and South African Sign Language (SASL). These are complete signing systems with linguistic characteristics, having a grammar of their own different to that of spoken languages. Sign languages are traditionally the communication channels used by the deaf communities. Although many gestures are iconic, some are not (e.g. those describing abstract concepts, conjunctions, pronouns and all morphological markers such as tense, plurality and possession). Figure 3.4 illustrates three iconic and three less iconic signs from SASL.
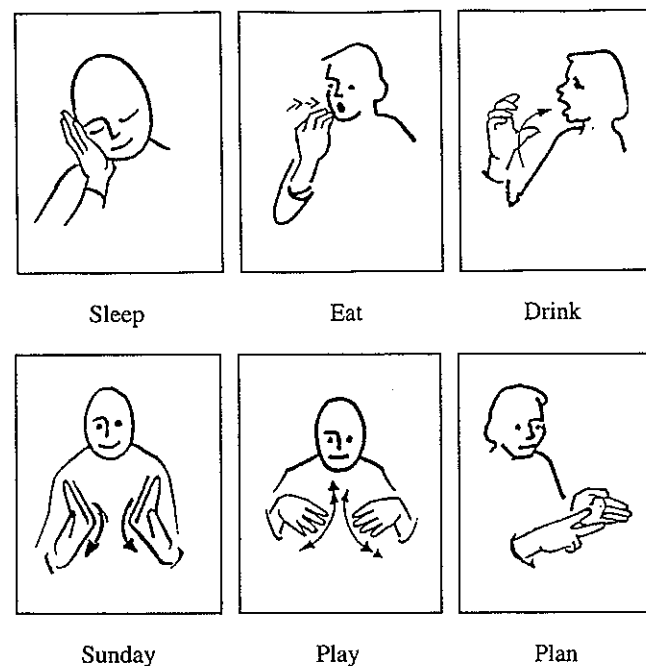

Sleep	Eat	Drink
Sunday	Play	Plan

Figure 3.4 Three iconic (top row) and three less iconic (bottom row) signs from South African Sign Language (SASL).

Manually coded languages (unaided system of iconic and opaque symbols)

Manually coded languages encode spoken languages by manual signs. The grammar of these systems thus follows the grammar of a spoken language. Seeing Essential English (SEE-I), Linguistics of Visual English (LOVE), Dutch with Signs (Nederlands met Gebaren – NmG) and the Paget Gorman Sign System (PGS) are examples of such manually coded languages. Such languages can thus be used simultaneously with speaking, although the signing of every word and even morphemes such as '-ing' or '-s' make this process very slow.

Key word signing (unaided set of iconic and opaque symbols)

Key word signing describes the approach whereby signs are used to represent only the most important words while the message is being spoken. For a person with difficulties in understanding spoken language, this practice adds a sign modality to aid understanding. A person speaking and signing key words at the same time also tends to communicate slower than by speech alone. By receiving this input, the person might, over time, learn these key signs and start using them expressively. However, when not accompanied by speech, these signs alone do not afford the person a means of grammatical expression. Similar to formalized key word signing approaches, such as Makaton (Grove and Walker, 1990), these types of symbols are limited to certain concepts, and can thus be regarded as a set.

Four-handed signing (unaided system of iconic and opaque symbols)

Also termed *co-active signing* (Von Balkom and Coumans, 2002), this method is employed by persons with dual sensory impairment to aid learning and understanding of manual signs. It entails the receiver touching the sender's hands while the sender produces a sign. The receiver thereby 'feels' rather than sees the sign produced.

Hand-cued systems (unaided system of opaque symbols)

These systems serve primarily to supplement speech reading, and are thus primarily receptive methods for persons with hearing impairment. Hand signs are used to supplement the information obtained from the shape of the mouth in order to distinguish between sounds. Examples of such systems are cued speech and Alphabet de Kinemes Assistes (AKA).

Fingerspelling (unaided system of opaque symbols)

Several manual alphabets exist, employing one or two hands to shape all the letters of the alphabet. Fingerspelling might be a useful tool for literate adults with acquired conditions – instead of having to learn many signs from sign language, they can make do with the 26 handshapes depicting the alphabet. However, as each letter needs representing, the communication rate is slow.

The use of manual symbols for a person with LNFS will be influenced by the motor and cognitive–linguistic skills. Furthermore the availability of teaching aids that are cheap and easily obtainable will play a role, especially in low-income-country contexts.

Other alphabet-based systems

Morse Code (unaided system of opaque symbols)

The binary nature of this system (dot and dash) makes this system accessible to persons with limited motor ability, as the dots and dashes can be signalled by eye-blink, vocally or with two gross motor movements. However, the system is cognitively taxing and requires good orthographic abilities.

Tactile methods

Tadoma (unaided system of opaque symbols)

Tadoma is a system aimed at improved understanding of speech by persons with sensory difficulties, particularly dual sensory impairment. The user places the thumb over the speaker's lips to discern lip movements and airflow, while the other fingers are spread over the speaker's jaw and throat to feel the vibrations as speech is produced.

Technical aids

This section will provide an overview of available types of technical aids relating to displays, selection aids and VOCAs.

Aided symbol displays

A symbols display refers to the way in which the symbols are going to be arranged or structured on a specific board, device or other surface (for example a carpet).

Lee and Thomas (1990) coin the term *selection set* to describe the aided symbols which need to be presented to the person using AAC in order that he/she may select from them. Such selection sets can contain auditory, visual or tactile symbols. Certain physical characteristics of these displays need to be considered in order to match displays successfully to the profiles of various persons in need of AAC.

Number of items

Beukelman and Mirenda (1998) alert us to the fact that the actual number of items on the display is a compromise of various factors. Consideration should first be given to the number of messages needed by the AAC user. If an alphabet-based system or an encoding technique is used, fewer items will be needed than if a one-on-one correspondence exists between symbols and messages. On a visual display, size and spacing will be further considerations. Multiple-page visual displays will further require navigational and visual memory abilities. Auditory memory as well as the ability to retain the organizational scheme of the display will be considerations when determining the number of items within an auditory selection set. Users need to remember that certain items will be announced after waiting long enough. For multi-level displays, users need to memorize the organizational scheme. 'Cake', for example, might be stored under 'food' in a topic-based organizational scheme.

Size

Physical size pertains to tactile and visual symbol displays. The user's motor access technique (i.e. direct or indirect selection) and visual abilities play a role here, while size, number and spacing of individual items obviously also influence the size of the display. The need for portability will necessitate a manageable size and weight of the display.

Spacing and arrangement of items

Once again pertaining to visual and tactile displays, the user's visual and/or motor skills, as well as the selection method used, influence the spacing and arrangement of the symbols. Items that are widely separated may enhance visual discrimination. Visual field problems such as tunnel vision, peripheral vision and blind spots will all influence the spacing and arrangement of items. Better motor control in one hand would necessitate adaptations in the spacing and arrangement of items to enhance success. Figure 3.5 illustrates the use of a communication board by a person with better motor control in the right hand. Items on the right are smaller and display the more frequently used concepts.

Orientation

The orientation of a visual or tactile display is influenced by the visual, postural and motor-control capabilities of the user. While a horizontal display provides hand and arm support as well as stabilization, a vertical display avoids neck flexion and provides easier access for light or optical pointers. Eye-gaze displays (such as the one illustrated in Figure 3.6) are made of transparent material (e.g. Perspex). User and partner are seated

Figure 3.5 Communication board for an individual with better motor control on the right side. Reprinted from Beukelman and Mirenda, 1998, p. 96.

on either side, and the user points to symbols by looking at the correct location. Eye-gaze displays need to be positioned upright to enable both user and partner a good view. Displays slanted at an angle between 30° and 45° reduce the neck flexion needed for horizontal displays, while still providing some measure of hand and arm support.

Fixed versus dynamic displays

All paper-based visual displays (e.g. communication boards and booklets) can be described as fixed, as symbols and items are fixed in a specific location. The number of symbols on fixed displays is usually limited by cognitive and/or motor factors. If a one-on-one relationship between messages and symbols exists, many symbols are needed to enable the user to access many messages. Displaying many symbols on various boards or on pages of a book may result in a system that is difficult to navigate and physically cumbersome. Encoding techniques or alphabet-based displays, in turn, need only limited numbers of symbols to encode many more messages. Displays in the form of paper-based overlays on many VOCAs, which do not make use of encoding, can also be described as fixed displays.

Beukelman and Mirenda (1998) distinguish between two types of dynamic displays. A dynamic display refers to a display on which selection

of one symbol changes the display. The first type of display makes use of a screen, on which selection of certain symbols results in an automatic change to a new display. The selection of the symbol for *hobbies* on a screen display containing a variety of conversational topics, for example, might change the display to one where all the person's hobbies are listed. Dynamic screens are employed by some computer software for communication, such as The Grid (Sensory Software International Ltd.; see website http://www.sensorysoftware.com), Speaking Dynamically Pro (Mayer-Johnson Inc.; see website http://www.mayer-johnson.com), ChatPC (Saltillo Corporation; see website http://www.saltillo.com) for the Casio palmtop, as well as by certain dedicated VOCAs, such as the Dynamo (DynaVox Systems LLC; see website http://www.dynavox.co.uk) and the Vantage (PRC; see website http://www.prentkeromich.co.uk).

Second, devices employing encoding techniques (e.g. Minspeak) may have displays that inform the user which items of the selection set are available for activation. While the symbols remain static, indicators (e.g. lights) change after each selection. VOCAs such as the ChatBox (Saltillo Corporation) and the Alpha Talker (PRC), where icon sequences can be used to encode messages, employ this technique. Once an icon is selected, all other icons that are linked to the first one light up, to indicate that they are available for selection.

Aids to select symbols

Depending on the type of symbol (auditory, tactile or visual), as well as the size, arrangement and number of items within a display, selecting from the display will require certain motor movements. Some persons in need of AAC may have motor skills limited to such an extent that they need an additional aid to select from a particular selection set. A head pointer might be useful for accessing visual symbols on a display if a person's arm/hand movement is inadequate to point to a symbol or press a button. A head mouse or infra-red tracker such as the one depicted in Figure 3.7 enables a user to access a device like a computer by head movements only.

Scanning entails that items from the display or selection set are systematically presented to the person using AAC by a partner/facilitator (partner-assisted scanning), or an electronic device (e.g. dial scan, computer or dedicated communication device). In partner-assisted scanning, the selection will often be made by a minimal body movement, such as an eye-blink. When scanning with the aid of an electronic device, the selection might be made by means of a switch. Figure 3.6 depicts some selection aids such as the dial scan and various switches used to access devices in scanning.
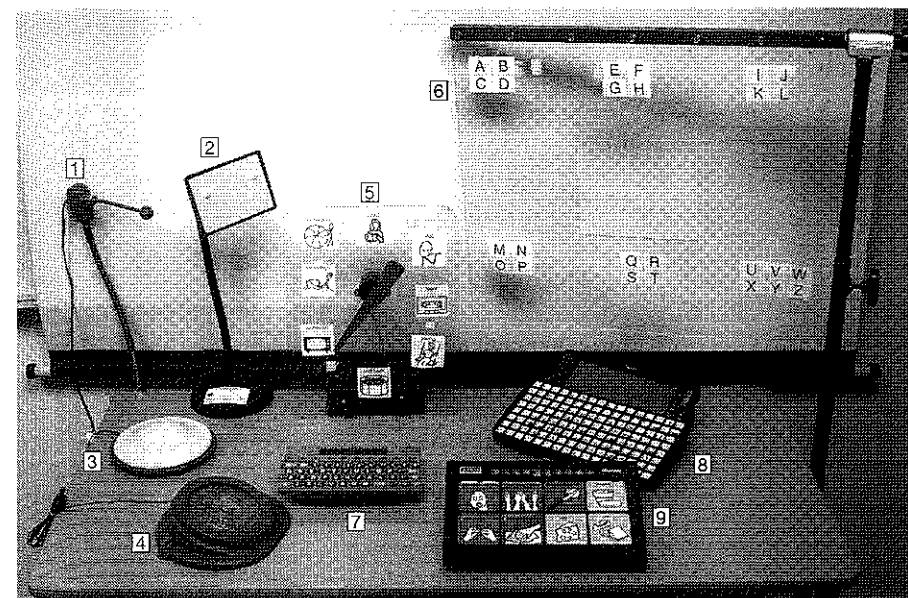
Figure 3.6 Various AAC aids.

(1) Ultimate Switch (Enabling Devices – see website www.enablingdevices.com); (2) Plate Switch on a Gooseneck (Enabling Devices); (3) Saucer Switch (Enabling Devices); (4) Lighted Signal Switch (Enabling Devices); (5) Dial Scan; (6) Eye Gaze Display or E-tran (Shonaquip – see website www.shonaquip.co.za); (7) LightWRITER SL35 LQBDO (Toby Churchill Ltd – see website www.toby-churchill.com); (8) Pathfinder (PRC) – see website www.prentkeromich.co.uk; (9) Macaw (Zygo Industries Inc. – see website www.zygo-usa.com).
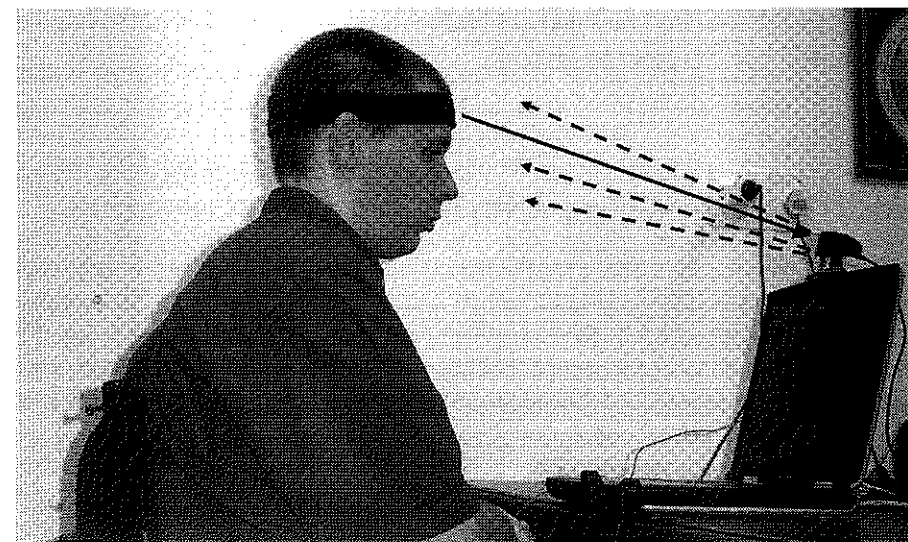
Figure 3.7 Head mouse used to access a laptop.

Voice output

VOCAs or SGDs have the advantage of making the message selected/compiled by the person using AAC audible to the receiver, thus closely simulating communication by natural speech. VOCAs can be classified as dedicated or non-dedicated, the former describing devices that are purpose-designed to act as communication tools while the latter term describes computers with specific software programs designed for communication purposes. Another important distinction is between synthesized and digitized speech. Synthesized speech entails the electronic conversion of text to speech; thus written words/sentences are converted to the acoustic form. Text might be entered directly into the device, e.g. on the LightWriter (Toby Churchill Ltd.), or stored under icons/pictures and then retrieved from this memory. This electronic conversion employs rule-based algorithms, which, of course, are unique to the language being simulated, e.g. English versus Dutch. While synthesized speech already exists for many spoken languages, it has not been developed for many languages of minority groups and also not for those used exclusively in low-income countries (See Chapter 9: AAC technology for development.) The LightWriter (Toby Churchill Ltd. see website www.toby-churchill.com) and the Pathfinder (PRC) depicted in Figure 3.6 both make use of synthesized speech.

Digitized speech, in turn, is directly recorded and stored onto the device. The person using such a device can thus only access whole words, and cannot compile his/her own new words (as with text to speech). However, any language can be recorded, making this option available to languages for which text-to-speech programs do not yet exist. The Macaw (Zygo Industries Inc.; see website www.zygo-usa.com) depicted in Figure 3.6 makes use of digitized speech.

Development of a communication system for an individual by using a variety of AAC strategies

As mentioned above, AAC entails more than a collection of strategies, techniques and aids. The ultimate aim of intervention should be for a person to communicate with maximal effectiveness across all contexts. An AAC strategy such as using a communication board should thus never be seen as the ultimate goal, but rather as one aspect within a multi-modal communication system.

Within most communication exchanges between speakers without communication impairment, multiple channels are used. A primary channel such as spoken words might relate the content or information contained within the message, while body language, facial expression and even prosodic

aspects such as intonation, rate and pitch add additional meaning or communicate the emotional aspects. Competent communicators employ all these modes selectively and skilfully within different contexts, in order to achieve effective and efficient communication. Similarly, persons in need of AAC need to build up a repertoire of different communication strategies (which might or might not fall under AAC), in order to be able to adapt to different contexts and partners. An AAC user might communicate with a laptop fitted with synthetic speech software at work (non-dedicated device), but prefer to use an alphabet board when chatting to friends during lunch, as this promotes better eye contact and a feeling of informality. Facial expressions might suffice to communicate with the person's spouse in certain situations. Some strategies might be combined within a certain situation – facial expressions and some gestures can enhance the message and increase rate of communication during exchanges where the alphabet board is primarily used. The combination of these strategies into a communication system makes communication more robust, flexible and adaptable to various situations.

Regardless of the system selected, the client's cognitive and/or motor skills need to be matched to the different AAC strategies. Matching the skills of the individual to the nature of the symbols to be used, and the way in which these will be selected and transferred, remain critical to ensure that the communication process is meaningful.

As previously mentioned, iconicity, degree of linguistic structure and complexity influence the learnability of various symbolic codes. At the same time, however, highly iconic codes with little linguistic structure and low complexity often do not afford the communicator a wide representational range and the opportunity to generate new meanings. While the communicator can participate (often in a rather stereotypical way) within certain limited contexts, communication remains on a superficial level – namely, routine exchange of information with limited involvement in the communication process (see Chapter 2 for the difference between participation and involvement).

Apart from symbol characteristics, other factors influence the success with which AAC strategies are acquired and used. The motivation of the person learning a new skill is an obvious factor. Motivation will be influenced by the extent the person sees the new strategy as useful – as a step to independence and improved life quality. In the beginning communicator, motivation is often externally instilled, for example rewarding the use of the sign 'more' with more of the activity/item requested. The way in which interventionists adapt AAC strategies to the client's interests and life circumstances cannot be underestimated.

Learning will also be facilitated by role models, especially in beginning communicators. Seeing the communication strategy in action can have a powerful effect on the motivation to learn and use it.

Populations in need of AAC

After having illuminated the components in the communication process and the requirements of these, the characteristics of various symbolic codes used in AAC, as well as the aids employed, we will now consider the different populations in need of AAC. The goal is to understand the characteristics of each group in order to become sensitive to intervention issues needing to be addressed within each group.

From the communication model, it is important to note that a person using AAC is both a receiver and sender of messages. Furthermore, AAC can be used for input and/or output, depending largely on the language abilities of the person using it. Von Tetzchner and Martinsen (1992) mention three functional groups which differ from each other with respect to degree of language comprehension as well as the potential to learn language in the future.

Expressive group

According to Von Tetzchner and Martinsen (1992), the expressive language group has a good understanding of spoken language but is unable to use speech, mostly due to physical disabilities or anatomical abnormalities. The majority of these individuals will never use speech, and AAC will become a permanent alternative.

The supportive language group

This group consists of two subgroups, the first comprising people who are in need of a supplement to encourage comprehension and expressive use of speech. Children with very delayed language development fall within this group, such as children with developmental aphasia and children with Down's syndrome. The second sub-group resembles the expressive group, except that AAC is an augmentative technique rather than a replacement of speech. People with severe articulation disorders may, for example, point to the initial letters of the words they are producing on an alphabet board in order to help the listener understand. In other words, their initial letter-cueing augments their speech to increase intelligibility.

Alternative language group

For persons falling into this group, AAC is probably the main input and output mode for the rest of their life. People falling into this category have little understanding of spoken language and therefore cannot use meaningful speech either. People with autism or severe cognitive impairment may fall within this group.

The use of graphic symbols has additionally been found to be helpful in multilingual educational contexts, as the graphics aid understanding of a spoken language which is possibly not the learner's home language. AAC symbols are thus used mainly receptively, and this population most resembles the first subgroup of the supportive language group.

The relevance of identifying different user groups of AAC is, first, that it makes professionals aware of the possibility of different subgroups or sub-profiles of AAC users. This in turn could be relevant problem-solving evidence-based outcomes, as certain strategies might be more useful for some groups than for others. Clearly clients with different pathologies could also manifest with varied responses to AAC intervention strategies. AAC can thus be used by people with disabilities with a broad range of etiologies, the common denominator being their lack of ability to express themselves through speech. Table 3.2 gives an overview of some etiologies which frequently cause LNFS.

Table 3.2 Categories of impairment frequently accompanied by LNFS

Cognitive impairment	Sensory impairment	Neurological impairment	Genetic condition (syndromes)	Structural impairment	Other
Developmental disabilities Cognitive impairment	Deafness Blindness Deaf-blind	Cerebral palsy Aphasia Apraxia Dysarthria Progressive disorders (e.g. myasthenia gravis, Parkinson's disease) Traumatic head injury	Fragile X Down's	Glossectomy Laryngectomy	Autism Attention-deficit disorders

Reprinted from Musselwhite and St Louis (1988).

Communication by augmentative and alternative means

As previously mentioned, the aim of AAC is to provide a person with LNFS the means to be involved in communication – engaging with others. Using the model, the potential challenges facing persons with LNFS can be identified at each step of the communication process. The degree of success with which the use of AAC addresses each of these challenges will, in the end, determine the degree to which the person can become an involved

communicator rather than only a passive responder, or worse, merely an observer.

Not all persons with LNFS face all of these challenges. The particular combination of challenges is directly related to the combinations of abilities and needs of the person using AAC, the communication partners and the environment.

Some persons using AAC might have trouble at the idea-formation stage. Persons with cognitive disability might find this difficult. However, starting to teach such a person the function of symbols – meaning that a concept, action or object can be represented by something else – provides a form of cognitive stimulation. The development of cognition and language (which, in essence, entails the use of symbols) is considered by many theorists to be inseparable (Bates, 1994; Fodor, 1975; Mandler, 1988; Piaget, 1926, 1960; Vygotsky, 1987). Helping such a person to start understanding the functions of symbols and then using these symbols to represent actions/objects (which is a form of AAC) can thus be the first step in helping such a person to start formulating ideas to be communicated to others.

Should a person be able to formulate an idea, the next critical need is the motivation to attempt to communicate this idea to another person. Very often, this motivation is lacking in persons with severe communication problems, due to repeated failure of communicative attempts, or a lack of expectations from partners. The phenomenon of learned helplessness is all too often observed in persons with LNFS. Providing a person with AAC should make an immediate difference and increase the degree of independence and control which the person has over his/her own life. Selection of the initial symbols to be learnt needs to be guided by the preferences of the person, as well as the ease with which these symbols can be learnt and used. However, within this process the interventionist should still not lose sight of the long-term implications of using a specific symbol set or system. The representational range of the symbol set/system, the degree to which the person using it can generate any message, the bridge it provides to literacy, and the ease with which symbols can be located and selected (this applies to graphic symbols) all need to be considered when making an initial choice of AAC symbols, techniques and aids.

Should a communicator have formulated an idea, and have the motivation to attempt to communicate this to others, the next critical need is to select a channel to transmit this idea. A person with LNFS often has a limited choice at this stage. By definition, speech is difficult or impossible to use, but physical and/or cognitive disabilities may even impede on the use of other channels such as writing, use of pictures, or facial expressions. For a person to be a competent communicator, AAC strategies,

techniques and symbols should be functional across different environments and types of communication exchanges. For example, a technical aid might not work in the swimming pool. Even if the person using AAC is literate, an alphabet board is not an option for communicating with a non-literate partner. Expanding the choice of channels of communication to a multimodal system should always be a goal for AAC intervention.

Once channels have been chosen to communicate the message, the person using AAC needs to produce and/or select the appropriate symbol. Various challenges are inherent in this process. First, persons using AAC often make use of symbols, which are not used by most other communicators. A lack of role models might impede the learning process. This becomes a factor, especially if the person has congenital disabilities. As a result of difficulties in learning the symbols, a person might have a limited number of symbols available, which would restrict the messages that can be encoded. In addition, the code used may be a set, which implies that there are a limited number of concepts within the code itself (e.g. PCS). If the symbols used are the type which necessitate the person to select words rather than smaller units (such as letters), the person will need to have many options available at the same time, putting a memory load on the person using AAC when in the process of retrieving the correct message.

Production or retrieval of symbols might also be a slow, laborious process. In particular, people making use of indirect selection through scanning need a lot of time. However, sufficient rate of conversation is of prime importance for successful communication (Damper, 1986; Scull and Hill, 1988; Venkatagiri, 1995). For people who use electronic AAC devices, long switching pauses have been found to be perceived as awkward and disruptive (McLaughlin, 1984). Similar problems have also been found for people using low-tech aided communication aids. For example, Beukelman and Yorkston (1982) reported a case example in which slow rate of communication between a person using an alphabet board and nursing home staff led to a drastic decrease in interaction.

Let us assume, however, that a person using AAC has managed to select a symbol to encode a message and the symbol is transmitted to the receiver. The obvious challenge now is for the receiver to decode this symbol. Due to the fact that AAC entails less commonly used symbols, this is often a major challenge. The receiver often needs to have prior training to understand the symbols, for example training in manual signs or Blissymbols. Most systems or sets of line drawings are accompanied by the written word (gloss), so that literate receivers can decode them quite easily. However, a non-literate receiver would not find this task so easy.

Apart from the challenges inherent in the process of AAC, variables outside of the communicators may impinge on the effectiveness with

which this form of communication can be used as a tool for involvement and relationship building. In the process of learning a new communication code, focus is placed on the how, i.e. the techniques, symbols and aids used and how to access and manage these. The ultimate goal – the promotion of communication events (as described in Chapter 2: Intervention issues) – may well become lost in the process. In addition, the focus upon the new modes of communication that are being acquired might detract from the assets the individual brings to the communication exchange – other modes or channels of communication that are in existence. A typical example is the situation whereby a person might use a gesture or eye-pointing to answer a question, but is then told to use the board to answer, in spite of the fact that his/her message has been understood.

Challenges relating to AAC implementation

Finally, some challenges in AAC intervention will be addressed to highlight some of the aspects mentioned before.

Myths related to AAC

In the first instance, the field of AAC is relatively new, thus there are various misconceptions still prevalent regarding the use of AAC systems. These attitudes and preconceptions held by team members involved in AAC intervention can hamper the intervention process and are thus critical to address.

- *There are certain prerequisites for an individual to use AAC.* The notion of prerequisites for AAC intervention holds that an individual needs a minimum level of skill in order to 'qualify' as a candidate for intervention. However, communication can almost be said to be part of life – all human beings communicate to some extent. It follows that anyone who is unable to communicate through speech will be given at least a trial period of AAC intervention. There are no prerequisites for the use of AAC strategies. Selection criteria become important only in determining what specific AAC system will be most appropriate for a particular candidate (Blackstone and Painter, 1985).
- *AAC strategies inhibit the development of speech, as the person might become 'lazy' if a different method of communicating is used.* However, research suggests that AAC can support speech development in individuals with a variety of disorders, such as aphasia, apraxia, dysarthria and autism (see Zangari and Kangas, 1997, p. 236, for an extensive list of references). As speech is a tool for communication, it

seems that the development of communication can encourage the development of speech and vice versa. As mentioned above, the intervention focus is always for the individual to become an involved communicator, necessitating a combination of strategies and techniques into a flexible and adaptable communication system. The focus is never exclusively on one technique or strategy, and thus exclusive focus on speech drilling does not comply with AAC intervention goals.
- *AAC requires expensive devices, therefore it is not really appropriate for those living in poverty contexts.* AAC is ultimately about human communication. It is focused on assisting people in finding ways to enhance contact with their fellow men and women. Regardless of the socio-economic status or mother tongue of the individual, an appropriate system can be developed to assist in communication. Having said that, as is the case with cars – there are many models available. Very few academics can claim to drive around in luxury German cars; perhaps it is not that foreign that the same applies to communication technology!
- *The provision of a communication aid such as a communication board or a device, in itself, is enough to solve an individual's communication difficulties.* Technology (including both high and low technology) is not magic! Training, role-modelling and creating opportunities for the use of a communication aid are essential to avoid an aid ending up unused in the cupboard.

Team involvement in implementation

Implementation of an AAC system cannot be the isolated effort of the interventionist and the user. All persons who are communication partners of the user are invariably affected by the use of AAC; and through their attitudes, knowledge and skills either foster or hinder implementation. The support network of the user (see Chapter 8: Support-based AAC intervention) obviously has a significant role to play – on the one hand providing physical and emotional assistance while, on the other, fostering independence and combating learned helplessness, which is often a great hindrance to implementation.

The motivation of a person with LNFS, as well as significant others, to use AAC is influenced by many variables. First of all the person with LNFS and significant others must perceive AAC to be beneficial, improving the quality of life of at least the person with LNFS. How beneficial AAC really is can be measured, among others, by the increase in independence, decrease in frustration caused by inability to communicate, and increased access to various communication contexts and partners. AAC is not only for school or home use. In order for it to become a useful communication

system, the individual must have it available for communication in all domains of life. This implies all those involved with the individual need to encourage the use and extension of the communication system.

The cost and perceived effort in learning and implementing AAC may seemingly outweigh benefits, which will decrease motivation to use it. For some people, use of AAC seems to be equated with the admission that 'something is wrong', or that the person with LNFS 'has a problem'. Such attitudes are often paralleled by feelings of shame and guilt concerning the person's disability in general. At times such feelings stem from cultural perceptions of disability as a 'curse' or a 'punishment' on the person and the family.

Dynamic nature of communication

Communication is not a static event – it changes as situations change and as people grow. This implies that for a communication system to be relevant and useful it needs to accommodate these changes and grow with the individual and family. These constant changes are important to ensure that the communication device does not become redundant and that AAC users do not grow bored with the content. A communication system, regardless of its nature, needs to allow for expansion and new messages. Clearly this requires dedication from all involved in the intervention team to ensure that this becomes an authentic tool for communication and not just a 'show piece' (see Chapter 2).

Funding

While funding is, of course, a real problem in poverty contexts, it should never be an excuse to do nothing. Clinical experience shows that creative and dedicated use of minimal resources can often promote significant increase in life quality. Low-cost, low-technology options might be more cumbersome to make and to implement, but often go a long way.

Fundraising for specific communication aids needs to be encouraged by providing contacts and encouraging the involvement of the whole community. The changing needs of individuals and families also need to be anticipated to prepare them for a lifespan intervention approach which focuses on assisting them to problem-solve their own situation. In this way they become more empowered in dealing with demands of the future (see Chapter 2).

Support and training in implementation

Shortage of trained professionals, long distances from intervention centres, and/or unaffordable transportation fees impact on the availability of

support and training in AAC implementation. In addition, the traditional medical model has engrained the roles of the client as the recipient of services, and the practitioner as the supplier. AAC interventionists working in multi-cultural contexts often struggle to understand the cultural and social context of their clients, as it differs so much from their own, which makes it difficult for them to support clients in spite of good intentions. Managers of health services often do not see the importance of understanding the cultural and social contexts of clients, and interventionists are not allowed the time or resources to increase their knowledge.

Culturally and linguistically appropriate resources

Many formalized symbol systems and sets are linked to the culture and language of industrialized countries. Chapters 5 and 6 illuminate the cultural issues surrounding graphic symbols. Similarly, synthesized speech has not been developed for many of the languages. Chapter 9 (AAC technology for development) deals with the issue of appropriate technology. Similar to regular interactions, AAC strategies need to be highly sensitive to the cultural and social context within which they will be used. The challenge is not only for the system to be appropriate, but also for the use of the system to be highly sensitive to cultural interactional patterns.

Cultural appropriateness can be defined on different levels:

- Selection of AAC strategy for communication: Within some cultures, particularly those with a stronger oral tradition, unaided systems could be more acceptable, as people might be less confident with visual representations on communication boards, which require a more literate orientation (see Chapter 6). As the interventionist might ultimately like to introduce an aided system as well, starting off with an unaided system might facilitate the long-term intervention process.
- Method of representation: Clearly the symbols used for communication will be strongly culturally influenced.
- Unaided systems: The manual signs or gestures used need to be similar to those used by others with disabilities in the area, to ensure that the system will be easily recognizable and familiar to those who use manual signs for communication. This will also facilitate the use of appropriate symbols that will not cause offence.
- Aided systems: Graphic symbols used on displays need to be relevant to the cultural context by, for example, using pictures that are culturally appropriate. Figure 3.8 depicts a communication display developed in India, while song displays developed in South Africa are illustrated in Chapter 13.

hello	Reena	Pinky	big
	you	Mamta	little
what	mother	Raja	smelly
	Mrs Banerje	father	fierce

मेरा नाम	मेरा दोस्त
मैं बीमार हूँ	पता है मेरे टिफिन में क्या है?
वाह ! स्कूल में क्या मज़ा आया !	मेरी बात सुनो
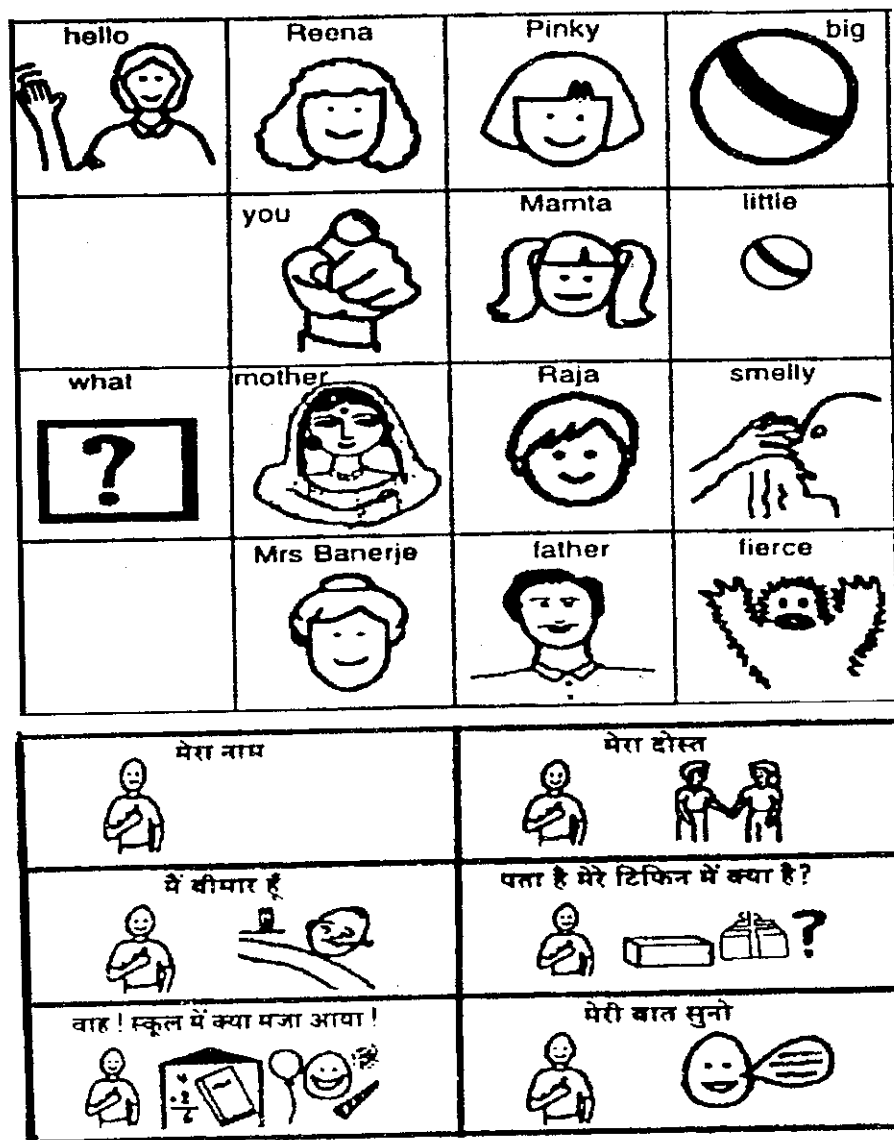
Figure 3.8 Extracts from communication boards adapted for use in India. Reprinted from Warrick and Kaul, 1997.

- Vocabulary selection: The selection of the content or vocabulary to be put on the communication display is pivotal to ensure sustainable interaction. Interactional rules prevalent in a particular cultural context need to be adhered to by ensuring that the individual has access to the vocabulary needed to participate.

- Use of communication system: This aspect clearly refers to the socio-cultural rules of interactions prevalent in any society or community. Involvement of significant others and community members are vital in assisting the interventionist in reflecting on various aspects of the communication system, to ensure that it remains culturally appropriate over time as the needs of the individual and family change.

Conclusion

This chapter provided a brief overview of some of the main considerations and issues in the field of AAC intervention. AAC intervention has over the years come a long way; in fact it is a most dynamic and rapidly growing professional field. However, the dynamic nature of communication, and its complexities and subtleties, will for many decades to come provide ample opportunities and challenges for the development and refinement of relevant user-friendly communication systems for AAC users and their families. Introducing an AAC system into an individual's and family's life induces changes – some can be predictable but others are unpredictable. The intensity of the changes and the intervention team's ability to cope with these will largely determine the sustainability of the system. Only by developing a more fundamental understanding of how the introduction of a different communication system impacts on small-group interaction and family life can AAC systems become long-term, sustainable solutions for clients and their families.

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CHAPTER 4
Disability and poverty

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This chapter describes the relationship between poverty and disability, in an attempt to enhance the understanding of clinicians in providing appropriate intervention within poverty contexts. The link between poverty, disability and development is emphasized so as to provide a comprehensive background for intervention, particularly within low-income countries. The chapter starts by defining the concept of poverty and emphasizing its multidimensionality. After defining the concept, the relationship between poverty and disability is discussed with disability being seen as both a cause and a consequence of poverty. In conclusion, the implications of the links between disability and poverty are highlighted, particularly for low-income countries where poverty is so pervasive.

Since the emergence of the disability rights movement in the 1960s and 1970s there have been significant advancements in human rights advocacy and international standards setting to promote equity for persons with disabilities. Starting with the United Nations' (UN) Declaration of the Rights of Mentally Retarded Persons in 1971 and the UN Declaration on the Rights of Disabled Persons in 1975, global commitment to equalizing opportunities for people with disabilities has grown steadily. These developments culminated in the adoption by the UN General Assembly in 1981 of the World Programme of Action Concerning Disabled Persons (WPA), which introduced a progressive and comprehensive approach to disability management and shifted the focus from a medical approach to disability to a human rights approach. The WPA was followed in 1993 by the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which aimed to provide a framework for disability policy implementation by member states.

In spite of these advances, disability strategies even in the industrialized countries have 'tended to consist of disconnected combinations of modern inclusive approaches, and elements of the rehabilitation, special education and/or custodial care approaches of the past' (Metts, 2000, p. ix). While the low-income countries have also begun to commit themselves to the new inclusive approaches, disability services have remained limited, reaching only small numbers of the disabled populations. In both the industrialized and low-income countries, issues of disability have been addressed by distinct government structures and policies, and academic and research endeavours relating to disability have retained distinctive disciplinary foci separate from mainstream societal concerns.

However, in recent years a number of developments have begun to point the way towards a more integrated approach to disability. In the past five years in particular, there has been renewed interest in the relationship between disability on the one hand, and poverty, gender inequality, social exclusion and other forms of social disadvantage and marginalization on the other. This renewed interest has included international development organizations such as the World Bank and the United Kingdom's Department for International Development (DFID) paying greater attention to the issue of disability, and incorporating disability within their policy agendas. It has, for example, prompted the DFID to declare, 'Eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account' (DFID, 2000, p. 1; Elwan, 1999; Yeo, 2001).

In tandem with these developments, the understanding of poverty has been deepening over the last two decades with the development of multidimensional conceptions of poverty that explicitly or implicitly include disability as a manifestation or even an integral component of poverty. A further development that has helped to focus attention on disability, particularly in Africa, where rates of infection are extremely high, has been the HIV/AIDS pandemic. With its high toll of death and disability, HIV/AIDS has become a major drain on the resources of poor families and communities and therefore an important factor in the creation and perpetuation of poverty. For example, a Food and Agricultural Organization (FAO) study in one African country showed that the cost of caring for one family member with HIV/AIDS and meeting funeral expenses exceeded the average annual farm income (Southern African Regional Poverty Network (SARPN), 2002).

This chapter sets out to explore the relationship between disability and poverty in order to examine the ways in which poverty and disability interact with one another to produce extreme forms of vulnerability and exclusion. The first part of the chapter is therefore devoted to understanding poverty as an evolving concept. In particular, attention is focused on the multidimensional nature of poverty not only in order to get to grips with the concept of poverty, but also to create a deeper understanding of the relationship between disability and poverty. The second

part of the chapter focuses more specifically on disability and its relationship to poverty, showing how disability may be both a cause and a consequence of poverty, and demonstrating how a full understanding of either concept is dependent upon an appreciation of the relationship between the two.

Understanding poverty in its different dimensions

In the last two decades, thinking about poverty has evolved from a narrow focus on income to a broader focus that takes into account other dimensions of being poor. The definition of poverty has been expanded to include, first, living standards such as longevity, literacy and health, then vulnerability and risk, and finally powerlessness and lack of voice. Even if this broadening of the definition of poverty had not fundamentally changed those whom we count as poor, it has resulted in a deeper understanding of poverty and the poor, and this has had a significant impact on the strategies developed to address poverty.

This broader perspective on poverty has altered approaches to policy reduction not only by increasing the number and types of interventions required, but also by exposing the complex relationships that exist between the different dimensions of poverty. The ways in which we define poverty have important implications for both the measurement of poverty and for the strategies we design to combat it. This approach also has important implications for how we understand disability and the kinds of strategies and interventions that might more effectively address disability, particularly within impoverished contexts.

Income and consumption

One of the earliest and most common conceptions of poverty is to see it as lack of money or income. Early conceptions of and attempts to measure poverty focused on income and expenditure (or consumption), that is, the amount of money or material goods (food, shelter, clothing etc.) necessary to secure subsistence. These approaches focused attention on objective measures of poverty, such as poverty lines, which usually involve the calculation of a minimum amount of money needed to support a family or household. All households falling below this poverty line are then defined as poor.

However, because levels of subsistence cannot be objectively established and are therefore dependent upon what is socially acceptable, they tend to change over time and from one place/country to another. The focus on households has also meant that the distribution of income or consumption *within* households is not taken into account. Using income and expenditure as a means of defining and measuring poverty has been strongly associated with policies that attempt to foster economic growth, although considerable attention has also been devoted to the complementary issues of inequality and distribution.

To define poverty purely in terms of income deprivation may be convenient for operationalization and measurement, but it is also arbitrary. This is because, while income undoubtedly plays a key role in determining the kinds of lives that people can lead, it is not the only influence on their lives. Nor can all the other manifestations of poverty be reduced to income deprivation. For example, one might think of unemployment as a social ill because it deprives the unemployed of an income. However, the lack of an income is not the only disadvantage associated with unemployment, as a broad range of individual and social costs can be attributed to it. These include psychological harm and ill-health (as a result of not having a job), skills loss, loss of output, loss of motivation, constraints on human interaction, weakening of social values, and so on. Loss of income is therefore not the only deprivation that is suffered as a result of unemployment, and even when compensation is provided, for example by way of unemployment benefits, other deprivations resulting from being unemployed have to be taken into account (Sen, 2000a).

It might still be argued that even if one takes the other ill effects of unemployment into account, one might still be dealing with essentially the same group of people; that focusing on the other dimensions of poverty may not fundamentally change those whom we regard (or count) as poor. Sen convincingly demonstrates that this is not the case, in relation to mortality and income in different parts of the world. For example, while African-Americans have considerably higher levels of income than many of the populations of low-income countries, as a group they suffer considerably higher rates of mortality than do the populations of nations that have much lower levels of income, such as China, Sri Lanka, Jamaica, Costa Rica and the Indian state of Kerala (Sen, 2000a).

These differences in the relationship between income and mortality may also be found within the low-income countries. Sen (2000a), for example, compares the GNP per capita and life expectancy at birth of seven low-income countries and finds that, in spite of their very low levels of income ($500 and less), Sri Lanka, China and Kerala had significantly higher life-expectancy rates than Gabon, South Africa, Brazil and Namibia. In spite of their considerably higher incomes (ranging between $2000 and $4000), these four countries had life-expectancy rates ranging between 54 and 65 years, in contrast with the three Asian countries, where life expectancies ranged between 70 and 73 years. As these figures were for 1994, they are unlikely to have been significantly influenced by deaths associated with the

AIDS pandemic. Statistical comparisons of GNP per capita and the Human Development Index (HDI) also show significant deviations within countries when they are ranked by these two variables (United Nations Development Programme (UNDP), 1990).

Human development

In the 1980s the narrow emphasis on income as the primary indicator of poverty began to be broadened to include other dimensions of impoverishment, in particular education and literacy, health and nutrition, and longevity and mortality. In particular the concept of human development, which is associated with the UNDP, has shifted attention from the preoccupation with income deprivation to concerns with well-being and the quality of life. The human development approach placed the emphasis on people, arguing that the primary objective of development is to benefit people. While acknowledging that people often value higher incomes, the proponents of human development argued that there were many other things (such as nutrition, health, education, security and social participation) that people have reason to value, which cannot be reduced to income (UNDP, 1990, 1996, 2000, 2002).

While it is sometimes argued that income is a good proxy for all other features of development because money can be used to purchase food, healthcare, education etc., this is only partly true. Income is a means and not an end. It may therefore be used for 'good' or 'bad' purposes, for example to feed a family or finance a criminal syndicate, or to buy medicines or narcotics. The well-being of society therefore depends more on the uses to which income is put rather than the level of income itself. Second, income and human development are not always related to one another, in that there are examples of countries with high levels of human development at modest levels of income and low levels of human development at high-income levels. The various human problems experienced in many of the affluent industrial nations suggest that by itself income provides no guarantee for human progress (UNDP, 1990).

Furthermore, improvements in health and education are not only important in their own right as contributions to the quality of life but they may also be seen as an investment in human capital that can yield returns by increasing income. There are significant interactions between health, education and income. For example, healthier children perform better at school, while more educated mothers are better able to care for the health of their children. Similarly, a healthy and well-nourished person can be more productive in the workplace than someone who is ill and undernourished, and thus has the potential to earn more, ensuring both her continued nutrition and greater work capacity.

One of the best-known indicators of poverty developed by the UNDP in the 1980s was the Human Development Index, which provided an aggregate measure of income, health and education. The overlap between the different indicators of poverty should not, however, lead us to believe that there is an exact correspondence between the different dimensions of poverty. While those who are deprived of income often also lack education, have poor health and die younger, as Kanbur and Squire (1999) point out, 'the correspondence is less than complete and can, in some cases, be quite small' (p. 15). For example, while Sri Lanka, Nicaragua, Pakistan and Guinea all had per capita incomes in the range of $400–$500 in 1994, their life expectancies and infant mortality rates differed markedly from one another. For example, while life expectancy in Sri Lanka was 71 years, the corresponding figure for Guinea was only 44 years. Similarly, the infant mortality rates of these two countries were 24 and 135 per 1000 live births respectively (Kanbur and Squire, 1999).

The Human Development approach was strongly influenced by the capability perspective of the economist Amartya Sen on poverty and development (Vizard, 2001, p. 2). Sen's (2000a) approach will be explored towards the end of this section.

Listening to the poor

The majority of poverty measures that were developed, including those that went beyond income, were generally defined by outsiders, i.e. people other than the poor. During the 1990s recognition grew of the need to take into consideration the views and perceptions of the poor themselves. As one extensive study of poverty, based on the perceptions of the poor, put it: 'There are 2.8 billion poverty experts, the poor themselves' (Narayan et al., 2000, p. 2). The same study quotes an impoverished Ghanaian as saying that 'poverty is like heat: you cannot see it, you can only feel it; so to know poverty you have to go through it.' Allowing the poor a say in how we define poverty not only helps to broaden our understanding of poverty and reduces poor people's sense of isolation, but also serves more pragmatic purposes in that it secures their greater commitment to implementation.

Extensive consultations of the poor provide confirmation of the multidimensional nature of poverty. The poor do not define their quality of life purely in terms of material deprivation, but see it as having multiple, interlocking dimensions, which combine to create and sustain powerlessness and to constrain freedom of choice and action. Although not all of these dimensions apply at the same time, and although they may vary between different categories of the poor, they manifest a consistency over both time and place and constitute a trap from which the poor continuously struggle

to extricate themselves. Narayan et al. (2000) identified ten interlocking dimensions of powerlessness and ill-being associated with the experiences of the poor:

- livelihoods and assets are precarious, seasonal and inadequate;
- places of the poor are isolated, risky, unserviced and stigmatized;
- the body is hungry, exhausted, sick and poor in appearance;
- gender relations are troubled and unequal;
- social relations are discriminating and isolating;
- security is lacking in the sense of both protection and peace of mind;
- behaviours of those more powerful are marked by disregard and abuse;
- institutions are disempowering and excluding;
- organizations of the poor are weak and disconnected;
- capabilities are weak because of the lack of information, education, skills and confidence.

Giving the poor a voice, and understanding how the poor experience poverty, have helped to refocus attention on two related aspects of poverty that had previously been raised in other contexts. One of these aspects of poverty revolved around vulnerability and risk, and the other around powerlessness.

Vulnerability and risk

In describing poverty the poor place heavy emphasis on their sense of vulnerability. As Kanbur and Squire (1999) point out, poverty is not just 'a state of having little, but also of being vulnerable to losing the little one has' (p. 20), and therefore of being plunged even deeper into poverty:

> Increasingly we are realizing that even such victories as the poor can achieve in improving their lot, no matter how virtuously linked to increasingly better outcomes, ultimately suffer from excessive fragility. Risks associated with being poor may wipe out hard-won gains overnight. [...] In many cases, risk prevents the poor from undertaking possibly high-return activities. The problem of risk has at least two dimensions, then: keeping the poor in low-risk, low-return activities, and endangering what they already have. (p. 23)

The poor are subjected to a range of vulnerabilities created by changes in their physical and social environments. Such changes cover a broad range of contingencies, including changes in the natural environment such as droughts and floods, market fluctuations such as increases in the price of food or a drop in the price of agricultural commodities produced by the poor, wars and civil strife, crime and violence, and even seasonal fluctuations that produce periods of financial and other stress. While external

changes (risks, shocks and stresses) are essential components of vulnerability, it is important not to lose sight of the 'internal' side of vulnerability, namely defencelessness, or the lack of means to cope without suffering damaging loss. This lack of a means to defend them from loss is a product of the lack of resources of the poor. 'The poor suffer from risk because they lack the means to protect themselves adequately against it – this is what makes them vulnerable' (Kanbur and Squire, 1999, p. 20).

The common strategies for dealing with risk – insurance and borrowing – are seldom accessible to the poor and, where they are accessible, usually involve high costs. Because the poor lack collateral (and therefore constitute a high risk to lenders) and can only afford to borrow small amounts, high administrative costs result in very high interest rates. Similar problems apply to insurance, particularly in relation to agricultural insurance. The lack of credit and insurance has severe consequences for the poor. A study of rural households in south-western China in the late 1980s, for example, showed that following a crop failure the poorest tenth of households suffered a devastating 40 per cent drop in consumption, in contrast with the richest third of households, which experienced a 10 per cent decline in consumption.

Under conditions of severe stress and the absence of more conventional strategies to protect themselves against risk, the poor have often to resort to survival and coping strategies that may provide temporary relief, but are counterproductive in the long term. For example, a common strategy of poor people is to diversify their livelihoods, to rely on multiple sources of income and other assets. While this strategy can often protect the poor from suffering severe losses when one source of income fails, it can also have the effect of preventing poor people from taking full advantage of more lucrative opportunities and of keeping the poor in low-risk and low-return activities. Similarly, it has been shown that when poor households face a loss of income, they often withdraw their children from school, thus limiting their children's prospects of escaping poverty (Kanbur and Squire, 1999).

Isolation and powerlessness

The above discussion places the emphasis on the economic vulnerability of poverty, but the poor are not only economically marginalized: they also lack social and political power. The social and political powerlessness of the poor finds strong expression in the ways in which the poor experience poverty. Consultations of the poor (see above) consistently demonstrate that the poor experience social relations as discriminating and isolating, that they perceive themselves as disregarded and abused by those with power, that social and political institutions are disempowering

and excluding, and that their own organizations are weak and discon-nected. The social and political vulnerability of the poor can be seen as having at least two aspects: an *external* aspect involving discrimination and exclusion by those who are not poor, and an *internal* aspect involv-ing weaknesses in their own organizations and social relationships.

Understanding the powerlessness of poverty has resulted in a greater emphasis on development strategies that attempt to empower the poor by involving them in the development process. Over the last few decades evidence has accumulated of the value of popular participation in devel-opment. It has been shown in a variety of contexts that top-down solutions often fail, and that the poor often have better knowledge of their own situations and needs and can therefore contribute to the design of policies and practices that are intended to help them. Kanbur and Squire (1999), for example, provide an example relating to the educa-tional expenses of poor rural households in Zambia. School fees and related costs such as school uniforms and books typically occur in the pre-harvest period when rural incomes are low and available resources are needed to ensure households' food supplies. This situation places con-siderable strain on the existing resources of poor households and points to the need to distribute school expenses over the year or to shift them to another part of the year when resources are under less strain.

Capabilities and freedom

The long list of issues and concepts that have been identified within the multidimensional concept of poverty raises some concerns about the con-ceptual coherence of the concept. As Lok-Dessallien (n.d.) suggests, the expansion of the concept of poverty to include other broad areas of con-cern may 'undermine the usefulness of the concept from a policy perspective'. Indeed, one might ask whether the concept has not become so broad as to render it meaningless. Does the new expanded definition of poverty have any conceptual coherence? And, if so, what theoretical underpinnings, if any, underlie the concept? From an empirical point of view, it may also be that adding new dimensions to the concept of poverty does not fundamentally change those whom we count as poor.

Trends in the development of multidimensional approaches to poverty and development may be seen as culminating in the work of the Nobel-prize-winning economist Amartya Sen (2000a). Rather than simply aggre-gating the various different dimensions of poverty, Sen (2000a) has developed a conceptually coherent framework in which poverty is seen as *capability deprivation*, that is, 'the lack of freedom to do certain valuable things' (Sen, 2000b, p. 5). Development, on the other hand, is seen as expanding the freedoms that people have in order to lead the kinds of

lives that they value. In terms of the capability perspective, the poor are subject to restrictions on their freedom that leave them with little choice or opportunity to exercise their will or agency to achieve the kinds of lives they have reason to value. The importance of freedom (as opposed to more 'objective' measures of deprivation) may be illustrated by Sen's (2000a) example of an affluent person who *chooses* to fast as against a destitute person who is *forced* to starve. While both of these people may consume the same amounts of food and both may suffer similar degrees of nutritional deprivation, the former still has the freedom to choose to eat well, while the latter does not.

The expansion of freedom to enjoy the kinds of lives that people have reason to value is understood as both the major *goal* and the principal *means* of development. From Sen's (2000a) perspective, therefore, devel-opment 'consists of the removal of the various types of unfreedoms that leave people with little choice and little opportunity of exercising their rea-soned agency' (p. xii) in countering deprivations. Because individual and collective freedom of agency (i.e. the ability of people to shape their own destiny and to help one another) is qualified and constrained by the eco-nomic, social and political opportunities that are available, Sen's (2000a) perspective on development and poverty is necessarily multidimensional.

While Sen (2000b) acknowledges the importance of income in being able to pursue what one values and as a powerful determinant of many of the freedoms we value, its importance is ultimately instrumental (i.e. as a means towards achieving certain ends):

> Income may be the most prominent means for a good life without depriva-tion, but it is not the only influence on the lives we can lead. If our para-mount interest is in the lives that people can lead – the unfreedom they have to lead minimally decent lives – then it cannot but be a mistake to con-centrate exclusively only on one or other of the *means* to such freedom. We must look at impoverished lives, and not just at depleted wallets. (Sen, 2000b, p. 3)

Social exclusion

An alternative approach that has attempted to come to grips with the mul-tidimensionality of poverty and deprivation has developed around the concept of social exclusion. This approach, or more accurately *set of approaches*, first made its appearance in France in the 1970s, and has become an important policy focus within the European Union and with-in the United Kingdom's Labour Government.

While there is considerable debate about what social exclusion means, definitions and accounts of social exclusion usually place their empha-sis on a number of specific characteristics. First, social exclusion is

multidimensional and involves more than a lack of resources or income. Second, and closely related to its multidimensionality, is an emphasis on the interconnection of problems and deprivations that have a cumulative impact on the individuals, social groups and areas subjected to exclusion. This is clear, for example, from the definition offered by the Social Exclusion Unit (2001) in the United Kingdom:

> [Social exclusion is] a shorthand term for what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime, bad health and family breakdown. (p. 10)

Third, both an outcome and cause of these multiple deprivations is a process of social marginalization involving a denial of opportunities for the excluded to participate in economic, social and civil life, with the consequent isolation from society. Fourth, the concept of social exclusion places emphasis on the *relational* features of deprivation, bringing out the social aspects of exclusion. (See also Peace, 2001; Silver, 1994; Watt, 2001; Sen, 2000b.)

It is this last feature, the way in which the social exclusion approach focuses attention on the relational features of deprivation, that Sen sees as the essential defining feature and contribution of the idea of social exclusion. For Sen (2000b, p. 8), the real value of the social exclusion approach is that it focuses attention on the relational features of deprivation. However, Sen (2000b) is critical of the often broad and indiscriminate way in which proponents of social exclusion use the term, so that almost every deprivation is seen as a case of social exclusion. Sen argues that while in some cases it is useful to conceptualize deprivations in the language of exclusion, in others it is not. For example, while starvation and hunger can be cast as exclusion from access to food, this does not add much to our understanding of hunger and starvation. If hunger were caused by the removal of food subsidies to a specific group of people, then it would make sense to speak of social exclusion; whereas if hunger is caused by crop failure, then depicting this situation in the language of exclusion contributes little or nothing to our understanding of the causes of hunger or famine.

Although the concept of social exclusion has been largely applied within the policy contexts of Europe (and in particular in France, the United Kingdom and the European Union), Sen (2000b) argues that it also has relevance elsewhere, particularly in Asia and Africa – as long as the concept is used in its narrower or more specific sense. In fact Sen regards social exclusion as a useful adjunct to capability deprivation in that it draws our attention to those deprivations that are exclusionary and relational.

Implications for policy

Changes in the definition of poverty have had important implications for the development of policies aimed at combating or alleviating poverty. On the most basic level, the move from income-based definitions to multi-dimensional definitions has meant that aspects of poverty other than income and expenditure have been accepted as legitimate goals in poverty-reduction policies. This in turn has widened the scope of poverty interventions and focused attention on the interactions between the different dimensions of poverty. Over the years policies that initially focused on economic growth have been supplemented by emphases on investments in physical capital and infrastructure, investments in health and education, on the provision of basic services for poor people, and on the role of good governance and institutions in promoting economic growth.

Emphasis on vulnerability and voice have resulted in increasing emphasis on participation of the poor in development as a requirement for sustainability, on the importance of social safety nets, on improving the access of the poor to credit, and on early warning systems to monitor the impact on climatic changes on poor people. Similarly, emphasis on risk, vulnerability and powerlessness has focused attention on reducing exposure to risk and freeing the poor to engage in more long-term strategies such as investing in their children's education. An important insight that underlay the focus on vulnerability and risk was the recognition that poverty is not stable or constant – people move in and out of poverty and experience different degrees of poverty as they are subjected to new risks, shocks and stresses. The focus on vulnerability and risk also resulted in different priorities for addressing poverty and in different policy mixes.

Poverty assessments have shown that poor people themselves often associate disability with poverty. For example, assessments conducted by Chambers (1995) in Asia and sub-Saharan Africa showed that many poor people regarded disability (i.e. blindness, mental and physical impairment and chronic illness) as an indicator of the lack of well-being associated with being poor. Other indicators included being widowed; lacking land, livestock and farming equipment etc.; being unable to decently bury their dead; and being unable to send children to school. Similarly, Narayan et al. (2000) identified ill health and physical disability as both a cause and a consequence of poverty. People with disabilities were also seen as socially isolated and marginalized.

These shifting emphases have had important implications for our understanding of disability, particularly when it is considered within the context of poverty and other disadvantages. Understanding poverty in its various interrelated dimensions finds resonance with the *social model* of disability that goes beyond the individual impairment to understand

disability as a *socially created problem* that requires *social action* and is the *collective responsibility* of society. Multidimensional approaches to poverty such as the capability and human development approaches also place considerable emphasis on human rights and on the removal of social and political restrictions that constrain human agency.

In much the same way that poverty represents not one but many limitations, so too does disability represent various limitations that go beyond the specific impairment. In some senses disability may be seen as an aspect of poverty, particularly when it is seen within the conceptual framework of capability deprivation. In this sense, disability may be reconceptualized as a capability deprivation on a par with hunger, mortality, morbidity, lack of access to education and healthcare and so on. While it may raise objections that a person with disability can be both disabled and economically well off, it can be argued that even a wealthy person's quality of life and freedom (to pursue those things which she has reason to value) may be impoverished by a disability.

This does not mean of course that high- and low-income persons with disabilities are *equally* disadvantaged or deprived. As we have seen, deprivations are often interconnected and cumulative, so that someone who both is disabled and has a low-income carries a double burden. The matter, however, goes further than this. If multiple deprivations interact with one another, then there is the possibility that one kind of deprivation may reinforce or even lead to another form of deprivation, so that multiple deprivations become concentrated in specific groups or segments of the population. This becomes clear in the next section of this chapter, where the relationship between poverty and disability is explored.

Poverty and disability

Disability can be (and has been) seen as both a cause and a consequence of poverty. This is because disability increases the risk of poverty, while poverty creates the conditions for increased risk of disability. Poor people with disabilities may therefore be seen as caught in a vicious cycle of poverty and disability. For example, poverty increases vulnerability to disability through poor nutrition, lack of access to healthcare, greater exposure to violence and unintentional injuries, lack of knowledge of prevention and so on. Conversely, disability increases vulnerability to poverty because of the costs associated with disabilities, discrimination in the labour market, difficulties related to accessing education and so on. On this basis, it has been argued that eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account (DFID, 2000; Elwan, 1999; Yeo, 2001).

While the linkages between poverty and disability have often been noted, they have not been systematically examined (Elwan, 1999). This applies in particular to the low-income countries where information and research are limited, and which rely heavily on anecdotal evidence and case studies. Rough estimates based on census, survey and registration data do exist for some countries, but these tend to be very divergent, and there is little information about linkages with the correlates of poverty (Elwan, 1999). In 1981 the World Health Organization (WHO) noted that it was impossible to estimate the number of disabled people more accurately than at 10 per cent of the total population (WHO, as cited in Elwan, 1999, p. 5).

From poverty to disability

The relationship between poverty and disability has been more clearly demonstrated for the industrialized countries than for the low-income countries. Demographic studies in the United States, for example, have found a growing relationship between poverty and risk for disability (Park et al., 2002). For example, longitudinal estimates of Fujiura and Yamaki (cited by Park et al., 2002) indicate 'a significant increase in the rate of childhood disability over the past 14 years among constituencies defined by poverty and single-parent headed families' (p. 152). On the basis of their review of recent findings, Park et al. (2002) concluded that 'poverty is not a secondary topic in the field of special education services and disability policy anymore' (p. 152).

In South Africa the disabled population are also disproportionately represented among the poor. The 1999 October Household Survey (OHS) data, for example, show that while less than 2 per cent of individuals living in households with monthly incomes above R10 000 were categorized as disabled, the disability rate was more than twice as high for individuals living in households with monthly incomes below R800 per month (OHS, as cited in Woolard, 2002).

While knowledge of the prevalence, incidence or epidemiology of disabling diseases in low-income countries is limited, it is clear that disability in impoverished contexts is strongly associated with *preventable* impairments arising from communicable, maternal and peri-natal disease and injury. Among the conditions that are frequently associated with disability in low-income countries are: malnutrition (including vitamin deficiencies); lack of basic sanitation; limited access to preventive health and maternity care; limited knowledge of health practices, diseases and disability; inadequate housing; dangerous work conditions; and injuries resulting from political and criminal violence, civil conflict and natural disasters (Elwan, 1999; DFID, 2000).

The WHO has estimated that as many as 20 million women a year suffer disability and long-term complications as a result of pregnancy and childbirth (DFID, 2000). Malnutrition can either directly cause disability or increase susceptibility to debilitating diseases. Malnourished mothers are at risk of bearing low-birth-weight babies, who in turn are at risk of contracting disabling diseases. Adverse environmental conditions, including inadequate shelter, the lack of clean water and poor or no sanitation facilities, compound the risk of infection. Failure to provide adequate and timely health care (whether due to lack of parental knowledge or poor or inaccessible health facilities) can intensify disease outcomes so that remedial impairments become permanent disabilities. According to one estimate, only 2 per cent of disabled people in low-income countries have access to rehabilitation and appropriate basic services (Despouy, as cited in DFID, 2000).

Among the major disabling communicable diseases are poliomyelitis, trachoma, onchocerciasis (river blindness), schistosomiasis, malaria, measles, German measles and leprosy. The WHO also estimates that up to 70 per cent of blindness in children in low-income countries is either preventable or treatable, and that about 50 per cent of disabling hearing impairments are preventable (DFID, 2000). It has been found that maternal education, access to information, dietary and food preparation practices, and the level and coverage of primary health care play a greater role in prevention than more specific interventions (Elwan, 1999). Because much of the disability in low-income countries stems from preventable impairments, a large part of this disability could therefore be eliminated through treatment or alleviated through rehabilitation (DFID, 2000; Elwan, 1999).

The complex interactions of risk factors in impoverished environments are vividly depicted in the following passage:

> The child in a poor family who is malnourished and living in an unheated apartment is more susceptible to ear infection; once the ear infection takes hold, inaccessible or inattentive health care may mean that it will not be properly treated; hearing loss in the midst of economic stress may go undetected at home, in day care, and by the health system; undetected hearing loss will do long-term damage to a child who needs all the help he can get to cope with a world more complicated than the world of most middle-class children. When this child enters school, his chances of being in an overcrowded classroom with an overwhelmed teacher further compromise his chances of successful learning. Thus, risk factors join to shorten the odds of favourable long-term outcomes. (Schorr and Schorr as cited in Pokempner and Roberts, 2001)

In low-income countries and particularly in sub-Saharan Africa, the relationship between disease and disability has been compounded by HIV/AIDS. Of the 40 million people estimated to be living with HIV/AIDS,

95 per cent (38 million) live in the low-income countries and, of these, 28 million are in sub-Saharan Africa. Although Africa is home to only 10 per cent of the world's population, it accounts for 90 per cent of all new cases of HIV infection and 83 per cent of all AIDS deaths (SARPN, 2002). Life expectancy in South Africa fell from 62 years in 1990 to 48 years in 1999, largely as a consequence of AIDS (Woolard, 2002).

Accidents and conflict are also an important cause of disability, especially in low-income countries, where levels of conflict are often high. In conflicts, both active combatants as well as civilians are at risk both during active conflict, and after such conflicts due to unexploded ordnance and land mines. In particular, persons with disabilities are especially vulnerable to deteriorating health (including psychological problems) under the conditions caused by war and political violence. Health care and social welfare systems are often disrupted or break down completely, and some conditions that might have been treatable under more normal circumstances can become disabling.

Furthermore, psychological trauma resulting from war or violence often remains undiagnosed and unrecorded. While information on disabilities resulting from war is limited, existing data show that civilians are equally likely to be victims of land mines, and a study of Afghanistan, Bosnia, Cambodia and Mozambique demonstrated that the economically active were most at risk. For example, Afghanistan had the highest proportion of child victims, where children often worked as herders (Elwan, 1999). Furthermore, poverty has been associated with demanding and risk-prone work environments, where disabilities can result from accidents or contamination by toxic substances.

From disability to poverty

In general, disabled people and their families are poorer than the rest of the population. In many of the industrialized countries, the presence of a disability has been shown to be associated with lower levels of income and an increased likelihood of being in poverty. Employment rates for persons with disabilities are usually lower, and both employment and income appear to be negatively associated with the severity of the disability. Disabled people are also likely to have lower educational and literacy levels than the rest of the population and, when disabled people are employed, they are likely to be under-employed relative to their levels of training. They are also less likely to have savings and other assets than the non-disabled population (Elwan, 1999).

These findings apply to both developing and industrialized countries. In the industrialized countries, the incomes of persons with disabilities do not match those of their non-disabled peers even when compensatory benefits are taken into account and, in spite of substantial transfer and

employment programmes, the disabled continue to face higher risks of poverty. In some low-income countries higher disability rates have been shown to be associated with higher illiteracy, poor nutritional status, lower inoculation and immunization coverage, lower birth weight, higher unemployment and under-employment rates, and lower occupational mobility (Elwan, 1999).

The International Labour Office estimated in 1984 that the unemployment rate for disabled people in industrialized countries was two to three times that of non-disabled people. Surveys conducted in Australia, Canada, the United Kingdom and the United States showed similar trends. While there is little data on relative employment rates in the low-income countries, data from Mauritius and Botswana suggest that similar trends exist in the low-income countries. Existing data also suggest that disabled people work longer hours than non-disabled people, are paid at lower rates, are more likely to work in poor working environments, have poor promotion prospects, and are at greater risk of becoming unemployed (Elwan, 1999).

Studies conducted in the industrialized countries show that disabled people generally have lower incomes than non-disabled people. For example, surveys carried out in the United States between the 1950s and the 1970s showed substantial disparities between disabled and non-disabled incomes, with the average wage rates of disabled people at about 60 per cent of those of people without disabilities. A survey conducted in the US and Germany in 1987 found that, on average, disabled men earned half of what non-disabled men earned. Studies in the United Kingdom also showed that home ownership was lower among disabled than non-disabled people, and that disabled people had fewer substantial assets and fewer rights to pensions and other welfare benefits. Furthermore, many of these disabled people had a need for higher incomes than those without disabilities. The lower incomes observed during their working years continued into old age, and disabled people were less likely to have the kind of pension or the level of provision that would adequately protect them from poverty in old age (Elwan, 1999).

On average, disabled people receive less education, and have lower literacy rates and educational qualifications than the non-disabled population. Recent studies suggest that about 2 per cent of children with disabilities in low-income countries receive an education. Boys with disabilities attend school more frequently than girls with disabilities, and disabled women, who suffer discrimination both on the basis of their impairments and their gender, generally have even lower literacy rates than disabled men. It has also been shown that women with disabilities are two to three times more likely to be victims of physical and sexual abuse than women without disabilities (DFID, 2000; Elwan, 1999).

Disability impacts not only on individuals, but also on households that have disabled members. This has meant that a larger proportion of the population is affected by disability than the percentage of individuals with disabilities. In the United States in 1990, for example, the proportion of families with a member with a disability was 29.2 per cent, while the proportion of individuals with a disability was 13.7 per cent (Elwan, 1999). Very similar trends were found in Scotland, where 13.7 per cent of the population had a long-term health problem or disability, whereas 29 per cent of households contained one or more persons with a long-termed illness (Scottish Poverty Information Unit, 1998). Analysis of Tanzanian survey data showed that households with disabled members had mean consumption levels of less than 60 per cent of the average and head-counts 20 per cent higher than the average. On the basis of these results the author concluded that disability was 'a hidden face of African poverty' (DFID, 2000, p. 4).

In addition to their lower income and consumption rates, persons with disabilities and their families are often burdened by additional costs resulting from disability. Such costs include special medical care, rehabilitative and restorative equipment and services, providing for special education needs, and costs incurred for or by care providers, including opportunity costs of foregone income. In low-income countries where income maintenance and other social-security programmes are uncommon, persons with disabilities are usually the responsibility of their families; even in the industrialized countries, families play an important role in providing care and financial support to the elderly. There are also various costs associated with marginalization or exclusion of persons with disabilities from services and social and community activities. Such exclusion and marginalization, which often reduce the opportunities that disabled people have to contribute to their households and communities, include negative attitudes to persons with disabilities, lack of adequate or appropriate transportation, physical inaccessibility, and lack of learning opportunities. Such barriers can affect access to education and employment, as well as reducing opportunities for social participation (Elwan, 1999).

Lukemeyer et al. (2000) studied the impact of caring for children with disabilities and chronic illnesses on poor families in the United States, and found that both out-of-pocket expenses and foregone earnings represented a substantial burden for many of the families studied. Using a sample of low-income families in California, the study found that almost half of those families with special-needs children had incurred some direct, out-of-pocket expenses in the preceding month, and about 20 per cent incurred costs of more than $100. Half of the mothers with disabled children indicated that having to care for the child made it difficult for

mothers to work and 19 per cent reported that special care responsibilities prevented them from working at all. Based on their data, the writers estimated an average loss of about $80.52 per month in mothers' foregone income for each household with a severely disabled child. They conclude that families with exceptional children are at 'exceptional risk for economic hardship, due to heightened demands on family resources and to reduced availability for employment' (Lukemeyer et al., 2000, p. 412).

Disability and other disadvantages

In certain segments of the disabled population, multiple disadvantages, including age, gender and location, may combine to produce greater vulnerability to poverty. In some communities, for example, disabled girls receive less care and food, have less access to health care and rehabilitation services, and may have reduced access to education and employment opportunities. Disabled women also sometimes have fewer marriage prospects than disabled men, and can be at risk of being physically and sexually abused (DFID, 2000; Elwan, 1999). As pointed out in the White Paper on an Integrated National Disability Strategy (1997) (South Africa), for example, 'Disabled women experience the same oppression as non-disabled women, but often without even the status that women traditionally receive as mothers or wives. In addition, disabled women experience more discrimination than other women from being unable to live up to the demanding ideals for womanhood imposed by society' (p. 4).

In the United States, poverty and disability have been consistently related to race. According to the 1994–95 Survey of Income Participation, for example, the proportion of persons with a severe disability between the ages of 22 and 44 years was 11.8 per cent for African-Americans, 5.6 per cent for whites and 6.7 per cent for Hispanics. For individuals aged 45–54, the percentages were 18.4, 10.5 and 15.7, respectively. African-American children, who are twice as likely as white children to be poor, also disproportionately experience illness and disability. While high rates of poverty among African-Americans and other minorities may in part explain these higher rates of disability, they only provide a partial explanation, because even when socio-economic status is controlled the correlation between race and the risk of ill-health and disability remains. Similar trends exist in relation to HIV/AIDS in the US. In 1991, for example, African-Americans were 3.5 times more likely to contract AIDS than whites. The risk was even higher among African-American women, who were 13.8 times more likely to contract AIDS than white women (Pokempner and Roberts, 2001).

In general, both the risk of disability and its impact on poverty appear to be higher in rural than in urban areas. This is particularly true in South Africa, where under apartheid the former homeland areas were severely under-funded and deprived of social and economic services. For example, access to assistive devices, which play an important role in disabled people's perception of their disabilities and have even been shown to influence access to grants, is biased towards urban and white populations. As pointed out in the White Paper on an Integrated National Disability Strategy (1997) (South Africa), the location of people in disadvantaged areas like the former homelands has 'had a particularly severe impact on people with disabilities who found themselves in an inhospitable environment, facing poor living conditions and unable to access the help they needed' (p. 6).

> The Disabled Children Action Group (DICAG) estimates that 98 per cent of mothers of children with disabilities living in rural areas are unemployed, semi-literate or functionally illiterate single women. Deserted by husbands and lovers, often socially ostracized by their communities, and banished into isolation by their extended families, they tend to withdraw into a world of their own. (White Paper on an Integrated National Disability Strategy, 1997, p. 6)

The cumulative impact of disability, poverty and other social disadvantages such as gender, race, age and physical location can create extreme vulnerability and exclusion for those sections of the population who suffer multiple and overlapping disadvantages. As the Taylor Committee (2001), which investigated the social-security system in South Africa, has stated: 'Disability is characterised by a collection of risks and vulnerabilities that push households into poverty and otherwise threaten the quality of living for a substantial portion of the population' (section 9.12).

Disability rates for women seem to be higher than those for men in industrialized countries, and lower in low-income countries. Lower female rates may indicate that severe impairments are male-dominated, and/or that females with disabilities may be under-reported or may receive less care and die sooner. Estimates from India and Pakistan indicate that male disability rates are higher than female rates. Elwan (1999) stated that this 'could indicate that girls and women with disabilities receive less care and support, and die earlier. Another possibility is that the gender division of labour is such that disabled women contributing to household activity are not identified as disabled, whereas the visibility of disabled men is greater' (p. 9).

The relationship between poverty and disability is therefore both complex and diverse. To provide an overview, the preceding discussion is summarized diagrammatically in Figure 4.1. As with any diagram, this is a simplification of a more complex reality, but does serve the purpose of highlighting and systematizing some of the issues involved in the interface between disability and poverty.
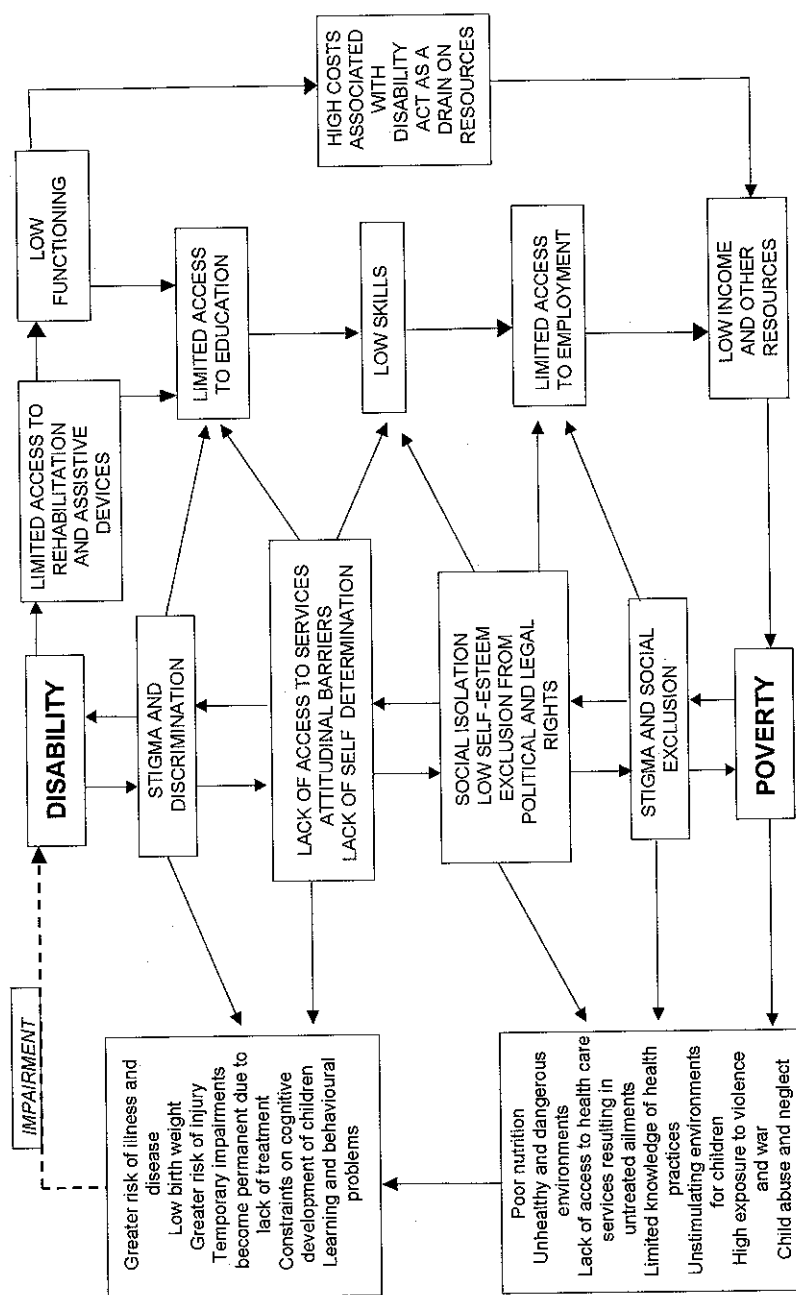
Figure 4.1 The relationship between disability and poverty.

For the purposes of analysis, three major elements may be distinguished in the diagram. On the right side of the diagram, some of the pathways between disability and poverty are represented, while on the left, some of the factors associated with poverty that increase the risk of impairment and disability are listed. Together these two elements create a vicious circle in which disability increases vulnerability to poverty, and poverty in turn increases the risk of disability. However, in order to complete the picture, a third element (represented by the boxes in the middle of the diagram) is required. Both disability and poverty are associated with discrimination, stigmatization and social exclusion that create attitudinal barriers and limited access to services, and lead to social isolation, low self-esteem and exclusion from political and legal rights. These factors reinforce the processes of impoverishment, as well as adding to the risks and vulnerabilities of impairment and disability. For example, negative social attitudes limit the access of persons with disabilities to education and employment over and above the constraints that physical impairments, might impose on the functioning or capabilities of the persons with disabilities. Similarly, the social isolation of the poor as a result of the stigmatization of poverty, for example, increases the risk of illness and disease, and therefore of the acquisition of impairments and disabilities. Moreover, the stigma associated with disability and poverty tends to be self-reinforcing and cumulative, so that a person who is both poor and disabled is subjected to greater stigmatization and discrimination. This stigma might furthermore be compounded by other social disadvantages such as those associated with race or gender.

Conclusion

Within the context of poverty, disability is not simply a problem in its own right, affecting only the quality of life and productivity of those people who suffer the disability; it has broader ramifications for the well-being of society itself. Disability contributes to poverty, adding to both the burden of and the vulnerability to poverty, and forces individuals and households deeper into the trap of impoverishment. As such, disability is a problem of development, and needs to be taken seriously by those concerned with issues of poverty and development.

The implications of the links between disability and poverty are far-reaching, particularly in low-income countries where poverty is so pervasive. Efforts to incorporate disability into the development discourse are still at an early stage and have yet to overcome the barriers associated with separate institutional, policy and disciplinary spheres in which the two issues have been incorporated. As Pokempner and Roberts (2001) point

out, an integrated approach to poverty and disability should challenge 'the traditional dichotomy between disability and poverty' (p. 18). According to the DFID (2000) this dichotomy is increasingly being challenged by disability advocacy groups who argue that the needs of disabled people

> have been marginalized by being categorized as 'special' or 'different' from those of the population at large. Conventional approaches have been criticized for being driven by a perception that people with disabilities need help to adapt to society's demands. This approach runs the risk of favouring technical or medical solutions that emphasize difference rather than promote inclusion. (p. 7)

A more integrated approach to disability and poverty would therefore be compatible with the demands of the social model.

What are the implications of a more integrated approach to poverty and disability for policy and intervention? On the most general level, agencies involved in addressing the needs of people with disabilities need to take poverty into account, just as development and poverty alleviation programmes should integrate disability within their agendas. Poverty is often an important constraint on augmentative and alternative communication (AAC) and more general disability-focused interventions, and as such agencies must accommodate these constraints within their strategies.

For example, impoverished households are often limited in the resources and time they can invest in members with disabilities, particularly children. As Yeo and Moore (2003) point out, where 'there are limited resources it may be seen as economically irresponsible to give an equal share to a disabled child who is perceived as unlikely to be able to provide for the family in the future' (p. 573). Lack of investment in children with disabilities is not merely a 'reflection of ignorance', but may involve 'a desperate but rational decision', as Yeo and Moore (2003) point out:

> Thus, disabled children often get last access to food and other basic resources. When disabled children become ill they are often not given any treatment. In households or communities already living in poverty, this exclusion is frequently a life or death situation. Erb and Harriss-White ... found that in their focus villages in Tamil Nadu 'disabled children were very rare,' and suggest that this is because they are either not disabled or they do not survive. Early and preventable death is the most extreme symptom of poverty; thus, disability must be a central concern of those committed to poverty reduction. (p. 573)

Under conditions such as those described above, one might well question whether interventions aimed at assisting individual children with disabilities – without addressing the contexts of poverty in which they live – can have any relevance or beneficial effect in the long term.

While income and other material resources are important constraints on impoverished households and therefore on external interventions, the multidimensional approach to poverty should also alert us to other, non-income constraints. For example, AAC and other disability-focused interventions are often dependent upon the social support of both the family and the community (see Chapter 8). However, both poverty and disability have been associated with discrimination, stigma and social exclusion. Issues such as discrimination and social exclusion have been allocated a central position within the context of the social model of disability, and are often considered the greatest obstacle that disabled people have to overcome. The DFID (2000) states:

> People with disabilities face numerous barriers in realizing equal opportunities: environmental and access barriers, legal and institutional barriers, and attitudinal barriers which cause social exclusion. Social exclusion is often the hardest barrier to overcome, and is usually associated with feelings of shame, fear and rejection. Negative stereotypes are commonly attached to disability. People with disabilities are often assigned a low social status and in some cases are considered worthless. (p. 5)

Discrimination, stigma and social exclusion not only impact on the quality of life of disabled people, but also limit access to services, undermine self-determination, and lead to social isolation and low self-esteem, all of which can limit the capabilities of persons with disabilities and their families. Furthermore, poverty also leads to stigmatization, social exclusion and isolation, both adding to and reinforcing the stigma associated with disability. These conditions clearly need to be taken into account in the context of devising policies and strategies to address disability and poverty. For example, social isolation is clearly going to pose a problem to interventions that rely on community support, particularly in poor communities that have undergone social fragmentation and disintegration.

Social isolation and exclusion also have important implications for vulnerability to acquiring impairments and disabilities. On the most obvious level, social isolation can cut parents off from important sources of support and information within their communities, making it more difficult for them to take appropriate action when a child becomes ill, for example. In turn, lack of knowledge of health and child-rearing practices can lead to temporary impairments (such as hearing loss) becoming permanent, owing to lack of appropriate treatment.

Furthermore, social isolation has been associated with higher levels of child abuse and neglect. A substantial body of research has developed since the 1980s which shows that parents who mistreat their children tend to be isolated both from informal networks of social support, as well as from institutions and formal systems of social support. Findings

demonstrated that maltreating parents had few social contacts, were less likely to belong to social groups or community organizations, were less involved in community activities, and made less use of community resources (Korbin, 2003; Gracia and Musitu, 2003).

There is also a growing body of research that has linked poor health outcomes to social isolation and low levels of social cohesion (Kawachi, 1997; Wilkinson, 1999a and b). Also of interest in this regard are findings that the beneficial effects of social and emotional support on parental behaviour towards children tend to be mitigated by stressful environmental conditions. Social support thus has a more beneficial effect on parenting practices in safer neighbourhoods, but as neighbourhood conditions worsen (become poorer and more crime-ridden), the positive impact of emotional and social support is weakened (Ceballo and McLoyd, 2002).

Findings such as these suggest that issues of social isolation and social cohesion may need to be addressed before more specialized interventions targeting the needs of children with disabilities can be fully effective. Similar circumstances apply to the prevention of disability. Because the causes of disability have become so intertwined with the conditions of poverty, in many cases prevention cannot be effective without understanding and addressing poverty and the conditions associated with it. Clearly, specialist disability programmes and services that focus on issues such as rehabilitation or special education are not geared to address the larger issues of poverty, and generally lack the resources and mandate to take on these issues. However, this once again underlines the need for more integrated or holistic approaches to poverty and disability, and for closer co-operation between specialized disability services and the development and poverty alleviation sectors.

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CHAPTER 5

Cultural and socio-economic influences on communication

ERNA ALANT

This chapter deals with cultural and socio-economic influences on communication by describing the process of symbolic interaction. Semiotic mediation is discussed as a background to understanding the relationship between symbols and their interpretations within context. The influence of culture on the processes of visual perception and comprehension are highlighted.

The literature abounds with strategies for dealing with cultural diversity in everyday communication and contexts. However, although issues surrounding culture and its importance in communication and learning are often recognized and stressed, dealing with cultural issues is often neglected due to the complexity and evasiveness of the definitions of cultural values and characteristics. Culture can be defined as 'a set of behaviours, institutions, beliefs, technologies and values invented and passed on by a group of individuals to sustain what they believe to be a high quality of life and to negotiate their environments' (Taylor and Clarke, 1994, p. 103). In addition, Lloyd et al. (1997) define culture as 'the total of beliefs, values, traditions, behaviours and communication patterns shared by members of a community learned as a function of social membership' (p. 528).

These definitions highlight some of the difficulties surrounding the identification of cultural values, meanings and beliefs. Cultural values are subscribed to a group; however, the definition of who exactly constitute the group is often vague. Professionals interacting with families generally have limited background knowledge about the cultural context within which the family lives and communicates. In addition, the heterogeneity between different subgroups in a culture, and individual differences within cultural groups and subgroups, complicate the process of understanding issues related to cultural values and beliefs.

The interaction between socio-economic status and cultural issues still further complicates the understanding of this dynamic process. The

argument of a 'culture of poverty' or generational poverty (see Chapter 2: Intervention issues) implies a set of values and beliefs that could be inherently part of a family's lifestyle for extensive periods of time. The differentiation of what constitutes culture and how closely these values are linked or not linked to social status seems most complex. Mills (1959) in his work emphasizes the impact of education in social inclusion and exclusion between the rich and the poor. Cognizance of the different factors impacting on the behaviours and belief systems of the individual and family is vital in facilitating understanding of their interaction patterns.

Viewing diversity in communities as a strength, rather than a challenge or problem, is a manifestation of the increased need to accommodate cultural and social diversity in a constructive way in society. This implies not only accepting different languages, but also ipso facto the different ways in which people from different cultural and social backgrounds use and interpret signs and symbols as part of the interaction process. To enable practitioners to do this, however, presupposes some understanding of the way in which symbols are interpreted and used within specific contexts, for example the way individuals interpret specific graphic symbols. Although practitioners in the field of augmentative and alternative communication (AAC) could argue that it is too time-consuming to dedicate time to understanding individual interpretation of symbols for interaction, the integration of the communication system into the everyday life of the individual might be greatly influenced by the way in which the AAC user relates to, for example, the graphic symbol set used on a communication board or on the device. It is vital that we keep searching for ways in which we can facilitate the individual's identification with and involvement in the communication process – not only by means of access to vocabulary, but also in relation to means of representation (Fuller and Lloyd, 1997; see also Chapter 6).

Communication as symbolic interaction

As discussed in Chapter 2 (Intervention issues), communication can be defined as the process of developing meaning between two or more individuals (Wenburg and Wilmot, 1973). This implies a process driven by an intention (overt or covert) to communicate certain messages to others in the environment. Individuals use symbols, which according to their experience and knowledge will be successful in conveying the message as accurately as possible, and thus elicit the desired response. The recipient interprets these symbols according to their own knowledge and experience, and chooses to respond in the way they feel appropriate.

Communication is therefore the process in which individuals or groups of people exchange symbols in an attempt to develop shared meaning. The interpretation and use of symbols is thus central to the process.

Issues surrounding symbol use and interpretation refer to the intersubjective nature of communication. This means that common meaning (inter) as well as the individualized meaning (subjective) form an inherent part of the interactive process. Meaning thus develops in interaction owing to participants sharing common meanings, and also by providing their unique meaning nuances within the context. Scaffolding is the process whereby individuals will use symbols to express ideas and in response to another individual will keep on responding to the other individual by slightly changing the way in which messages are expressed to facilitate mutual understanding. This process, however, presupposes that individuals share enough common symbols to engage in the development of meaning. People assume some sociocultural set of expectations (based on experiences in similar situations), which enable participants to predict how interactions are likely to unfold. They develop common interpretative schemata or frames of reference, which enable them to interpret contextual cues (e.g. facial expressions, lexical and prosodic characteristics) and engage in a process of meaningful interaction.

The implication is that individuals who do not share the same frame of reference are excluded from the interaction process. Even though they might have the ability to distance themselves to evaluate the outcome of their message, they will be unable to predict the effect or outcome of the message effectively to enhance the development of meaning in interaction with that particular group of people. This means that even though you constructed what you regard as a well-formulated message, you will not be able to predict how the partner will interpret it. Luckmann (1975) refers to the world-taken-for-granted, thus there are implied presuppositions in any community which are difficult to objectify, but certainly contribute to the exclusion of others from the community. This attempt to objectify hidden or latent messages and meanings is at the heart of the communication intervention process. Developing a more in-depth understanding of cultural influences in the process of interaction is thus central to any human intervention process. The different levels at which breakdowns can occur as well as the dynamic nature of the interaction process reflect the complexity of cultural influences on this process. The following example might illustrate this point. Traditionally, within the Afrikaans community in South Africa, it is regarded as impolite to address an older person as 'you'. Children are expected to refer to adults by either addressing them as 'Mr/Mrs' or by calling them 'oom' (uncle) or 'tannie' (aunt), even though they are no relations of the child. A child's lack of understanding of this rule often leads to uneasy silences or the child being labelled as 'voor op die wa' (impertinent).

Semiotic mediation

One of the most important contributions of Charles Sanders Peirce to the field of semiotics lies in the concept of semiotic mediation. This refers to the fact that there is a world in itself, which is different from a world as represented, and that these two realities are brought into interaction by the mediating role of signs (Parmentier, 1994). He describes a triadic relation between any sign, an object and an interpretant. The sign itself is considered as an expressive form; the object of the sign is that which the expressive form stands for or represents; and the interpretant is the resulting mental or behavioural effect produced by the sign, and thus the meaning or significance. In essence what this triadic relationship highlights is that meaning between a sign, its referent (object) and its signifier (interpretant) essentially develops in the relationship between these three components. The characteristics of this relationship can be summarized as follows:

- First, the relationship between sign, object and interpretant is dynamic, and changes depending on the situation within which it is used. This implies that this relationship will change from context to context and from culture to culture.
- Second, this relationship is not necessarily a conscious one, as people use signs and symbols in interaction without specifically attending to the meaning of each.
- Third, many of these relationships are embedded in the rule-governed activities of everyday life. Much of this 'taken-for-granted' use has an underlying pattern, or is rule-governed, which is important. These rules are generated within an experiential social and cultural framework (Sigel, 1978).

For Peirce (1991), the communication process involves a relationship between two fundamentally opposed elements: *objects* and *signs*. All knowledge that the individual has at a given point is about something that he/she is already acquainted with to some degree (object). Opposed to this, however, are the forms of representation (verbal, graphic and gestural etc.), which stand for, substitute, or exhibit the object in such a way that the next stage of comprehension will consist of a further development of the representation of that particular object. He therefore identifies two vectors in the field of semiosis: the vector of determination from object to sign, and the vector from sign to object. From this, it also flows that 'a sign does not function as a sign unless it be understood as a sign' (Parmentier, 1994, p. 4). In the previous example, therefore, the silence will not be noted unless it is regarded as a sign of uncomfortableness.

Visual signs, referents and interpretants used can be seen to be closely related to visual perception and the development of pictorial comprehension within a specific community or context. Although Peirce (1991) uses the term sign, for the purposes of this discussion it can be regarded as similar to *symbol*. To understand graphic symbols and their role in interaction, some basic understanding of aspects impacting on visual perception and pictorial comprehension seems pivotal.

Sociocultural variations and symbolic interaction

This relationship between a sign and what it represents, and its relationship to the knowledge (object) of the individual is, therefore, central to the process of communication. This influence between knowledge of the individual and its relationship to the sign is dynamic and depends on the interactional and cultural context within which the event takes place. An understanding of the process of communication, therefore, implies a thorough understanding of the knowledge, or cognitive framework, of the individuals as well as the way in which these realities are represented by using signs in interaction. Witkin (1967) linked a cognitive-style approach to cross-cultural research, and defined cognitive style as the characteristic self-consistent modes of functioning found pervasively throughout an individual's perceptual and intellectual activities. This style is highly related to family experiences and the outcome of a socialization process. Generally these styles are assessed according to the field-dependent independence dimension (Almanza and Mosely, 1980; Taylor, 1994; Taylor and Clarke, 1994). In a field-dependent mode of perception, the organization of the field as a whole dominates perception of its parts; thus an item in the field is perceived as fused with the whole. However, in the field-independent mode of perception the person perceives items as discrete from the whole. This approach is similar to that of Hall (1976), who describes low- and high-context cultures in an attempt to understand different communication styles. High-context cultures depend on the context of an interaction and on pre-programmed information shared by the interactants, while low-context cultures, like most Western cultures, are more oriented towards the content or meaning of a specific message rather than the context.

Few publications in the field of AAC have included some reflection on issues related to multicultural issues. Some of the published material includes a chapter by Soto et al. (1997) discussing issues surrounding attitudes and assessment and intervention principles, and an issue on 'Cultural diversity and the AAC community' in the *Augmentative*

Communication News (ACN) (Blackstone, 1993), which focuses on practical guidelines in acknowledging and exploring attitudes and beliefs, as well as identifying cultural elements in communication behaviours which she adapted from Harris (as cited in Blackstone, 1993). Some attention is also directed to issues surrounding interpreters and translation of evaluation and intervention material. Most suggestions identified as part of the guidelines for facilitating cross-cultural understanding revolve around basic principles of good interviewing and intervention practices – for example, the art of listening, acceptance of diversity, non-evaluative attitude, awareness of stereotypes, and an awareness of one's own prejudices and cultural biases. Barrera and Corso (2003) also refer to respect, reciprocity and responsiveness, which they regard as the basic qualities of skilled dialogue.

Visual perception and comprehension: a cross-cultural perspective

Although much of daily interaction centres around verbal communication, the focus of AAC is largely on those strategies that can support, augment or substitute speech. For this reason, the focus in the following discussion will be more on visual aspects of communication.

Perhaps one of the most important issues in intercultural collaborations relates to visual perception. This process was traditionally defined as the process whereby visual stimuli are responded to, while recent approaches toward perception have become more sensitive to the complexity of this process. Bloomer (1990), for example, stated that perception is not only determined by sensory stimulation, but at least equally controlled by cognitive factors such as expectancy, normalizing and verbal coherence. Thus the flow of information runs upwards and downwards. This means that the process is highly influenced by the cultural and social context within which the individual lives. Sigel (1978) specifically described pictorial comprehension and stated that comprehension firstly involves active engagement and subsequent *construction* of the external into '*menta*' representations. Second, the cognitive system functions as both a filter and a moderator for behaviour. This process refers to the process of 'getting to know' pictures.

He also refers to pictures as any two-dimensional representation that can vary in at least three ways: in the detail presented (detailed as opposed to sketch or outline), in the representational level (degree of approximation to the object or event depicted) and in the spatial perspective (flat, or illusion of a third dimension) (Sigel, 1978). He also postulated that as there are rules for comprehending written language,

there could also be rules for comprehending pictures. There are also rules relating to the relationship between written language and the pictures that it represents; for example, there are rules governing what picture could acceptably represent the word 'cat'. Sigel (1978), however, does point out that although development studies on linguistic comprehension have been conducted, very little is known about the development of pictorial comprehension.

There are, however, investigations indicating differences in pictorial recognition between cultural contexts in perceiving pictorial representations and pictorial depth. It is well documented that some African subjects do not respond to pictorial depth cues as other Western subjects do, which raises the question of whether pictorial representation constitutes a universal tongue. Deregowski (1973) pointed out various studies conducted by Herskovits (1950); Warburton (1951) found that an African woman and a Gurkha from Nepal had difficulties in recognizing pictures of objects they knew well, with similar observations made in Nigeria and South Africa. A study by Forge (1970) also indicated that the Abelam in New Guinea were unable to recognize pictures of familiar objects. He observed that they learned to do this 'after a few hours of concentrated looking and discussion on both sides' (Deregowski, 1973, p. 166). However, correct recognition of a depicted object even in pictorially rich cultures does not mean that pictures evoke the same responses as do the objects they portray. For example, Klapper and Birch (1968) found that when children were presented with a picture of a functional object and asked to show by gesture what it meant, their responses were less vivid than when they were asked to do the same thing with objects. Similarly some American children had more difficulties in categorizing pictures (of objects they knew) than the real objects.

Visual perception and pictorial comprehension

Visual perception can be described in a number of different ways, first by referring to responses of the nervous system to certain external stimulation (sensation). At the other extreme, perception can refer to more complex and higher-level thought-processes (cognition), as in 'I perceived deep moral dilemmas in the paintings.' Until recently, perception has been defined as an intermediate step relaying sensations to higher-order levels of processing (simple-to-complex hierarchy). Current experts, however, suggest a richer and infinitely more complex view whereby perception is thought to be less determined by the sensory stimulation, and equally or more controlled by cognitive factors such as expectancy, normalizing etc.; thus the flow runs top-down as well as bottom-up (Bloomer, 1990). There are at least four overarching processes that shape perception:

- mental operations that affect meaning, e.g. expectations, memory, selectivity, habituation, salience, normalizing, dissonance and closure;
- the effects of words on perceived meaning, e.g. simply naming a stimulus often greatly affects the perception;
- interplay between perception and behaviours, e.g. other people and the cultural context play a major role in perception;
- framing of perceptions by social and cultural context, e.g. learning how to interpret signs, and definition of deviance and creativity.

Visual perception per se is, therefore, the process whereby individuals are able to develop pictorial comprehension. This process of comprehension develops first, through active engagement and subsequent construction of the link between the external (pictures or stimuli) into the internal *mental representations*. In the second instance, the cognitive system functions as both a filter and a moderator for behaviour. In relation to Peirce, visual comprehension is closely integrated into the interpretative function within the triadic relationship. It is the mental structures that will provide the key to understanding how the viewer came to interpret the pictures (Goodman, 1968).

Pictorial comprehension is the understanding of the picture, i.e. coming to know pictures (Sigel, 1978, p. 94). This process is analogous to reading the printed word in that the 'reader' must transform a set of symbols or signs from one system to another. It is only through this process of transformation that comprehension can begin. In a first instance, the definition of a picture is influenced by cultural learning. According to Sigel (1978) pictures can be described by referring to:

- picture types, which in turn include: detail (full or schematic); representational (realistic or non-realistic) and spatial perspective (flat or depth);
- pictures can also differ in relation to organization of elements, complexity and themes depicted.

It is, however, important to differentiate between *picture labelling* (or *recognition*) and *picture comprehension*. To comprehend means to extract meaning from the picture, to relate to it as a representation of a referred object or concept. Recognition is the mere identification or labelling of a picture and does not imply or require understanding.

Some research with pictures has found evidence in young children for innate or early abilities to interpret pictures (Hochberg and Brookes, 1962; Bower, 1971), as well as the benefits of using pictures as learning aids. In a study by Ninio and Bruner (1976) they explored the development of lexical labels over a period of 8–18 months and described the child's reaction to pictorial representation through a process of manipulation, language skills (names and dialogues), and perceptual–cognitive skills (decoding

pictorial representations). Ultimately this research provided some insights into the importance of interaction between mother and infant as part of the picture-learning process. Picture decoding is thus a learned response. Additional evidence for the learned perspective includes some cross-cultural research.

It can be argued that pictorial comprehension is a cultural convention. Some cultures do not have pictures and thus cannot comprehend that pictures can represent an idea or object (Miller, 1973; Serpell, 1976). It is, however, also argued that these skills can easily be acquired once the general picture as a representation is explained. The respondent will grasp the principle in a single trial. The evidence is not at all clear and there is some question regarding the degree to which non-Western societies have difficulty in comprehending pictures, but the bulk of the data supports the notion that instant recognition is not present, and that some learning must occur (Arnheim, 1969; Deregowski, 1971). Not even one trial should be necessary.

Much of cross-cultural research has focused on depth perception (Serpell, 1976). Miller (1973) found that African people less schooled in Western ways had more trouble perceiving depth than European children. Depth perception must thus be learned (Deregowski et al., 1972).

Another body of research indicated that pictorial literacy is more than recognition and/or labelling. This research is rooted in the ideas of Goldstein and Scheerer (1941), which suggested that neurologically intact individuals would organize the array of objects on the basis of logical abstract categories and take an 'abstract' attitude, while neurologically impaired respondents would tend to be concrete – would organize things based on familiar functions having difficulty in creating logical classes. In young children, saliency of meaning rather than physical attributes is a criterion for matching (Bearison and Sigel, 1968). The meaning of familiar objects, therefore, is the prominent characteristic in grouping (Sigel, 1954).

Similar to the above findings, children from lower socio-economic status (SES) also tend to classify objects differently (replicated study Sigel et al., 1966). Significantly fewer classifications were made with photographs than objects (Sigel and McBane, 1967; Sigel and Olmsted, 1967). Such behaviour might be interpreted as unfamiliarity with pictures or difficulty in class-grouping behaviours, but this is rejected as all objects and pictures were identified at the appropriate level, and groupings with three-dimensional objects were constructed, but not pictures. Pictures seemed to represent a different class of instances, despite sharing common labels and physical attributes. A concept that is a prerequisite for picture comprehension is the *concept of equivalence*. This concept holds that while pictures could be partially sharing characteristics but in some

way appearing different, the meaning derived can be judged as the same (Sigel, 1978).

Conclusion

From the above, it is evident that the uses of graphic symbols or signs are intricately related to cultural and socio-economic diversity, which characterizes present-day societies. The relevance of the above research and implications for AAC graphics clearly need further consideration.

In the first instance, these studies emphasize that a subject's responses to various kinds of cues in two-dimensional representations are largely a function of that subject's experience with such cues. The ability to perceive anything requires some experience with pictures (Kose et al., 1983; Macintosh, 1977; Duncan et al., 1973). The nature and extent of these experiences might impact on the meaning derived from pictorial stimuli to varying extents.

However, various studies seem to confirm that it may require very little experience with pictures to gain the skills needed for the interpretation of pictorial stimuli. Perception in a three-dimensional world is, however, not sufficient to perceive pictorial representations. That individuals not exposed to pictures can comprehend pictures quickly when they are explained to them is a most interesting finding (Deregowski et al., 1972). Once underlying principles of the picture are objectified, people can understand and relate to it (translucency). This could be raising issues about the relevance of iconicity and first-exposure studies in facilitating understanding of the use of graphic symbol systems for intervention. Learnability, thus, how easily particular symbols can be learned, seems to be a more important factor. However, this extrapolation needs to be considered against the background of additional findings indicating that differences in depth perception between cultural contexts do exist.

Direct experiences with pictures might be necessary for the perception of depth cues. The ability to derive meaning from more minimalistic pictorial representations that require differentiation between figure-background elements or imply movement indicators seems to be more dependent on prior experience. These statements, however, require caution as clearly the experience with pictures also interacts with other variables, for example age differences in visual perception (DeLoache, 1991), exposure to schooling and thus exposure to a literate environment (Martlew and Connolly, 1996), and ability to categorize and group objects or pictures according to categories of different abstraction.

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CHAPTER 6
Issues in graphic symbol communication

ERNA ALANT

This chapter discusses selected issues in using graphic symbols in different language and social contexts, and explores different variables that might impact on first exposure and learnability of graphic symbols. The purpose is not to present a comprehensive overview of graphic symbol learning, but rather to stimulate discussion by introducing selected studies conducted in low-income contexts. Issues surrounding cross-cultural investigations are discussed, focusing on the issue of equivalence between the different data sets. Thereafter, the focus is on culture-specific research studies in graphic symbols. Discussions focus on the error analyses of the studies and explore potential reasons for participants' varied responses. The chapter concludes with the development of a clinical procedure for guiding the interventionist in understanding ways in which clients can interpret graphic symbols as a background to facilitate intervention.

Over the years, a variety of studies have been conducted on topics related to graphic symbols, their characteristics, comparative ease of recognition and learnability, as well as their use in intervention. Specific graphic systems were investigated in relation to their ease of recognition and learning. It is, however, outside the scope of this chapter to list these studies. For more specific references, Lloyd et al. (1997) can be consulted. This chapter highlights issues varying from a discussion on issues of equivalence in cross-cultural studies, to a discussion of studies demonstrating various approaches to cultural issues in augmentative and alternative communication (AAC) research.

Cross-cultural research issues

Few research studies to date have been conducted within the field of AAC graphic symbols in multicultural contexts focusing on cross-cultural

comparisons (Nakamura et al., 1998; Huer, 2000; Quist et al., 1998). Cross-cultural studies require that researchers compare responses of participants from different cultural contexts. This process of comparing responses across cultures is a most complex and challenging process. The pivotal issue in cross-cultural research relates to the issue of achieving equivalence on various levels of the process. Sechrest et al. (1972) and Serpell (1976) identified some of these issues, which will briefly be explored.

The first problem addressed by Sechrest et al. (1972) relates to the orientation of the subjects to the research conducted. This refers to the rationale given to the subjects for their participation in the process. Clearly although the researcher could be attempting to keep the rationale for the study similar, to increase equivalence in method, the actual interpretation and motivation of subjects could be vastly different. For example, the rationale for doing a study conducted on graphic symbols for use in AAC in some Western countries could be much different from the rationale for the same study conducted in a more developing context where people are not familiar with AAC. Whereas participants in a more developed context might identify with the need to do research on graphic symbols to facilitate better understanding of different perceptions and interpretations elicited by graphic symbols, participants from less literate environments might find it more difficult to relate to the need for studies of this nature. This might impact on their motivation to participate in the study and consequently influence their performance. Also, the political context within specific countries and the power relations within research environments could impact significantly on the attitudes and perceptions of participants in the process. Clearly these issues affecting the reliability and validity of results are not new (Ackroyd and Hughes, 1981; Marshall and Rossman, 1995) but they are highlighted in cross-cultural research studies.

The second type of issue relates to the problem of translation and equivalence in translation. Using verbal translations from one language to another implies that there should be equivalence in the message produced. This equivalence needs to be proved and cannot be assumed. An example of this is the translation of the word *disability* within different cultural contexts, which would be translated to 'slow learner', 'a person in a wheelchair' or a 'person with mental disabilities'. Werner and Campbell (1970) pointed out that it is more difficult to translate a shorter utterance, owing to the lack of context in short phrases, as the redundancy is quite limited. In research conducted on graphic symbols, for example, the translation of the label used as a stimulus for indicating which symbol it represents could elicit different responses from the participants depending on the specific translation; for example, in a study conducted by Haupt (2001) the Picture Communication Symbol (PCS) label for the English 'puff it up' (which was an instruction on what to do

with the pillow during the task of making up a bed) was translated into 'have to make it fat' in isiZulu. Similarly 'Let us take it off' was translated to 'let us remove it' and 'let us take it away' (Haupt, 2001, p. 83). Clearly although these labels can be described, the basic issue remains one of proving equivalence in cross-cultural research. Issues of equivalence in translations can be described in relation to vocabulary equivalence, idiomatic equivalence, grammatical–syntactical equivalence, experiential equivalence and conceptual equivalence (Sechrest et al., 1972). To address some of the issues of translations within graphic symbol research, Haupt (2001) developed a procedure for translation of labels of graphic symbols based on forward and back translations of graphic symbol labels. Brislin (1980) discussed four basic translation methods, namely back translation, the bilingual technique, the committee approach and pretest procedures. Steps suggested by Bracken and Barone (1991) are similar, and include source-to-target-language translation, blind back-translation, translation–back-translation repetition and bilingual review committee. The study by Haupt (2001) used a synthesis of blind back-translation, review committee and pretest procedures. As an example of a translation process that can be used in graphic symbol research, Figure 6.1 describes the procedures followed during the process of translation of PCS symbols in the study of Haupt (2001).

The first three translators independently translated the source phrases into isiZulu. These three translations were reviewed by three translators and modified until they reached consensus (first consensus). Individual translators then translated the first consensus back into English. The researcher then compared these back-translations and identified those items that were not the same as the initial translations.

The second translators were shown the source text and asked to suggest better isiZulu phrases for the problem items or phrases. These suggestions were presented to the first translators who ultimately decided on which phrases would be used to form the second consensus. The second consensus was presented to two (third) translators who once again translated it into English. At this point it seemed that no more changes were needed.

The basic tension relating to equivalence in translations, however, lies in what Secherst et al. (1972) refer to as the paradox of equivalence. The paradox implies that if one demands that one form of a test or other measure produces comparable results in two different cultures in order to demonstrate equivalence, then the more equivalent the two forms become, the less the probability of cultural differences. This paradox highlights the need for researchers to make informed decisions about what aspects or components of equivalence are relevant in producing the desired outcomes between the cultural groups, and which are not.
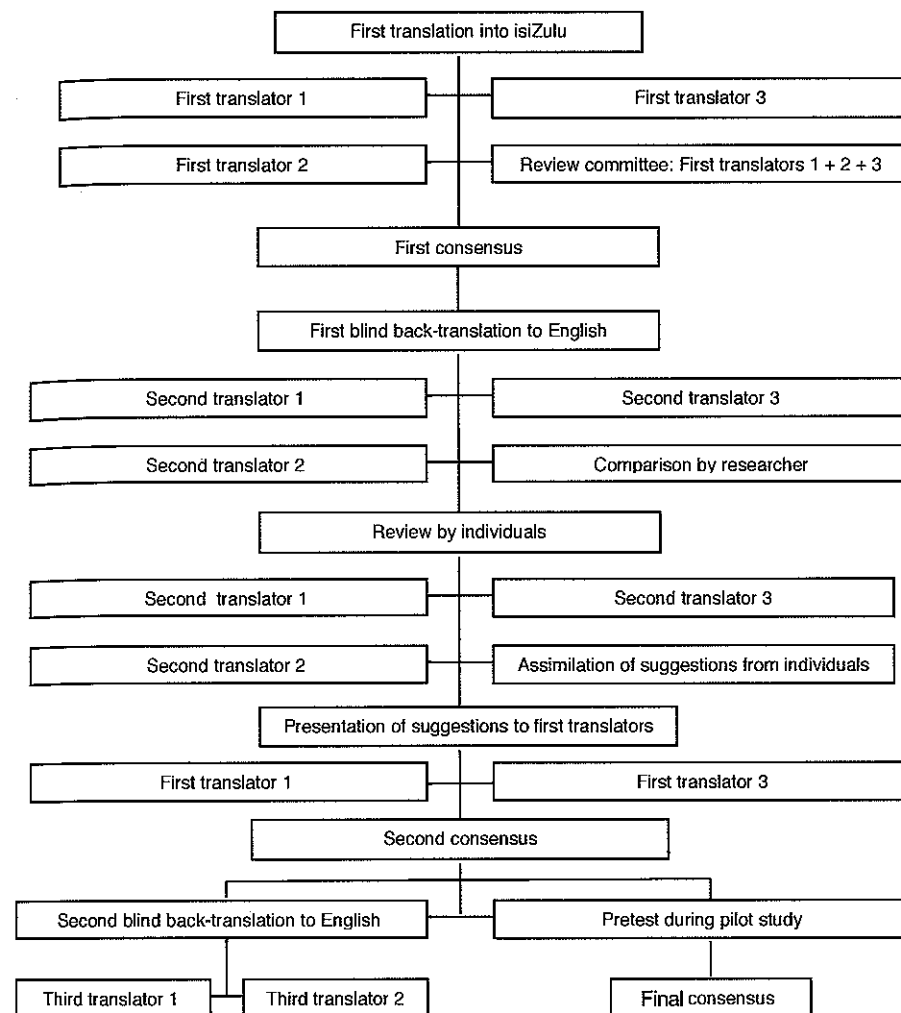
Figure 6.1 Schematic representation of the translation process (Haupt, 2001).

Culture-specific studies

Apart from studies in the United States (see Lloyd et al., 1997) there have been a variety of culture-specific studies conducted (e.g. Carmeli and Shen, 1994 (Israel); Flouriot and DeSerres, 2000 (Canada); Fujisawa, 1998 (Japan) and Marimon et al., 2000 (Chile)) on a variety of graphic symbols including

PCS, Bliss and PIC. Some interesting findings are reflected in some of these studies; for example, the study by Fujisawa (1998) investigated young children's comprehension of the Japanese version of the visual symbols PIC (see Chapter 3: Augmentative and alternative communication) and found that the typical children's ability to correctly identify a label increased over age.

As most of the research studies in the field of AAC focus on Western populations, this discussion will focus attention on some studies conducted in low-income countries as a basis for stimulating further discussion on cultural and social issues in AAC graphics. The first study was conducted in South Africa on rural Zulu-speaking children.

The iconicity of selected PCS symbols for rural Zulu-speaking children

A study by Haupt and Alant (2003) investigated the iconicity of PCS symbols (see Chapter 3: Augmentative and alternative communication) in rural Zulu-speaking children. The Zulu culture can probably be described as a secondary oral culture, namely a culture that originally could be described as predominantly oral, but due to the impact of television and other literate technology has been exposed to literate events in recent years (Ong, 1982). Duncan et al. (1973), Macdonald (1990) and Solarsh (2001) report on the limited access of these children to books and magazines. Today Zulu culture still includes oral traditions such as the performance of folktales, prose and praise names (Canonici, 1996).

This study aimed at investigating the accuracy with which 94 rural Zulu-speaking children aged eight years could identify PCS symbols on a 36-symbol overlay display (Goossens' et al., 1994) in response to a verbal label, 'Show me'. During the pre-experimental phase of the study the appropriateness of this particular overlay was explored for this group of children to ensure familiarity of concepts; afterwards it went through a process of systematic translation and back-translation to ensure content equivalence (Haupt, 2001). Table 6.1 illustrates the PCS symbols used and the presentation numbers.

When looking at the symbols in Table 6.1 it is interesting to note that the primary function of the symbols depicted can be summarized as: action-directed (14); descriptive (7); expressive (6); nouns (3); questions (3); and actions (3). From this it is clear that the majority of the symbols were oriented towards the direction of action. Thirteen out of the 36 symbols include the use of arrows to indicate movement or direction. To explore potential reasons for the errors the children made in the identification of the pictures/line-drawings in this study, the symbols were ranked from those with the highest to those with the lowest errors (see Table 6.2, which is based on data of Haupt (2001) and Haupt and Alant (2003)).

Table 6.1 Symbols used and presentation numbers of symbols.

Pres Nr	Label in English	Target symbol	Pres Nr	Label in English	Target symbol	Pres Nr	Label in English	Target symbol
1	What is next?		13	It is finished.		25	Puff it up.	
2	It is nice and soft.		14	Let us make the bed.		26	What a mess!	
3	No.		15	Thank you.		27	It looks like a bomb went off.	
4	You need to change them.		16	...the blanket.		28	Let us do it again.	
5	Whoops!		17	Let us put on...		29	Yes.	
6	We forgot.		18	...the sheets.		30	Put it here.	
7	What do you think?		19	Where is it?		31	You are welcome.	
8	It is nice and clean.		20	Look at this.		32	...the pillow case.	
9	Let us take it off.		21	Tuck it in.		33	Let me...	
10	It is crooked.		22	It is dirty.		34	It looks bad.	
11	You need to pull.		23	Fold it back.		35	Hold this, please.	
12	Put it in the tub.		24	Help me, please.		36	It looks good.	

Only four symbols were incorrectly identified less than 50 per cent of the time, with the biggest group of symbols being incorrectly identified between 91 and 100 per cent of the time.

Because there is no comparative data in other countries it is not possible to attribute these findings to cultural issues exclusively. However, there are some interesting trends in the error patterns of these children that can be discussed.

The four symbols (numbers 11, 14, 12 and 25) which indicated the least percentage of errors – less than 50 per cent – were all

Table 6.2 Error patterns in students' responses on identification of PCS symbols.

1	2	3	4	5	6
91–100% incorrect					
31 You are welcome	Expression	X			
13 It is finished	Descriptive	X			
23 Fold it back	Action-directive				X
28 Let us do it again	Action-directive				X
8 It is nice and clean	Descriptive		X		
18 ...the sheets	Noun		X		
33 Let me...	Action-directive		X		
3 No	Expression				X
9 Let us take it off	Action-directive				X
20 Look at this	Action-directive				X
24 Help me, please	Action-directive		X		
19 Where is it?	Question		X		
2 It is nice and soft	Descriptive		X		
4 You need to change them	Action-directive				X
21 Tuck it in	Action-directive				X
36 It looks good	Descriptive	X			
81–90%					
22 It is dirty	Descriptive		X		
30 Put it here	Action-directive		X		
1 What is next?	Question				X
29 Yes	Expression				X
26 What a mess!	Expression		X		
15 Thank you	Expression	X			
7 What do you think?	Question		X		
17 Let us put on...	Action-directive		X		
10 It is crooked	Descriptive				X
34 It looks bad	Descriptive		X		
71–80%					
6 We forgot	Action		X		
32 ...the pillow case	Noun			X	
61–70%					
35 Hold this, please	Action-directive			X	
27 It looks like a bomb went off	Action			X	
51–60%					
5 Whoops!	Expression		X		
16 ...the blanket	Noun			X	

Key
1. Presentation number and label
2. Main depicted function of symbol
3. Unfamiliar with the visual symbol
4. Difficulty with association between symbols on picture
5. Part/whole perception
6. Difficulty in understanding indication of directionality

action-directives, but included no arrows in the pictures themselves. These pictures can all be described as depicting the complete action or concept with quite a bit of detail (see Table 6.1). The 13 symbols that included arrows all presented with 81–100 per cent errors. Subsequently, the errors (those over 50 per cent) were further analysed to explore possible reasons for the difficulties in identifying these symbols correctly.

The errors were analysed according to three categories: first, unfamiliarity of the symbol used; second, unfamiliarity of the associations used (this refers to the unfamiliarity of the *combination of symbols* used or unfamiliarity in relation to *part/whole relationship*); and, third, directionality (those symbols indicating specific direction of action or placement). The error analysis presented in Table 6.2 is discussed below in terms of culture and experience.

From the errors it is indicated that three of the symbols might be described as unfamiliar to the students even though they knew the concepts. This might be understandable, as these symbols represent manual signs that are unfamiliar to the majority of the children. It is interesting to note that symbol 31, 'You are welcome', also requires depth perception – for the child to understand the movement between the face and the midline. Depth perception in itself is a well-researched topic, as stated by Serpell (1976): 'There is evidence that certain more elaborate illusions are dependent for their effect on experience of a "carpentered world" in which straight lines and right-angles are often viewed from various vantage-points' (p. 94). Allport and Pettigrew (1957) also found that rural and urban Zulu boys showed differences in their depth perceptions. Clearly these were studies conducted within a specific context, but they do provide some material for thought!

Nineteen of the errors could be attributed to unfamiliarity of the association between the visual aspects related in the picture, or to difficulty with part/whole perception. For example, for symbol number 30, 'Put it here', the child would identify the man and the cross, but is unfamiliar with the use of the cross as indicating a specific spot. A picture of a bed, which is made up, represents symbol 18, 'sheets'. Difficulties in separating the part (sheets) from the whole (bed) seem to be prevalent. Similarly, picture 26, 'What a mess!', depicts some familiar objects, but associated with an unfamiliar concept, 'mess'. The kind of mess depicted is clearly not that familiar to these children, who live in a rural context. Similarly, symbol 22, 'It is dirty', depicts dirt on a surface whereas dirt might be more strongly associated with dirt on clothes, or on the body. It is clear from some of the explanations that the errors made by the students could be due to their experiences, and could be reflective of a field-dependent cognitive style where they tend to perceive the whole rather than discrete aspects of the picture. Growing up in a deep rural setting within a strong orally oriented culture could indeed impact on their performance.

Ten of the errors are attributed to the use of arrows in the pictures (Haupt, 2001). This is most interesting as arrows are such an integral part of the computer and literate world. However, interpretation of arrows is a learned skill that implies an understanding of movement and three-dimensional perception within two-dimensional representations. For example, Symbol 28, 'Let us do it again', does require some perception of depth in order to make sense of the visual representation of the arrows. Symbol 3, 'No', and symbol 29, 'Yes', both require the perception of movements indicated by arrows. Although students are familiar with the head movements they did not recognize these in the visual representations.

From this study, it is indicated that students had a range of interpretations of the graphic symbols presented. These findings highlight the need for further exploration to investigate the relevance of specific graphic symbol systems within particular contexts. The study by Nigam and Karlan (1994, 1996) focused on the cultural validation of the PCS in India and will be briefly described.

Cultural validation of the PCS for Asian-Indian AAC users

A study by Nigam et al. (n.d.) and Nigam and Karlan (1994, 1996) was conducted to culturally validate the PCS lexicon for adult Asian-Indian AAC users and to develop a relevant core lexicon for Asian-Indian AAC users. One hundred and twenty individuals from five different regions of India participated in the study. A composite list of lexical items was identified, using a structured social validation technique involving non-categorical and categorical nominations and a rating of lexical items from a PCS lexicon. Results indicated that 88 words nominated were not found in the PCS lexicon and that 247 PCS lexical items were rated as having no meaning to Asian-Indian AAC users. In addition, variations in lexical needs across regions were found. These findings further emphasize the complexity of cross-cultural studies in AAC, as these participants did not assign meaning to some lexical items used in the PCS.

The above descriptions are not intended as conclusive or comprehensive; however, they highlight the need for increased understanding of graphic symbols in AAC intervention. First exposure to a communication board or device is important as it can impact on learnability and at times produce lasting impressions. It is therefore critical that interventionists become more aware of the initial response of children and adults to the use of a specific graphic system. Research on pictorial recognition suggests that people who do not recognize pictures at first exposure can quite easily learn to identify these if the pictures are explained and their perception is guided to facilitate understanding (Deregowski, 1968, 1980). Research on learnability of specific symbols used within the field of AAC in different cultural contexts has, however, been limited and needs to be addressed. The next study investigated the learnability of two different graphic symbol systems with a group of Northern-Sotho-speaking children in South Africa.

Comparison of the learnability and recognition of CyberGlyphs and Blissymbols on a group of Northern-Sotho-speaking school-going children in an urban context

In a paper by Alant et al. (2004) the authors further explore data which was based on a master's study by Koekemoer (2000) in which the ease of learning and recognition of Blissymbols and CyberGlyph symbols (see Chapter 3: Augmentative and alternative communication; Lloyd et al., 1997) was compared in a group of 50 grade-4–6 pupils whose mother-tongue is Northern Sotho (one of the official languages in South Africa). A quasi-experimental crossover design between groups was used. Each of these groups was exposed to learning the same concepts in either Bliss or CyberGlyph symbols using two tasks of 40 concepts each. Training was scripted, and consisted of a description of the different elements of the symbols.

Table 6.3 An example of some rules for CyberGlyph production.

RULE	EXAMPLES	
Rule I The symbol > is an action indicator. When it precedes a noun the compound symbol will become a verb. By reversing the direction of the arrow, the meaning of the verb is reversed.	Noun:	('aeroplane')
		('to fly')
		('to return by plane')
Rule II The symbol ∧ signifies location. When placed on top of a symbol representing a vehicle or vessel it denotes the location where the vehicle is usually boarded or parked. When placed on top of a symbol other than that of a vehicle or vessel, it indicates the public location where services or facilities are present.	Vehicle: ('ship')	
	('harbour')	
	('church')	
Rule III When a symbol serves simultaneously as a subject and as a verb, the action indicator goes to the right side of the sign that is being conjugated. Although not mentioned as a rule, the location of the action indicator in relation to the symbol depicts the tense of the sentence.		('the eye sees')
	instead of:	('the eye sees')
		('the eye saw')
		('the eye will see')

It was decided to compare these two graphic systems, as CyberGlyphs (Zavalani, 1991) were intended as a generic graphic symbol system with its own rules which, similar to Blissymbols, has the potential to generate new symbols by combining rules and elements. Table 6.3 provides an example of some of the rules for CyberGlyph production as summarized by Koekemoer (2000, p. 12). The system describes rules for symbol production, symbol formation, different types of symbols, and symbol composition. From Table 6.3 it is evident that this symbol system is intended to be hand drawn.

As research on learnability has repeatedly shown that Blissymbols are more difficult to learn than other, more pictorial systems, investigators were keen to explore another graphic system that might be easier to learn for children, but might have similar potential to the Bliss system in generating new symbols.

Similar to previous studies on iconicity and learnability (see Lloyd et al., 1997; and a Brazilian study by Thiers et al., 1998), this study confirmed that students found it more difficult to recognize and retain Blissymbols after exposure to learning. This was persistent throughout the different withdrawal phases. This finding was not surprising as, on first exposure, CyberGlyphs do seem more pictorial in nature. However, perhaps the more interesting aspects of the study relate to a qualitative analysis of the difference between the systems and the exploration of reasons contributing to these results.

Table 6.4 provides a comparison between the two symbol systems in relation to some of the symbols used in the study. The symbols included in this table constitute the three categories of parts of speech that showed up significant differences between the two systems throughout the different phases of the testing. The first 10 alphabetical concepts used in the study, representing the different parts of speech included in the vocabulary taught, are included: 10 action words, 10 adjectives and 6 pronouns.

From Table 6.4 the following factors might impact on performance:

- On first impression, CyberGlyphs seem to be more pictorial in nature, for example the symbols for climb, grow, dance, beautiful, cold. Bliss on the other hand consists of more formal geometric forms, for example the symbols for angry, black, brown, blue.
- The associations between the elements of the CyberGlyph symbols also seem to be more transparent; for example, the symbol for 'catch' indicates a ball moving towards the hand.
- The action indicator in CyberGlyphs appears in front of the symbol (e.g. *to* catch). This could facilitate perception, as the action indicator on top of the geometrical symbol (as with Bliss) might add to the visual complexity of the symbol.

Table 6.4 Comparison of CyberGlyphs and Blissymbols on part of word categories that indicated significant learning and recognition differences throughout the study.

Word categories	Symbol (verbs)	Bliss	CyberGlyphs
ACTION	Catch		
	Climb		
	Cough		
	Dance		
	Give		
	Grow		
	Hate		
	Kneel		
	Kiss		
	Laugh		
ADJECTIVES	Angry		
	Big		
	Beautiful		
	Black		
	Brown		
	Blue		
	Cold		
	Green		
	Good		
	Healthy		
PRONOUNS	I		
	It		
	Them		
	Us		
	We		
	You		

- Another difference in performance was on the symbols representing colours of the two systems. Blissymbols use the association with the eye (something that you see) with the earthline and skyline for 'brown' and 'blue' respectively. CyberGlyphs on the other hand uses a diamond shape with a filled-in top half for 'blue' and a filled-in bottom half for 'brown'. It seems that the association between earth and sky as illustrated in the diamond shape was easier for children to interpret.

From the above study, as well as the previous study by Haupt (2001), it is clear that participants found certain graphic associations easier to relate to than others. However, as the different associations are explained to them they might indeed learn them quite quickly. The differences do suggest that children found it easier to relate to the associations and visual representations of the CyberGlyphs system. It is, however, important to point out that generative characteristics of the two systems might well differ. CyberGlyphs is a new system that has not been used extensively and does not have the extensive support material to facilitate use as compared with the Bliss system. Although it is described as a generative system, the range of the system needs to be explored further. Initial findings do suggest, however, that this system might be well worth investigating further.

Graphic symbols/icons and language variation

Although the above studies all used language populations other than English, issues surrounding variations of the same language in different cultural contexts also necessitate some investigation. It is often assumed that American-oriented programs, like the Unity application program of Minspeak, could be relatively easily transferred to other English-speaking countries owing to similarities in culture, linguistic structures and language use. A study by Cross (1994) confirms the difficulties involved in trying to design a symbol set where symbols have only one meaning. Although the field of sociolinguistics – which focuses on the role of social context in language use, language variations and dialects – has added much insight into the differences between the use of the same language in different contexts, these issues have not received much attention in relation to AAC research (Van der Merwe and Alant, 2004).

One study which attempts to deal with some sociolinguistic issues of Minspeak symbols was conducted in South Africa and explored the associations that university students at the University of Pretoria made with Minspeak icons (Van der Merwe, 2000; Van der Merwe and Alant, 2004). All the students were studying through the medium of English and would typically work in a predominantly English industrial context after their studies were completed. This group of students represented 89.1 per cent English and Afrikaans mother-tongue speakers with the rest of the students using a variety of African languages. It was decided to investigate the associations these young adults made with Minspeak as a basic point of departure in comparing their associations with those proposed in the Unity software. The associations of the Unity software are represented by the words and concepts included in the program. The comparison was thus largely based on the comparison between the English words used to describe specific icon associations.

Associations were elicited from 480 tertiary education students using cueing questionnaires. Thirteen cueing questions were used to assist students in completing the task. These questions included: What do you see? What do you do with it? What group does it belong to? Who uses it? How would you describe it? and so on. All the responses were checked and then rated according to specific guidelines to identify the most common associations and words used in describing the associations. The 12 icons used with the UniChat were used in the study, as shown in Figure 6.2.
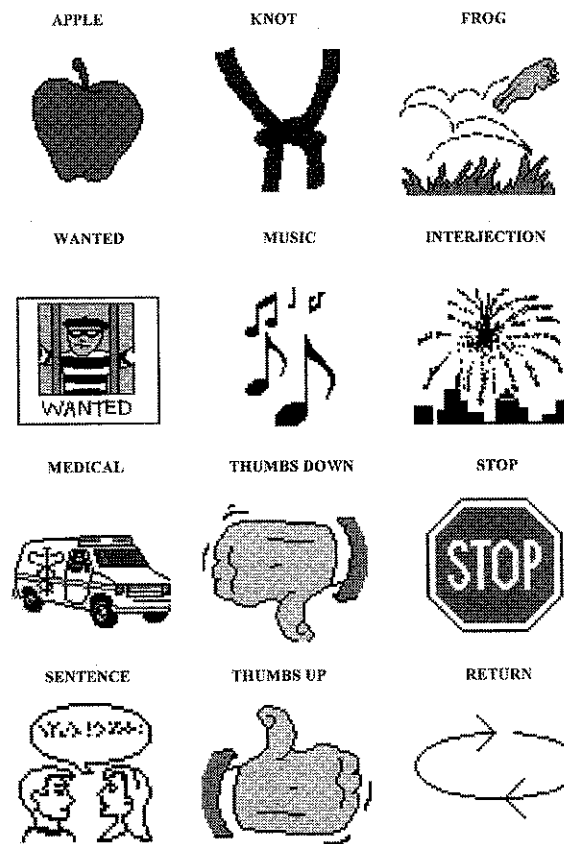
Figure 6.2 Icons used in this study.

Figure 6.3 provides a more specific description of the agreement between the most common association (first level) made by the students and the Unity software lists. The outcome of the analysis indicates that in most cases the percentage agreement between the two lists was below 35 per cent with only two exceptions (STOP and WANT), which achieved agreement of 60 per cent and 40 per cent respectively. It indicated that even though the study was conducted in English, for the majority of icons there were more than 60 per cent of vocabulary items that were not similar. Table 6.5 describes a comparison of associations with the APPLE icon elicited in the study and the current Unity vocabulary. Although there is some conceptual agreement between these two sets, the words used to describe the concepts are different from those of the Unity vocabulary. As with the previous discussion, it is not possible to know how much of this disparity would be due to specific cultural and social differences, as similar studies on Minspeak icons have not been conducted in the USA or other countries.

Figure 6.3 — Bar chart. Percentage of agreement (%) by Icon:

Icon	Percentage of agreement (%)
Stop	60
Wanted	40
Thumbs up	35
Apples	28
Frog	27
Return	22
Music	21
Medical	20
Thumbs down	13
Knot	7
Sentence	5
Interjection	3
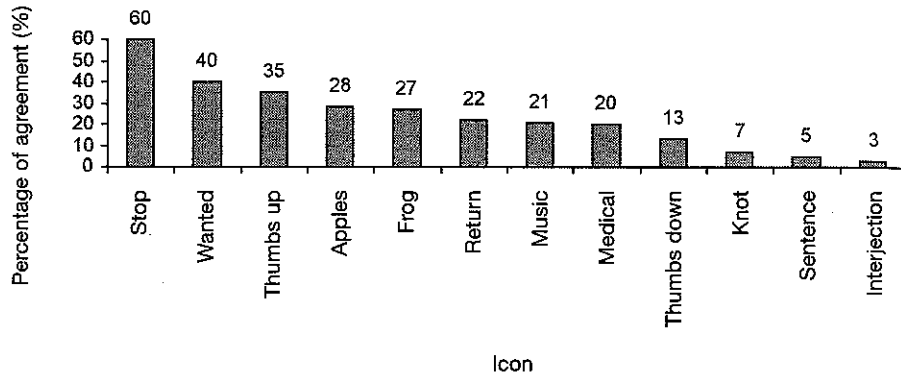
Figure 6.3 Summary of agreement between compared lists.

The argument could be made that, regardless of the kind of spontaneous associations made by individuals in different cultures, these associations could be taught – and in this manner standardized software does become more accessible to more people who use AAC. This argument clearly is relevant, although the issue is related to the appropriateness of this approach for people with severe disabilities who might take a long time to learn new associations. The issue remains at what cost the individual using AAC would be learning to use the software.

Table 6.5 Associations with the APPLE icon elicited in the study, and the current Unity vocabulary. Source: Van der Merwe, 2000.

Associations elicited in this study only	Communal words	Associations included in the current Unity versions only
construct the theory of gravity peel*; peel*; use as weapon; mothers; people on a diet; healthy†; herbivores; round†; sphere; circle; heart-shaped; oval; off-round; voluptuous; fibre; water; tree; grow*; shops; Pick 'n' pay; cafeteria; market; greengrocers; fruit markets; kitchen; fridge; crunch; munch; crack; ah; nice; smacking lips; eeeuu worm!; 'I'm hungry'; 'An apple a day keeps the doctor away'; nutrition; nourishment; essential; vitamins; minerals; balanced diet; tasty†; thirsty†; portable†; common; juicy†; fruity†; pips; twig; branch; leaves; naartjie; mango; juice; canned*; puree; chopped*; baked*; grated*; rotten*; squashed*; small blocks; cut*; ice cream; fruit salad; cinnamon; apple tart; toffee; syrup; refreshments; cream; pie; worm; content; satisfied; energized; enjoy; fulfilled; good†; great†; happy†; refreshed*; relieved*; non-fattening	apple; bite*; chew*; eat*; taste*; ice-cream; pie; food; fruit; delicious†; hungry*; sour†; vegetable; sweet†; apples; banana; cherry; grape; grow*; lemon; anybody; orange; peach; pear; pineapple; strawberry; tomato; candy; sauce; anyone; salad; cheese; pork; salt; pancake; red; yum; sugar; yogurt; chocolate; horse	egg; butter; cracker; crisp (UK); potato chip(US); nut; popcorn; pretzel; sandwich; biscuit (UK); cookie(US); cake; cupcake; custard(UK); pudding(US); doughnut; bacon; beef; bologna; cheeseburger; chicken; ham; hamburger; hot dog; pepperoni; sausage; steak; turkey; butterscotch; vanilla; cereal and grain; condiment; dairy product; flavour; meat; Mexican food; refried beans; salsa; menu; letter; pasta; snack; bagel; bread; cereal; oatmeal(US); porridge(UK); rice; toast; waffle; angel hair; fettucini; linguini; macaroni; noodle; pizza; ravioli; rigatoni; shell; spaghetti; tortellini; honey; jam(UK); jelly(US); ketchup; mayonnaise; mustard; oil; peanut butter; pepper; salad dressing; vinegar; bean; drool; enchilada; taco; beet; cheek; order*; set*; plow*; teatime; tractor; broccoli; Brussels sprout; cabbage; carrot; cauliflower; celery; chips(UK); French fries(US); corn; cucumber; lettuce; mushroom; onion; pea; potato; spinach; any time; anyhow; anymore; anything; anyway; anywhere; crisp; lime; kiwi; berry; melon; plum; pumpkin; burrito; nacho

* Word is found in all the different verb forms, including 'verb', 'verb + s', 'verb + ed', 'verb + en', 'verb + ing', 'to + verb'

† Word is found in all the different adjective forms, including 'adjective', 'adjective + er', 'adjective + est'

Concluding comments: international trends

It is important to point out that other than research on Blissymbols there has been very little research conducted on iconicity of graphic symbols that are commonly used in the United States (e.g. PCS or Minspeak icons). This dearth of data on how symbols are perceived and interpreted makes it difficult indeed to interpret findings of research conducted in a specific country.

Clinically, however, there has been increasing sensitivity towards international needs for culturally specific symbols in using AAC systems. For example, Mayer-Johnson Inc. have over the past years developed PCS symbol sets for use in specific countries, including Austria, Australia, Brazil, Canada, Chile, Denmark, Finland, France, Hungary, Israel, Mexico, Poland, Spain, Sweden, United Kingdom and India (Johnson, 2001). Similarly, the Minspeak system and overlays have been adapted for use in European countries, e.g. Germany (Gulden and Andres, 1994) and the Netherlands (Deroost and Baker, 1994), to allow for different icons to be used on the overlays, in addition to adapting the system to a different language and cultural context.

Increasing attention to cultural issues in the AAC literature is also evident, for example the articles by Huer and Saenz (2002) and Huer et al. (2001). Also, in a recent forum discussion on 'Do individuals from diverse cultural and ethnic backgrounds perceive graphic symbols differently?' in the *AAC Journal*, Nigam (2003) and Huer (2003) debate critical methodological issues related to the difficulties in cross-cultural comparisons in which issues like acculturation are mentioned (see also Chapter 9 on the issue of acculturation).

Experiential variations in first exposure of graphic symbols: a clinical procedure

The above discussions highlighted the nature of potential cultural and social influences on the use of graphic symbols within AAC intervention. These discussions are, however, exploratory as there has been very little research done on the impact of cultural and social differences on graphic symbol use. These issues are, however, complex as culture itself is evasive, and difficult to define owing to multifaceted influences, heterogeneity within cultural groups, and acculturation. However, with increasing awareness of diversity and the need to accommodate diversity in meaningful and constructive ways, the field of AAC will need to pay increasing attention to ways in which cultural differences can be accommodated on different levels to ensure that communication systems are used and not left to gather dust.

One way to sensitize AAC interventionists towards cultural issues in the use of graphic symbols is using a set of questions to determine the individual's ability to recognize and use the symbols before finally deciding on a particular set or system. Apart from merely determining whether a candidate can recognize transparent line drawings and match these with objects, interventionists should move beyond this to look also at non-picture-producing symbols to evaluate the potential of the symbols in being taught to convey a specific message.

The difficulty is, however, that it is not feasible for therapists to develop new symbols if there is a possibility that the individual could use existing symbol systems. Any additional modification clearly requires additional time and effort from the person extending the communication system. The following procedure is intended to assist the therapist in evaluating ease of learning of a particular symbol set. The intent is to use a structured procedure to identify potential confusions and difficulties in learning and using the symbol set/system.

From the above it is indicated that clinicians need to become more aware of the associations and meanings that children and adults from different social and cultural contexts could infer from graphic symbols used in AAC intervention. Although these procedures seem to be common sense to the experienced clinicians, some specific guidelines might be of benefit.

The procedure suggests various steps that assist the clinician to obtain some understanding of the client's familiarity and associations with the graphic symbol set or system intended for use in AAC intervention. This procedure was an existing communication board (for example, a display of selected symbols, a generic communication or activity board) as a basis for the procedure. The procedure consists of five steps.

- Step 1 aims to obtain a first-exposure response from the client by asking the client, 'Show me _____' (provide the target label, e.g. 'happy'). The second step will follow if the identification of the symbol is not the same as the expected response.
- Step 2 aims to understand more clearly how the individual relates to this particular label by asking if they can see another symbol on the display that could also mean 'happy'. This provides the clinician with additional insight in relation to other graphic symbols that might be confused with the target label. The clinician might proceed to ask for an explanation of why this particular graphic symbol is chosen – and if the individual is not able to respond to this request, to ask the client to expand by pointing to other symbols that they think are associated (have similar or opposite meanings), to facilitate an understanding of association between label and graphic symbol. Clearly the more sophisticated this investigation is, the more extensive the array of symbols needs to be.

- In step 3, the clinician proceeds to show the individual the target symbol representation (e.g. 'happy') – and asks the client to provide it with a label of what he/she thinks it means. Once again this step is an attempt to understand the salient features that the individual sees in the graphic symbol. This information could guide the clinician in understanding what features in the graphic symbol could facilitate misunderstanding or more effective identification.
- In step 4, the clinician teaches the individual the desired symbol–label association to allow for testing of retention at a later stage. The fourth step requires that the symbols be taught to the individual by paired matching. The number of exposures can be determined by the clinician, but should be sufficient to allow the client to learn the associations.
- Steps 1–4 should be repeated with at least six symbols (or more, depending on the client's ability) of different word types and complexity. Specific attention should be paid to include picture and non-picture-producing symbols to enhance understanding of how pictures could be used in teaching associations.
- In step 5, at the end of the session (after other activities are completed), the client is tested to see how many of the symbol associations are recognized or retained. This process thus provides the clinician with some insight into how easy/difficult the individual is going to find it to learn the specific labels attached to the graphic symbols of a particular symbol set or system.

Table 6.6 Summary of the procedure to explore first exposure and learnability of symbols for use in intervention.

Example: Target symbol and label 'happy'

Step 1	'Show me "happy".' If response is not the expected PCS symbol then proceed to step 2.
Step 2	'Why do you say this picture means "happy"?'
	'Is there another picture on this board that can also mean "happy"?'
	'Is there another picture that can show the opposite of "happy"?'
Step 3	'Show the PCS symbol for "happy". What does this picture mean to you? Why?'
Step 4	'Pictures can mean different things for different people, but, on this communication board, this picture [symbol for "happy"] means "happy", because [reason].' Repeat the association between symbol and label to provide opportunity for learning.
Step 5	Testing of associations between symbols and labels taught.

This approach does not imply that the clinician will have to draw new pictures or symbols, but provides better understanding of how associations between graphic symbol and label can be presented to facilitate learning. Similarly, if certain visual representations are particularly confusing, the clinician might substitute those symbols to facilitate further learning. Table 6.6 provides a summary of the procedure.

Conclusion

In a society that is increasingly globalized, the temptation is to use standardized symbol systems and strategies in intervention. While this is appealing from a financial, economic and training perspective, AAC interventionists need to apply caution so as not to become insensitive to the individual's prior experiences and learning, which, in a client-centred approach form such a vital part of effective intervention.

Clearly, the challenge is to balance the understanding of prior knowledge and learning of the individual client with the use of existing graphic symbol sets or systems in developing a communication system that can have lasting impact on the interaction of individuals who use AAC and their families. Communication is a highly personalized process – and while the field of AAC has made great strides in the development of advanced technology and communication systems, the basic issue remains one of adaptability to the individual and the sociocultural context that the individual lives in.

Little research has been conducted on the impact of using standardized AAC strategies on the nature of the interaction between AAC users and their partners. It is often said, '*that* an individual communicates is much more important than *how* he/she communications'. This might well hold true for many interactions; however, let us not become blind to the more subtle nuances of communication and exchanges – which might be most important in facilitating more personalized and extended communication efforts.

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CHAPTER 7
Service delivery in low-income countries

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This chapter deals with issues related to service delivery in the broader sense as well as in augmentative and alternative communication (AAC) intervention, particularly within low-income contexts. Different levels of service provision are discussed – primary, secondary, tertiary and prevention. Service shortcomings are considered as well as the challenges countered in bridging specialist, primary and secondary services. A variety of strategies are outlined in meeting the challenges of service delivery in emerging countries.

In recent decades a range of health, social and educational services has evolved in response to the needs of people with disabilities and their families. These are most developed in the affluent countries of the North and are often conceived at three levels, as Figure 7.1 shows.
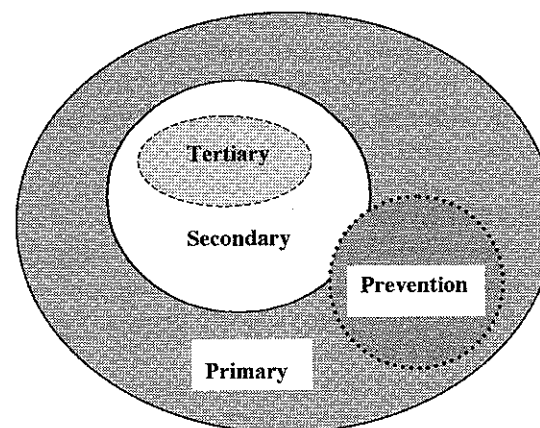
Figure 7.1 Different levels of service provision.

Primary services are available to everyone within a society or community. They could include medical assistance for common illnesses, schools for children aged 6–15 years, or community services such as job-finding. Comprehensive, primary health care services, including health promotion and disease prevention, are further examples, as are preschool and nursery school provision. These services aim for universal coverage within a community and everyone has an entitlement to use them. In many instances they are available at little or no cost to the recipients, but are paid for by governments.

Secondary services tend to deal with the particular needs of a smaller proportion of persons, for example hospital services for those requiring surgery, or special schools for children with disabilities. People usually have to be 'referred' to these services and 'assessed' as requiring them before they are accepted. These services usually employ specially trained personnel and generally a charge is levied on service-users. In many emerging countries particularly, these services are often only available to more affluent families.

Tertiary services are more specialized again and they focus only on people who have particular and often complex needs. Examples could include rehabilitation services for persons with disabilities, or assessment and treatment units for children with severe communication difficulties. There are usually strict admission criteria, and placements are often of short duration while intensive treatment is given. Highly trained professionals are employed in these services and hence the costs are very high. Many emerging countries cannot afford them, although the affluent citizens of these countries will travel abroad to avail themselves of them.

This triad model of provision has evolved for health services throughout the world but variants of it have been developed for educational as well as social support systems (Bronfenbrenner, 1979).

Another suggested refinement has been the addition of *preventative services* targeted at vulnerable children and families (Hardiker et al., 1996). These services usually straddle primary and secondary levels, as Figure 7.1 shows. They are most often based at the primary care level but they tend to be staffed by persons from secondary services (and maybe even tertiary level services). A primary distinction though is that preventative services aim to be *proactive* in identifying and addressing needs whereas primary and secondary services are mostly reactive to the people who approach the services for assistance.

In less affluent countries, these four levels of service delivery are often not well developed but nonetheless they are discernible as the basis for most health care and they can be seen to some extent in the provision of services for persons with disabilities.

Service challenges

Although this model of service delivery has much strength, its shortcomings also need to be noted.

- Comprehensive coverage for all persons in need of a service has been difficult to attain. In particular, persons living in low-income families and in more rural areas are less likely to avail themselves of services (Helander, 1993). Equally, professional time is insufficient at all levels to meet the demand so clients may not receive the help they require.
- Co-ordination among different levels within the system can be poor. This can lead to inconsistencies in approaches and failure to sustain interventions as the child grows. Moreover, effective co-ordination across different service systems, such as the linking of educational, health and community services, remains elusive (Harbin and McNulty, 1990).
- Existing service systems and professionals tend to focus on the individual with the presenting problem rather than working with the child's wider support system such as family members. This is particularly significant when the presenting problem is communication impairment. Therapy that treats only the child has limited impact on the child's communication in everyday contexts (Dunst et al., 1988).
- Balancing the investment of resources across these sectors has proved especially challenging. Tertiary level services often attract a higher proportion of the costs, with relatively little investment going into primary and preventative services. When resources are limited it is even more crucial that they give value for money (Witter et al., 2000).
- The model does not address the issue of service quality, which can be very variable within and across service levels. Latterly, evidence-based practice has been promoted so that clients receive appropriate and effective interventions (Brownson et al., 2002).
- As with most service-delivery models, this one has not been compared to other models in an experimental or controlled manner to ascertain whether there are more cost-effective ways of meeting the needs of service-users.

These same shortcomings are even more apparent in less developed countries, as they struggle to meet the needs of many more persons with fewer resources and trained personnel (Stone, 1999). Yet in many ways the strains within service systems are the inevitable 'growing pains' as professionals and organizations learn how to develop services that meet the diverse needs of all children and families within the country. Our endeav-

ours in the field of disability at creating universal services based on need rather than wealth are less than a generation old. There is much we still have to learn.

AAC as tertiary level service

This conceptualization provides a useful service framework for considering the delivery of services in AAC. The most obvious question is: At what level should AAC services function? For many the answer is obvious: AAC is a tertiary level service that addresses the specific needs of a small number of persons. Indeed AAC specialists share many of the same attributes of professionals who work in tertiary services, notably knowledge and expertise built up over years of overcoming the various problems their clients encounter. Staff working in primary and secondary systems do not have such opportunities.

Specialists are also much more likely to contribute to research and development in their field, thereby providing evidence that interventions do work, or refining and discovering new approaches to the problem.

It is also more feasible and cost-effective for a team of specialists to be gathered in one place but who accept referrals of clients from a wide area. This is especially so with people who have complex problems that no one professional has the expertise to deal with.

In conclusion, there are strong arguments for making AAC service delivery a tertiary specialism and indeed this has happened in many countries, especially the more affluent ones. But this is not to imply that tertiary provision should be the only form of service delivery. On the contrary, as we will emphasize throughout this chapter, it is essential that AAC features in all levels of service provision. Our goal is to demonstrate how this can be done.

Desirable features of tertiary provision

We start with tertiary provision as experience suggests that this will continue to be the bedrock on which other initiatives are built. However, for these services to be fully effective, consideration needs to be given to the following points.

- Tertiary services tend to be based in specialist settings such as hospitals and clinics, with limited engagement with their clients in their home and community settings. This greatly limits a complete assessment of the child's needs and of the assets that can support the child's communications (Kretzmann and McKnight, 1993).

- Specialists tend to focus on the persons with the disability and strive to identify their deficits and to institute treatment or remedial procedures to address these shortcomings. They tend not to be concerned with the person's strengths or in meeting what could be considered as 'ordinary' needs, such as for companionship, education and social inclusion. Hence their treatments are not integrated within a wider programme of interventions (Gallagher, 1992).
- Each specialism has developed a unique vocabulary – jargon – which makes it difficult for other professionals and lay people to understand the implications of their advice and to act accordingly. Moreover they can create the impression that only they as specialists can adequately perform certain therapeutic techniques (Mittler and Mittler, 1994).
- The demand for specialist services usually outstrips supply, and consequently there can be long waiting times for their services during which time little is done to help clients, consequently their problems can be exacerbated. Moreover large sections of the community may not have the financial resources to access tertiary services (Zinkin and McConachie, 1995).

In summary, specialist services tend to be most effective when they can implement an intervention that produces a quick and long-lasting change for the better so that the client can be discharged, somewhat like a surgeon doing an ENT operation. However, if clients need sustained and complex interventions then the specialist alone is unlikely to be able to provide these, although many strive valiantly to do so.

Disabled activists have been particularly critical of specialists whom they accuse of being wedded to a medical model of disability – 'fix the person' – rather than with addressing the disabling aspects of the environment and society (Bickenbach et al., 1999). They would prefer to see professionals being 'on tap' to assist people with disabilities rather than, as at present, specialists perceiving themselves to be 'on top' (Werner, 1995).

Thus the issue becomes one of bridging specialist AAC services into other levels of service provision. This is particularly pertinent in poorer countries, where the availability of tertiary services is limited, and with low-income families, who are often unable to access such services even if they are available (Coleridge, 1993).

Bridging secondary and primary services

In nearly all countries of the world and even in the most impoverished communities within them, there are two forms of help available to all families. First, there will be some form of community health services,

which target the health and well-being of mothers and infants and, second, there are schools or informal educational initiatives for children from 5 to 12 years, if not longer. In addition many communities will have some form of preschool facility such as a crèche or nursery school (Jones, 1999).

These services are often staffed by people from the community who are known to the families and may even be related to them. Hence these indigenous resources could be invaluable allies to specialists involved with children who have communication problems, from both a preventative as well as primary care perspective. In particular:

- Health workers can detect children and families who may be experiencing communication difficulties at any early age and could be encouraged to make referrals.
- They could provide the families with basic information about handling the communication difficulties proactively.
- Health workers and teachers can put families in touch with other families in the locality who may have a child similar to theirs and encourage the growth of family self-help groups.
- They can provide ongoing emotional support and encouragement to families or find others in the community who may undertake this role of supporting families.
- They can support the child's engagement in community life such as school enrolment through their networks and status within the community. People with disabilities have needs that cannot easily be met within specialist systems – for companionship, productive work and marriage. These have to be addressed within their communities.

However, these potential benefits cannot be realized unless there is an ongoing partnership between the specialist systems, with their knowledge, expertise and resources in disability, and the community systems, with the knowledge, expertise and resources of the local culture and society (Baine, 1996). How may this be achieved?

Sharing knowledge

Arguably one of the greatest shortcomings of specialisms and specialists is their reluctance to share their knowledge and skills beyond their own profession, especially in ways that are meaningful to lay people. Yet this failing makes it extremely difficult to forge partnerships based on shared language and common understanding of the problems and means for overcoming them. Hence a prime responsibility of any AAC specialist must be to share knowledge actively in meaningful ways with community-

support personnel and family members. However, traditional means for doing this among professionals, namely written articles and talks, are less likely to prove successful with these groups.

More successful approaches will have some or all of these characteristics:

- The emphasis in training needs to be on *learning by seeing and doing*, rather than from talks and books, as levels of literacy among the target groups are likely to be poor (Werner and Bower, 1982).
- These people need to be given information that is *practical and relevant* to the needs of the people with whom they are working and to the job they are expected to fulfil. Examples of good practice occurring in their culture and under similar conditions to those that they experience are likely to be the most useful. Hence indigenously produced training materials are preferable to those produced elsewhere (Thorburn and Marfo, 1990).
- The training must take place *locally* and it should be *easily repeated* for differing groups within the community and over time as new people come along. Trainees have other commitments in their homes and community that make it impossible for them to travel even if they could afford to do so.
- The training must help to develop *better services within local communities*. Too often training is divorced from service goals by focusing on the acquisition of knowledge and skills whereas training also needs to embrace methods for changing attitudes, planning service goals and nurturing partnerships within communities (Hope and Timmel, 1984).

Among the more effective methods for sharing information are the following (McConkey, 1993):

- demonstrations with children, in vivo or on video recordings;
- practising 'new skills' with children and being given constructive feedback;
- role-playing;
- the making of simple communication aids and playthings;
- activity planning in pairs or small groups;
- provision of print materials with high visual content, e.g. line drawings and photographs. These can take the form of posters, leaflets and booklets.

These methods can be used within a range of training options including:

- one-to-one tutoring;
- short sessions, 20–60 minutes long, focusing on a specific topic;

- half-day, one-day and two-day workshops, which can be adjusted accordingly to the availability of personnel to attend and the distances involved;
- longer training courses held over a period of time and requiring a substantial amount of study time – around 120–200 hours.

Technology options

The design, preparation and delivery of training events can be demanding on scarce specialist personnel. However, modern technology does offer some solutions, especially if the learning is 'packaged' so that local personnel can act as tutors for others in their locality.

- *Self-instructional training manuals* – Word-processing and desktop publishing software makes it easier to produce a package of self-instructional materials which learners can work through at their own pace and in their own locations. This works best with courses that are largely information-giving. The manuals can then be emailed to colleagues at distant locations or placed on a computer linked to the World Wide Web (Internet) so that people can download the file to their own computer.
- *CD-ROM* – Information can be stored on a CD-ROM and played back through a computer. This has advantages over the written training manuals, and short video clips can be included on the CD-ROMs along with animated visuals and audio soundtracks – for example an interview with a mother. It is also possible to design the training so that it is interactive; that is, depending on the learner's responses to questions or choices, they can be directed to particular 'sub-lessons'. It is possible for the content of CD-ROMs to be downloaded from the Internet as well as being sent on a disc through the mail.
- *Video-based training packages* – McConkey (1993) and his colleagues have used this approach extensively for educating families and communities about a range of topics relating to children and adults with disability. Video lets viewers see new ideas and approaches in action. A variety of activities can be quickly displayed and viewers can watch the sequences a number of times to reinforce their learning. Local scenes depict the viewer's reality and emphasize that the messages are appropriate to the culture and that they are already being applied there. It is relatively easy to dub commentaries in local languages on to the video programmes thereby making training more accessible to everyone. Moreover, videocassettes can easily be taken or sent to any place which has video playback equipment. This is becoming more readily available throughout the world. Likewise video-recorders and televisions can be battery operated. The programmes can easily be repeated with different groups of parents or community workers.

Ready-made video packages are available for purchase or at no charge. However, specialists may need to produce their own video programmes to meet their specific training needs. The advent of digital cameras and computer-based editing makes this much easier than before and the quality of the product is much superior. Nevertheless it is time-consuming but eased if there is access to people with experience in using video technology. O'Toole and McConkey (1998) documented the impact of video-based training in Guyana, South America, and Holloway et al. (1999) in various African countries.

- *Internet access* – Access to the Internet makes an abundance of information available to people even in the remotest of locations. Leaflets, articles, training packs and video sequences can all be downloaded. Likewise email makes it easy for individuals to communicate with one another and to exchange information. This can include groups of people communicating with one another if they are all logged on at the same time. Usually this is done through the printed word, with people typing on their computer's keyboard, but more modern computers offer the facility for audio-chats and video-conferencing. To date these facilities rely on computers and an electricity supply. Future technology will mean that many of these functions will be available through mobile phones and satellite communication. As yet these options may be expensive, but they may become more affordable in the not-too-distant future.
- *Internet learning* – All the above benefits of the Internet are being harnessed to deliver training courses that enable students to study interactively from their own homes while communicating with tutors and fellow-students through integrated email and discussion facilities. Internationally a huge number of courses are now available, from basic level (equivalent to secondary-school courses) up to Master's level courses in universities.

All these methods can make it possible for people to access information and knowledge in their own locality and at a time and in a format that best suits them. Moreover, because the information is stored and packaged it makes little demands on the specialists, who are no longer needed to be available in the direct delivery of the courses.

Local facilitators

Nonetheless our experience suggests a need for local facilitators to help community personnel to gain access to these materials. McConkey (1993) argued that a range of personnel could fulfil these functions, including community-based personnel, disabled activists and parents of children with special needs. He proposed that their personal qualities

often outweighed their technical knowledge and expertise, noting in particular the following:

- They should be very familiar with the local culture. If they are expatriate workers they should have been in the country for five or more years.
- They are able communicators who form a ready rapport with the trainees.
- They are highly motivated to help people with disabilities and their families and provide inspiration to others.
- They have a clear vision of service goals and they have a detailed plan for bringing it about. Central to these endeavours is their direct involvement in the training of local workers and families.

In summary, a key role for AAC specialists is the sharing of their knowledge and expertise with targeted groups within communities, health workers and educators in particular. This should be done in ways that are meaningful to the learners, preferably in local settings and with an emphasis on practical strategies that can be easily accommodated into existing family and community routines. Moreover there needs to be ongoing monitoring of the implementation of the training, otherwise the efforts may be wasted or misdirected (Mendis, 1995).

Bridging tertiary and secondary level services

Primary and preventative services will struggle to meet the special needs of children and adults with particular communication difficulties. Many will require some form of ongoing assessment and intervention services, perhaps over long periods of time.

One means of doing this is for AAC specialists to work alongside – or to instigate some form of – secondary level provision. In this section we review international practice in merging specialist provision with community-based services, giving our analysis of their applicability to people with communication problems and the advantages and limitations of these approaches. Again, the focus is on low-income communities.

Five options are discernible in the broad field of disability, although combinations of approaches are often used by a second level service (O'Toole and McConkey, 1998; Zinkin and McConachie, 1995; Stone, 1999).

Note that these often involve a therapist/teacher working individually with a child and family but combining this with other strategies to enable more people to be helped than through individual casework alone.

Clinic outreach

One common approach is for specialists to base their assessment and treatment clinics in community facilities rather than specialist settings, and using local health centres, school classrooms or community halls instead of hospital clinics.

Indeed a team of specialists may visit different locations on a rota basis, say once a month. However, an important corollary of this approach is to have a cadre of local people working with the team, such as community health workers, so that they can encourage families to attend the clinics as well as provide some follow-up support to them.

This approach is good at giving specialists an insight into family and community life of the child with the communication problem and for building personal relationships with community personnel. In itself though, it does not provide for ongoing support of families unless the team returns regularly to the locality.

Special units attached to mainstream facilities

This option has been favoured by educationalists in attempting to meet the needs of children with disabilities. A class for these children is established in the local school and ideally a teacher with particular expertise is appointed to teach the pupils.

Similarly, disability resource units linked to district hospitals have been provided with specialists on hand to offer assessments and treatments rather than having families travelling long distances to hospitals and clinics in major cities.

These units can serve a number of additional functions, notably the provision of local training courses for families and community personnel. However, a recurring problem is the recruitment of suitably qualified staff and retaining them in their posts, especially in more rural areas. These positions do not have very high status within the educational, medical and paramedical professions.

Recruitment and training of 'therapy aides' for community settings

Another option has been to create a new category of professional worker who works under the supervision of specialists and who has been trained specifically to deal with more 'routine' work, and for this to be done across a variety of disciplines. For example, they will receive basic physiotherapy and occupational therapy as well as communication training.

These community-based staff are recruited from local communities and based full time there so they are able to build up trusted relationships

with families and community personnel. However, they may refer people to the specialists with whom they are linked as well as receiving supervision and monitoring from them; in under-resourced services the latter dimensions can be overlooked.

The development of suitable training courses for this grade of worker has not been easy to resolve as it does not fall under the remit of any existing specialism. Likewise some health systems are reluctant to create a new grade of worker.

Home supporters

Another approach is not to base the service around some form of specialist but rather to try to recruit a group of local people and train them so that they in turn can offer advice and support to families in their locality (Helander, 1993). These workers, sometimes paid and other times volunteers, are known by various terms – community-based rehabilitation (CBR) workers, home visitors, local supervisors – but essentially their tasks are similar. They advise and guide the family on coping with the disability. This may mean informing families about the help that is available in the locality, such as hospital and clinic check-ups. They may recommend equipment or aids to assist the person, or demonstrate exercises or learning activities which the family can use at home to help the person acquire new skills.

By visiting the family regularly, for example every 2–3 weeks, the home visitor can build a trusted relationship with the carers – usually the child's mother or grandmother. Their role may then extend into one of counselling carers – listening to their concerns and advising on marital difficulties, financial problems and hurtful reactions of family members or neighbours. The fact that they come from the same culture as the beneficiaries tends to make them all the more acceptable.

However, home visitors are not a new concept. The extended family or 'tribe' has often provided an advisor or confidante to new mothers with whom they can discuss their concerns. The home-visiting concept builds on this tradition by introducing the family to a person who has particular expertise or interest in the disability. Indeed some services have set out to employ people with disabilities or parents of children with disabilities for these roles, or to engage experienced mothers from deprived communities to assist other families in these communities. Home visitors can relate much more readily than specialists to families and can be more easily contacted by them.

However, certain cultures vary in their tolerance of an 'outsider' becoming involved in family issues, and services must be sensitive to this when recruiting staff to act as home visitors.

Equally the role can be demanding and the effectiveness of the home visitor will depend not only on their personal qualities but also on the training they receive – often short courses lasting around four to six weeks. We will return to this issue later.

Community-managed services

In this option the ownership of the service to families lies not with the specialists but rather with the community. This mainstreaming option, as it has been termed, depends on equipping the existing community personnel – such as teachers and health staff – to meet the bulk of the needs of people with communication difficulties. In this model the main role of specialists is to provide the training required by the personnel already in the post.

This option is furthest developed within education with ordinary schools meeting the special needs of their pupils with disabilities but with adaptations possibly to buildings, resources, the curriculum followed and the teaching methods used. This model of service aims to ensure equal access to the same opportunities that are available to other persons, and retains people within their communities rather than segregating them from the rest of society, albeit with the best of intentions, namely to meet their special needs. Of course specialists are still required. They will certainly have a key role to play in training staff; they may act as consultants for children with particular problems and they could even be appointed to the agency to provide ongoing support and assistance to the staff.

When there are no suitable existing services within communities, an option is then to create a new service but to make it one that is managed and owned by local personnel rather than specialists. Thus the trend in CBR is to ensure that disabled people, family members and interested local people are supported to form their own organization rather than having specialists designing and implementing these services for them (Joint Position Paper, 1994).

This requires an emphasis on capacity building among local persons and a willingness on their part to take on the responsibilities involved in running an organization, especially when paid staff are employed. As with existing community organizations, specialists can make a major contribution to the success of these agencies through training, consultancy and taking up employment with them.

Which options to choose?

We have presented five options whereby specialist and community services can be merged to create new models of service delivery that will

better meet the needs of families and people with communication diffi- culties.

They are better in two senses. First they will produce a service that is more attuned to the particular cultural and social needs of the people with disabilities and, second, they should enable greater numbers of peo- ple to be helped and at a cost that is much less than the specialist service option (Witter et al., 2000).

In reality, of course, these five options are not mutually exclusive and indeed a mix of them is not only possible but desirable, as there is no one perfect model to suit all needs. The particular challenge for AAC special- ists – as with other specialists – is to be able to align themselves in some way with one or more of these initiatives and to develop the necessary skills and expertise in helping to nurture and sustain them.

In this respect an important starting point is for AAC specialists to get to know the communities they are endeavouring to help (Kretzmann and McKnight, 1993). What resources already exist there? Who are the influ- ential people who might 'open doors'? Who are the potential allies they might work with and learn from? What are the common needs of the peo- ple as well as the particular needs that they can easily focus on?

Equally, specialists need to assess their own strengths, talents and motivations. They may have come into this work because of their love for children and the pleasure they derive from interacting with them and seeing the children grow and develop. Now they read that the job entails much more than this and, although they may be willing to take on fresh challenges, what is the help and support they require to do this?

This may mean that those specialists who are unwilling to make this change will need to negotiate a role for themselves that ensures they are not an impediment to others who are willing to forge new options.

Service processes

Thus far our focus has been on service structures and how AAC expertise and skills can be made more widely available to persons involved in pri- mary, preventative and secondary level services. Yet it is clear from research and practice that, the way services function, the processes they follow are also essential in order to produce the desired outcomes for their client (Handy, 1993). This section identifies the key factors that should feature in all levels and types of service delivery aimed at helping people with communication problems. Implementing these processes will produce a better quality of service.

Familiarity with culture

Human communication is inextricably bound with culture yet too often specialists are recruited from different cultural and social backgrounds than those to whom they provide services. At a minimum, specialists need to be able to communicate with families and communities in their local languages but, more than this, they need to be exposed to the val- ues and traditions of the culture, particularly with respect to child-rearing practices. If these conditions cannot be met, then the option of recruiting and training local people as co-workers should be pursued, as they are more likely to develop meaningful relationships with the service recipients. In the longer term, more determined efforts need to be made to recruit people for specialist training from a range of cultures (Wirz, 1999). (See Chapter 5 for a more extensive discussion of cultural issues.)

Family engagement

In many societies mothers are already overburdened with many responsi- bilities, which can leave them with little energy to address the needs of the child with special needs (Coleridge, 1993). Efforts should be made to mobilize other resources and to involve them intimately in the promotion of communication. Grandparents (or surrogates who can take on this role) and siblings are the most obviously available in most societies. It is essential that they too have opportunities for training and for them to be involved when personnel visit the home. Equally, fathers and grand- parents need to be kept fully informed even though they may not be active participants, but this may avert any prohibitions they could other- wise impose on their womenfolk (Jaffer and Jaffer, 1990).

Teamwork

No one person can possibly know what is best for a child and still less take on the sole responsibility for all the different dimensions of supporting families. Teamwork is the obvious solution but this needs to be a team of equals with mutual respect and appreciation shown in words and deeds. The sense of solidarity engendered by teamwork is particularly crucial in sustaining motivation and enthusiasm when the problems seem to out- weigh the successes. The opportunity to learn from one's colleagues is another value of teamworking. However, all these benefits will not hap- pen simply by calling a group of people a 'team'. Rather the team needs to develop shared goals, values and methods of working – a capacity to exchange roles among the members of the team and a common set of

standards and outcomes to which they work. Leadership is crucial in forging effective teams (Ovretviet, 1993).

A learning organization

Training and development opportunities need to be made available for all those who hold a responsibility for sharing knowledge and expertise with others. Successful organizations are ones that grow and develop through their own learning and by assimilating the wisdom of others (Peters and Waterman, 1995). This can include: the provision of appropriate magazines and books to staff; having regular meetings when team members take it in turn to present a topic to their colleagues; constructively reviewing videos of each other's practice; inviting 'experts' to visit the team; or sending staff to visit comparable services elsewhere or seconding staff to undertake further training courses. Throughout, the emphasis is on acquiring knowledge and skills to update practice.

An emphasis on prevention: early identification and intervention

Services need to be proactive in promoting good practices that will reduce the incidence of problems or the severity of their presentation (Alexander, 1992). Failure to do this usually means that resources get focused on crisis management and tackling problems that are more intractable and less susceptible to change. And while it is easy to proclaim this work as others' responsibility if they are not discharging this function, then at a minimum you need to prompt them to do so but more likely you will need to support them in these endeavours. This investment makes it more likely that effective outcomes will be attained for your client group. Indeed some would go so far as to say that services that have scarce resources should focus exclusively on young children and not dilute their efforts by taking on an ageing and possibly intractable caseload.

Monitoring performance

Effective services need to have in place systems for monitoring whether or not they are achieving the outcomes they have set for themselves. Otherwise it is easy to mistake activity for achievement (Gosling, 2003). Among the methods commonly used are regular client-centred reviews in which family members, the person themselves (if possible), and service personnel reassess what has been achieved and the difficulties encountered. These meetings can also be used to draw up new action plans, which are then communicated to all the people who are involved with the person.

A second strategy is to hold regular service-review meetings, every six months, say, when all members of the team have the opportunity to review their performance and to propose changes to their practices that may address the blocks they have encountered.

Third, every second or third year a group of 'outside' people can be invited to 'peer-review' the services. They can be chosen as having particular expertise in the area of work and in sympathy with the aims and philosophy. This outside review can provide valuable affirmation of good practice while also drawing attention to aspects of the work that need improvements or which falls short of acceptable practice elsewhere. They can also act as an alert to innovations and advances taking place elsewhere (Hughes et al., 1996).

Evidence-based practice

Health services have a tradition of evidence-based practice, namely ensuring that decisions taken about the methods specialists use with clients are informed by evidence of their effectiveness. Modern medicine uses random-control trials to establish the effectiveness of particular treatments in curing biological illnesses. A further refinement of this approach factors in the costs of the treatment so that decisions can be made in the light of resource constraints.

In education and social services there has been less concern with evidence-based practice. Although not all of the methods devised to assess effectiveness can be applied to communication interventions, the important point is that specialists need to be able to weigh up the evidence that has been reported in various publications. Second, they need to collect evidence relating to their own practice that demonstrates its effectiveness. This can take the form of subjective opinions, the collection of objective evidence through reassessments, and direct observations of the client in natural contexts. It is sad to say that many specialists in disability services have ignored the need for evidence-based practice and have been content to persist with routines and practices whose only justification is, 'That is how we have always worked' (Mitchell, 1999). However, AAC is moving towards evidence-based practice. A recent book by Schlosser (2003) provides a more extensive discussion on evidence-based practice.

Sustainability

A crucial test for services is whether or not they are sustainable (see Chapter 2). Too often in the past, new styles of services have been created, sometimes funded from special monies, who do exemplary work

during the initial period when staffing levels are high, client numbers are small and enthusiasm is abundant. But when the money comes to an end or is cut back, demand starts to exceed supply, and staff move on, the service may falter and can even close – it was not sustainable.

This experience can be avoided if sustainability is a core aspiration in all decision-making, from the choice of communication aids through to the training courses provided for community workers (Hartley, 1998). This means focusing on the essential and what is possible, rather than striving to emulate what happens elsewhere but which cannot be replicated in the circumstances. However, we acknowledge the conflicts that can arise with perceptions that these low-technology approaches are 'second-best'. But is a sustainable service not better than one which promises much but soon collapses? (See also Chapter 2.)

Quality services

It is not easy to attain services of good quality. In this section we have identified some of the processes that are most likely to produce quality services in terms of communication interventions. Of course a lack of resources makes it more difficult to implement some of the procedures we have identified, but if you read back over these topics, it is often not a question of having the money to do them but more an issue of both how we have chosen to structure our work and the value – or more correctly the lack of value – that we place on certain procedures. Hence the bigger obstacle to producing quality services is often in shifting the attitudes of those who staff the service and of the higher authorities in health, education and social systems (McConkey and O'Toole, 2000).

Meeting the challenges of emerging countries

Much of what we have written thus far is applicable to rich and poor countries alike, but we want to turn to the priorities as we see them for action in emerging countries. Our listing is probably incomplete and our suggestions inadequate but they are intended to provoke discussion and hopefully action by the new generation of AAC professionals in low-income countries.

Training of specialists

Communication specialists working in low-income countries need to be equipped with the skills of working in communities and of mobilizing family and community resources. More emphasis needs to be placed too on learning about other cultures and devising culturally sensitive interventions. This will mean reviewing the existing curricula of specialist training to tailor it more closely to the needs of the people being served. Indeed it could mean that new styles of shorter training courses are developed for personnel who serve an intermediary function such as communication aides or community-based service managers (Wickenden et al., 2001).

Another option is the development of post-experience/post-graduate courses to equip practitioners with specific skills. Given the specialized nature of these courses, the small number of potential students and the even smaller number of tutors with relevant experience, distance learning options – perhaps delivered through the Internet – could be the best way forward.

Within all these courses, emphasis must be placed on documenting and evaluating practice within low-income countries so that literature and a body of knowledge are accumulated which can balance and enrich the extant literature, which is heavily biased to North America, Britain and Australia. Once again the Internet offers a medium for making the so-called 'grey literature' of reports and working papers more readily shared among personnel in emerging nations (an example of this is available at www.healthlink.org.uk).

Awareness-raising of AAC

Health workers, preschool personnel and primary school teachers in particular need to be aware of AAC and how they can contribute to its implementation for those families who can benefit from it. This could be done within the pre-service and in-service training of these personnel or through short courses that are offered by AAC specialists. Some of the methods described earlier under 'Sharing knowledge' are well suited to this task.

Self-help groups of parents and local community personnel

Given the dearth of specialists in many emerging countries, particular emphasis needs to be placed on encouraging self-help among families and communities (McConkey et al., 2000). We do, however, appreciate that this is more easily said than done, but there is a growing body of expertise among those involved in community development that could guide and inform our practice in this regard. This theme is dealt with in more detail in Chapter 14.

Development of resource materials

There is an urgent need to produce resource materials in AAC that are reflective of the various cultures within emerging countries rather than relying on resources from the developed world. This includes the production of print, audio, video and computer resources. These can be used in awareness-raising, training and self-help groups (Powell, 1999).

New staffing models

There is the need to reflect better the realities and needs of emerging countries by revising staffing models that have been imported to a large extent from developed countries. There appears to be some merit in developing a grade of staff that can bridge the roles of various disability specialists with existing community resources (Myezwa and M'Kumbuzi, 2003). These are sometimes referred to as 'mid-level' workers and they will require a dedicated training course, probably of two years' duration, full-time, or the equivalent part-time. They would, however, be chosen for their personal qualities and community networking skills as much as on educational attainments. Indeed, in some countries, communities elect the individuals to be sent for this form of training.

This could be a cost-effective option of making services more readily available to more people, although we do acknowledge that it will take time before national coverage is attained. In the meantime the challenge is to get training institutions, professional organizations and government departments to work together to create this new category of worker (Lorenzo, 1994).

Other constraints

This chapter has emphasized what AAC specialists should be doing to respond better to the needs of their clients. However, all these initiatives have to be placed within a wider social and political context that often defeats the best efforts of those eager to improve services (Coleridge, 1993). In particular four constraints are noted below:

- Education constraints, particularly in access to post-primary education and higher education. Removing these constraints will allow new training opportunities to develop and provide a better-educated pool of recruits.
- Economic constraints, especially in developing effective community health and family support services as scarce resources are targeted at hospitals.

- Professional politics, which can stifle change, prevent co-operation and act in the interests of the professional worker rather than of the clients they serve.
- Long-established service structures that were created to meet the needs of previous generations, which are no longer fit for the new purposes required by modern society. Often the people with the power to change these structures are the very ones most wedded to them: as the system has worked to their advantage, why should they change?

There is no easy answer to any of these constraints other than urging that they need to be challenged and that this is best done in the company of like-minded allies.

Conclusion

Although much has been achieved (and more could be achieved) in promoting AAC in emerging countries, we have to admit that progress in developing better services will be slow, patchy and will initially benefit the already advantaged – the same pattern as in more affluent countries!

We have emphasized the need for AAC to be a bridging specialism into mainstream community services such as education and health. However, this will be a slow process and may never be fully achieved, simply because AAC will always be a specialism in the sense that only a small proportion of the population requires this form of help.

There is a need to increase the sharing of knowledge and expertise about AAC with families and communities. In responding to this challenge, AAC could be a catalyst for producing changes in the way other specialisms share their skills.

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CHAPTER 8
Support-based AAC intervention

ERNA ALANT

This chapter describes a support-based approach to augmentative and alternative communication (AAC) intervention by using an integration of the resource-based approach (Dunst et al., 1988) and the asset-based approach (Kretzmann and McNight, 1993). These two approaches are compared and used as a framework for the development of a support-based approach to AAC intervention. The principles of the support-based AAC community intervention approach are described, and case studies are used to facilitate the visualization of the intervention process. The chapter concludes with the identification of challenges relating to the approach.

In recent years there has been increasing recognition of the need to move beyond the confines of the therapy room into the broader community to facilitate impact in the life of people with disabilities and their families. The lack of social validity of intervention conducted within isolated therapy rooms has necessitated broadening the scope of intervention to facilitate change where it is most relevant (i.e. in real life).

The development of social networks and participation in social activities are pertinent in facilitating inclusion of people with severe disabilities (Dunst and Trivette, 1988; Dunst et al., 1993; Kretzmann and McKnight, 1993). These contacts create opportunities to participate on different levels within a community, and allow the individual to engage in the *social* construction of reality in society. By being visible and involved in activities of daily living, people with disabilities not only facilitate other people's understanding of disabilities, but also work towards a more authentic basis for demonstrating issues relating to diversity in society. Allowing diversity to be accommodated to this extent presupposes an attitude that focuses on what the individual can do to facilitate the expansion of skills necessary for participation. Different strengths and weaknesses of individuals are acknowledged to allow for growth and development. This approach

towards recognizing strengths of individuals with severe disabilities has been well entrenched in the field of severe disabilities and AAC, as interventionists realize the value of focusing on human resources rather than deficits and disabilities (Fox and Sohlberg, 2000; Light and Gulens, 2000).

Apart from the AAC model of Fuller and Lloyd (1997), another example of an AAC model oriented towards focusing on the importance of the environment and resources, or strengths of the individual in context, is the participation model by Beukelman and Mirenda (1998), which focuses on communication access and opportunities. This model describes, first, ways of providing access to communication that allows people with little or no functional speech to participate and, second, provides a detailed analysis of the opportunities for interaction that the individual is exposed to. This description is then complemented by an analysis of barriers experienced on different levels that might inhibit or prevent participation. The importance of understanding the nature of the problems experienced is pivotal, as families, teachers and other professionals as well as community members collaborate to develop shared vision and understanding of the realities confronting a particular person with disabilities.

Inherent within this approach are therefore two elements:

• A description of the problems inherent to the individual's abilities and communication system, which implies a solid understanding of the nature of the difficulties experienced by the individual in different contexts; based on this description, specific strategies will be recommended to overcome difficulties or facilitate interaction by the individual.
• An analysis of the opportunities for interaction, namely the context that the individual participates in, including the identification of communication partners and conversational topics. From this analysis, the intervention team will plan strategies to extend existing communication opportunities and work towards breaking down communication barriers relevant to the context.

Typically, the intervention team will focus on existing skills of the individual as a basis for expansion. They will create opportunities for optimizing the interaction skills of the individual as well as facilitate the use of the AAC system within the context. In addition to learning a new system of communication, the person needs to be exposed to a facilitative environment to ensure the systematic use of the AAC system. This is a complex process and perhaps the biggest challenge in AAC intervention. Under-use of AAC devices and abandonment of these systems are well reported in AAC literature (Parette and Angelo, 1996).

There have been various attempts to analyse the reasons for the breakdown in the use of communication devices. It has been acknowledged that inappropriate AAC devices are recommended, at times, together with inadequate or insufficient training in using devices (Bridges and Midgette, 2000). Commonly, not enough time is dedicated during the process to, first, developing joint understanding with the family about the use of the AAC device (Judge and Parette, 1998; Parette and Angelo, 1996) and, second, encouraging support from other professionals working with the individual and community participants in facilitating the use of the system (McConachie and Pennington, 1997). Limited time spent by the AAC interventionist in facilitating interaction networks, and training partners in interacting with the individual who uses AAC, constitutes a major part of the difficulties experienced. The major responsibility for the training and facilitation of the intervention process lies largely with the AAC interventionist. The importance of the inclusion of families as equal partners in this process has been acknowledged, although with little reflection on the implications of this approach for a service offered by a highly specialized group of professionals.

In practice, the extension of communication opportunities of individuals who use AAC within the community has increased the demands on families and others in the environment as AAC interventionists accommodate elements of a stronger community-based model as part of AAC intervention. Similarly, AAC interventionists focusing on enhancing opportunities for interaction within the community face an onerous task with high demands on time and energy. McDonald (1997) indicated that professionals traditionally work with repairing the individual at the psychosocial level rather than on structural change, and that these efforts have been inadequate in work with poor families: 'As a result, professionals often feel overwhelmed, burned out and cynical' (p. 115). Although she does not elaborate what exactly is meant by structural change, the comment is made within the context of 'building on strengths and assets of families and communities' (McDonald, 1997, p. 115). It is reasonable to deduct that structural change refers to the facilitation of changed functional structures or systems within the family as well as within the community or environment. The change that is required of professionals within this approach is the realization that sustainability of behaviour outside the treatment context needs to be regarded as one of the major indicators for effective intervention. The focus on the social outcomes of intervention is, however, relatively new in the field and leaves the interventionist with new challenges and guidelines as to how to proceed.

Another interpretation of this statement by McDonald (1997) proposes that for too long the professionals have worked with an inappropriate unit in intervention. The focus was on the individual and their skills while using the family to support the individual intervention. Although this approach is focused on the family, it is not family-centred. Supporting the individual with disabilities is an additional responsibility the family has to cope with.

Resource-based approach

Dunst and Trivette (1988) describe a family-centred approach in which they promote the use of the family as the unit of intervention. This approach essentially aims to provide support to the family as a whole, while also addressing the specific needs of the individual with disabilities. It implies that the interventionist is concerned with facilitating coping strategies within the family and assists in the general improvement of the conditions for all members of the family, including the individual with disabilities.

> Considering the family, and not the child, as the unit of intervention, recognizes that the family system is comprised of interdependent members and that by strengthening and supporting the family unit and not just the child the chances of making a significant positive impact upon ALL family members are enhanced considerably. (Dunst and Trivette, 1988, p. 6)

This statement clearly describes the main characteristics of most family-centred approaches to intervention. It acknowledges the importance of viewing the family, more specifically the nucleus family, as the primary system of intervention. The family, and not the interventionist, is the primary agent in intervention. The family unit has to develop an understanding of issues confronting them and develop (in interaction with professionals) ways of addressing these in a meaningful and appropriate manner for the family. Intervention is therefore a beneficial process, not just to the individual with the specific difficulty but also to the whole family, as all participate in the problem-solving process. The needs and aspirations of the family therefore need to be understood to facilitate assistance to the individual child and to create a beneficial intervention experience for all in the family. The issue is thus to improve and facilitate development within the family as a basic unit.

The concept of a 'resource-based' approach focuses on allowing the family to look within to find internal resources to enhance the process of intervention. Empowerment of the family is defined as a process whereby the family becomes aware of their own resources and strengths to allow them to develop meaningful solutions to their problems. As part of this process Dunst and Trivette (1988) acknowledge that the ecological map of the child and family is embedded within other social systems. In fact, they identify the major sources of support available for meeting family needs as the nuclear family, kinship, informal network, social organizations, generic professionals, specialized professionals and policy-makers. The vision is thus for intervention to be conducted within an ecological framework to facilitate change. Figure 8.1 briefly identifies the components of a resource-based intervention process. It involves identifying

sources of support for the individual and family, then mapping where in the community these resources are and, finally, building community capacity. Although this approach clearly discusses the acknowledgement of links and associations with the community, it is not clear how this approach extends into building community capacity. The focus is on the family and the family's support system within the community.
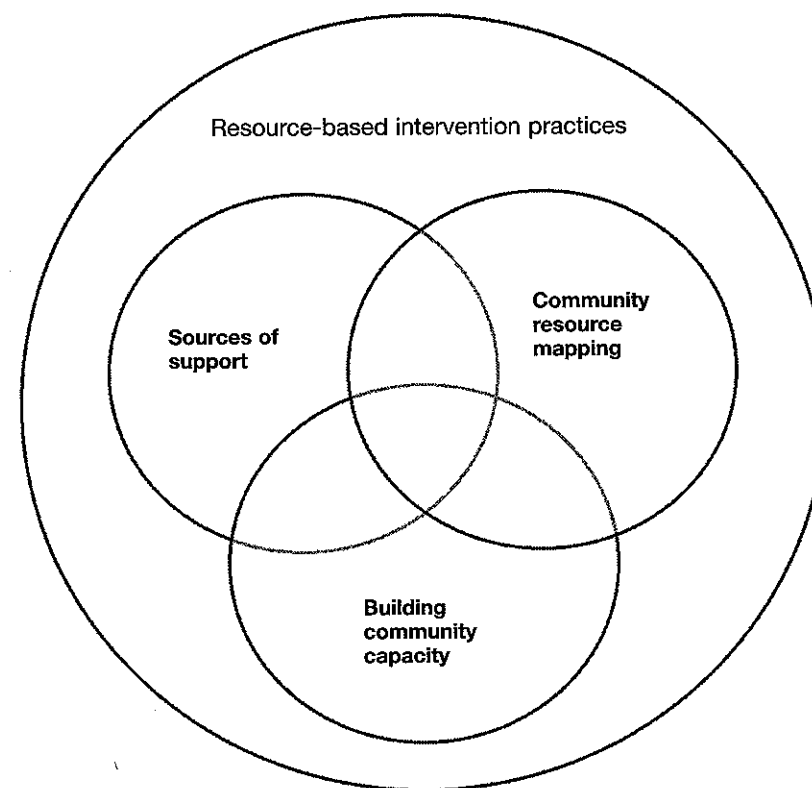
Figure 8.1 Components of a resource-based approach. Reprinted from Trivette et al., 1997, p. 84.

If the importance of community development is, however, seen as an integral part of human and social development, particularly within developing countries (Burkey, 2000), then a closer look needs to be taken at community development approaches. For the purpose of this discussion the community development approach of Kretzmann and McKnight (1993) and McKnight (1997) will be discussed and its implications for intervention explored.

An asset-based approach to community development

The asset-based approach of Kretzmann and McKnight (1993) is a community development approach, focusing on the processes needed for a community to recognize and benefit from their own resources or assets and consequently to enable them to use external resources more effectively. It regards the community as the most meaningful unit to work with and emphasizes the need to consider development within the broader context of the socio-economic development of the community. Personal development of the individual only becomes meaningful within the framework of broader community development.

This approach emphasizes the development of policies and activities based on the capacities, skills and assets of lower-income people and their neighbourhoods, and the acknowledgement that 'community development takes place only when local community people are committed to investing themselves and their resources in the effort' (Kretzmann and McKnight, 1993, p. 5). This then explains why communities can never be built from the outside in – even though assistance from the outside may be valuable. A focus on the internal resources is also necessary, as sustained assistance from the outside is unrealistic and creates long-term dependency in a context where communities need to become more empowered to direct self-development (Riedijk, 1987).

The approach by Kretzmann and McKnight (1993) then illustrates the process of defining the assets of a community by describing the capabilities of the individuals, associations and institutions, and capturing these in a community assets map. The focus is on building relationships within the community to mobilize the community for economic and social development by developing a joint vision and a plan. An integral part of this approach is for community builders to identify the associational (formal and informal) structures that can become involved in the process: 'It is clear that even in suburbs and inner cities there are many informal associations doing critical community work. Just because they do not have a name or officers does not mean that they are not there' (Kretzmann and McKnight, 1993, p. 375). Clearly, within this approach the community is the unit of intervention to facilitate development.

Intervention within this context implies a rethink of the different roles and functions of systems – services and community associations. In a further article, McKnight (1997) describes the preoccupation of policy-makers to focus on service systems in an attempt to permit a few people to control many people, to produce many of the same thing, i.e. broad-based services. The limitation of this system is, however, the lack of capacity for producing individualized outputs rather than mass products, which according to

McKnight (1997) is why so many systems fail to meet individualized needs and leave the workers 'burned out' in frustration. He stresses the inadequacy of services to really provide effective individualized interventions. The service focuses on delivering intervention packages to all – without really accommodating strategies for individualization of services.

McKnight (1997) draws a distinction between systems and associations within a community and postulates that they are useful tools for mapping and understanding communities. He describes the *system tool* (e.g. services) as a mechanism for control, whereas a community of associations depends on willing consent because it has neither money nor grades to control people. The community is not designed to deliver services – rather it produces a context within which care is manifested. 'Care unlike services cannot be produced' (ibid., p. 120). He thus makes a strong plea for a partnership between service systems and community associations in facilitating community development. This differentiation between service and community associations emphasizes the need for interventionists to ponder the relationship more consciously between services and community associations, to provide a more meaningful framework for intervention. Services can provide products to clients; however, it is associational communities that can allow choice, care and citizen power. According to McKnight (1997), the nature of the relationship between these two mechanisms can differ – being focused on one of the following:

- an outreach model (whereby the service dominates the community associations);
- community as a source of unpaid workers for systems (i.e. volunteerism rather than partnership);
- citizen advisory group (where the citizens serve as advisor for the service, but have no authority).

None of the above can be described as a genuine partnership in a relationship of equal power between two parties with distinctive interests (ibid.). McKnight describes these all as consumer models and regards them as producing an unprecedented belief system and culture of its own. A genuine partnership is a relationship of equal power between two parties with distinctive interests. Each preserves its own authority and capacity and ownership, but gains power through the relationship. Clearly, this approach focuses on a social definition of disability, with a strong emphasis on the creative interaction between service and community associations.

For the interventionist used to working within a medical model, this approach could be most threatening:

- Does this mean the family does not have to accept all the professional decisions?

- What then is the role of the professional?
- Surely, the community cannot make decisions that are clearly within the domain of the professional?

A strong mutual respect for the respective roles of the different participants is pertinent in acknowledgement of the different skills they bring to the process. Joint decision-making and empowerment is of utmost importance in this process. However, this does not imply that the community becomes the major decision-maker in matters related to AAC implementation; but rather that they become more comfortable and supportive of the role of the professional within the relationship. The openness to participate in debate and inquiry on why and how AAC systems work, and the disadvantages of these systems, is an essential part of the partnership process. The association between community (family, individual) and professional thus implies that:

- the roles of both the community and professionals change as mutual understanding increases (it is thus a dynamic relationship);
- the roles complement each other;
- both components of service and care are vital to the process and both of these processes need to be maintained and extended from the beginning.

McKnight (1997) thus views the rendering of services or intervention as an integral part of community development through the involvement of community associations as part of the process. Intervention becomes sustainable only as far as the community cares enough to sustain the intervention. From this it is implied that the community – not only the family – needs to make a commitment to the process. The cardinal issue in community development is, however, 'care' and the willingness to become involved to create a better context for living. People need to develop some sense of engagement with one another to want to become involved in development as a community-driven process.

As a basis for the rationale for the development of the support-based approach to intervention, the resource-based and the asset-based approaches will be compared to highlight the different focus in approaches.

Comparison between the resource-based approach and the asset-based approach

The resource-based approach (Dunst et al., 1988) and the asset-based approach (Kretzmann and McKnight, 1993; McKnight, 1997) are summarized in Table 8.1. From this table it is clear that both these approaches have a contribution within AAC intervention by addressing two cardinal

components in any intervention process (i.e. the family and the community the individual lives in).

Table 8.1 Characteristics of the resource-based and the asset-based orientations towards intervention

	Resource-based family intervention (Dunst et al., 1988)	Asset-based community development (Kretzmann and McKnight, 1993)
Unit of intervention	Family	Community
Initial description	Needs, aspirations and family functioning	Capacities and talents Asset-based profile/capacity inventory: skills information, community skills, enterprising interest and experience and personal inventory
Focus	Resource-based Internally focused Relationship-driven	Asset-based Internally focused Relationship-driven
Process	Focus on family and direct and indirect influences of social support	Focus on community associations as the bedrock of healthy neighbourhoods
Outcomes	Enabling and empowering families to extend their support systems	'Caring community' Enabling and empowering communities

From Table 8.1 it is evident that the resource-based model of Dunst et al. (1988) regards early childhood intervention essentially as a family-centred approach. Kretzmann and McKnight (1993), on the other hand, see community interactions and development as pivotal in sustainable service delivery and intervention. McKnight (1997) argues that the service has to be couched within the informal, or caring, relationships within a community for it to have long-term impact. The starting point thus is to identify the capacities in the community that can be extended to provide more support to the individual and family and at the same time strengthen the associational community. Both these approaches focus on the internal strengths of the intervention unit as a basic departure point from where intervention becomes viable. Kretzmann and McKnight (1993) describe the families' capacities and the interactions with the community associations as vital in developing a caring society that will support and

sustain efforts. Clearly, this process is much more broad-based than that of Dunst et al. (1988) and, consequently, much more slow-moving, albeit the argument being that it will be more sustainable in the long run. Impact will be less intensive, but more broad-based.

The visualization of this process is, however, difficult in view of the many challenges and pressures that communities often have to deal with. Poverty, disintegrating families, lack of housing and health issues are familiar challenges in many developing countries and can be seen as major factors contributing to the dwindling care experienced within these communities.

AAC intervention as a support-based process

Apart from the increasing challenges all families experience in coping with the demands and pressures of everyday life, the family-centred approach needs to acknowledge the challenges relating to the definition of 'family' in different contexts. Challenges in relation to who constitutes the nuclear family are complicated, as the concept changes depending on the social context people are living in, for example single-parent families or child-headed families. The number of AIDS orphans, for example, is estimated to be 35 million by 2010 (World Bank, 2000). As parents become deceased, the concept of a nuclear family becomes even more problematic as the children and community have to grapple with the creation of a new unit that can function as an immediate support system for the individual.

Although the concept of family-centred approaches to intervention has merit, the underlying assumption of an existing and functioning nuclear family can present challenges, particularly within poverty contexts. In many present-day contexts, the argument for using the family as the unit of intervention can be viewed critically by asking whether the family will be an appropriate intervention unit. Nuclear families, particularly those in poverty contexts, are often faced with major difficulties in dealing with the challenges of everyday life. To subject these families to the additional stressor of participating in the process of intervention could be putting more pressure on an already dysfunctional system.

This idea about extending the support system beyond that of the immediate family has received considerable attention in the literature. Researchers like Uri Bronfenbrenner (1989) and Cochran (1993) extensively discuss the concepts of social support and personal network structures in relation to the family.

The present approach (support-based approach to intervention) argues for the inclusion of a third unit of intervention, namely the immediate support network as an extension of the family, in addition to the family

(Dunst and Trivette, 1988) and community (Kretzmann and McKnight, 1993) as basic units for intervention. The immediate support network implies that the basic unit of intervention includes the family, but is broader than just the nuclear family and includes relations, friends and neighbours – all those frequently interacting with the individual and family who are providing support or can potentially become more supportive. In terms of the above definitions of social support and personal networks, the concept of immediate support systems includes the family as well as close (more intense or prominent) personal ties. It emphasizes the importance of viewing the individual and family as an integral part of broader community development. In comparison to Dunst et al. (1988) this approach is more focused on the interaction between the immediate support system and the broader community associations, to facilitate development in both. It therefore stresses the role of each immediate support system within the community to facilitate community development on different levels. Similar to the difference between a family-focused and a family-centred approach, this approach centres on the support or close networks of the individual and immediate family as an integral part of community development. Focusing on the family unit is thus not sufficient: the unit of intervention needs to be broader to include close personal networks.

Intervention in AAC can be seen as an interaction between three tiers:

- Individual: The individual has to gain access to a communication system. This implies that the person's physical, cognitive, social and sensory skills need to be adequately described to allow for the development of an appropriate communication system.
- Immediate support network: This includes the family as well as close personal networks primarily committed to facilitating the development of further support for the individual and family.
- Community associations – the involvement of relevant community associations or networks to form a sustainable intervention context. This implies that an understanding of the problem/difficulties of the individual and family can only become meaningful within the context of an understanding of the caring relationships or potential relationships around the person/family.

Instead of these three components being viewed and described separately, however, there needs to be a sound understanding of the interrelationship between these components. As the interventionist and individual (or family) become involved in describing the problem, at the same time they need to include the immediate support system as well as the community associations. Earls and Buka (2000) make a strong argument

for looking at neighbourhood development as an integral part of early childhood intervention. 'For those working at a practical level in communities or neighborhoods, it would be desirable to know that measuring a community's contribution to developmental outcomes could be differentiated in some sense from influences that are located within families and from characteristics of individual children' (Earls and Buka, 2000, p. 310). The argument is thus that outcomes of intervention not only should be defined at the family and individual level, but also need to be measured at the community level. Clearly, this is particularly relevant within poverty contexts as families and individuals are less likely to have the support to cope on their own.

Intervention in this context is defined as the development of an integrated action plan oriented towards the accommodation of multiple perspectives aimed at facilitating outcomes of common interest. This means intervention is a collaborative process representing a variety of views, but with movement towards a common goal in the best interest of all involved. Clearly, the concept of 'for the good of all' or 'in the best interest of all' is not unproblematic (Wellman, 1988), particularly as the process broadens to include a larger network of people. Rather than describe interventions as based on consensus within broader social networks, it may be more appropriate to refer to collaboration as based on dialogue.

Intervention in AAC, being a specialized service, will focus on the individual and the development of a communication system within the context of multi-perspectives. Even though it is specialized, the service has to interface with the broader community structure. This means that time needs to be dedicated to work with the immediate support system, the community associations and broader policy context to facilitate joint responsibility for the process. No longer can intervention be conducted without close involvement of disability interest and support groups, community organizations and associations.

Figure 8.2 describes the AAC interventionist's role within the ecological framework by first acknowledging the focus on intervention with the individual, but within the context of the immediate support network and community organizations and associations. This implies that intervention needs to be conceptualized from the beginning as a support-based community process that implies gains for the target individual and the family, but which also has benefits for the broader context in that all participate and learn from the intervention interaction, to allow them to extend the benefits to others who might have similar needs. The rectangle within the circles represents the process of AAC intervention. First, intervention is concerned with the individual using AAC (centre circle), and intervention is indicated by the rectangle that goes across the different levels of the concentric circles. The community is participating from the beginning of
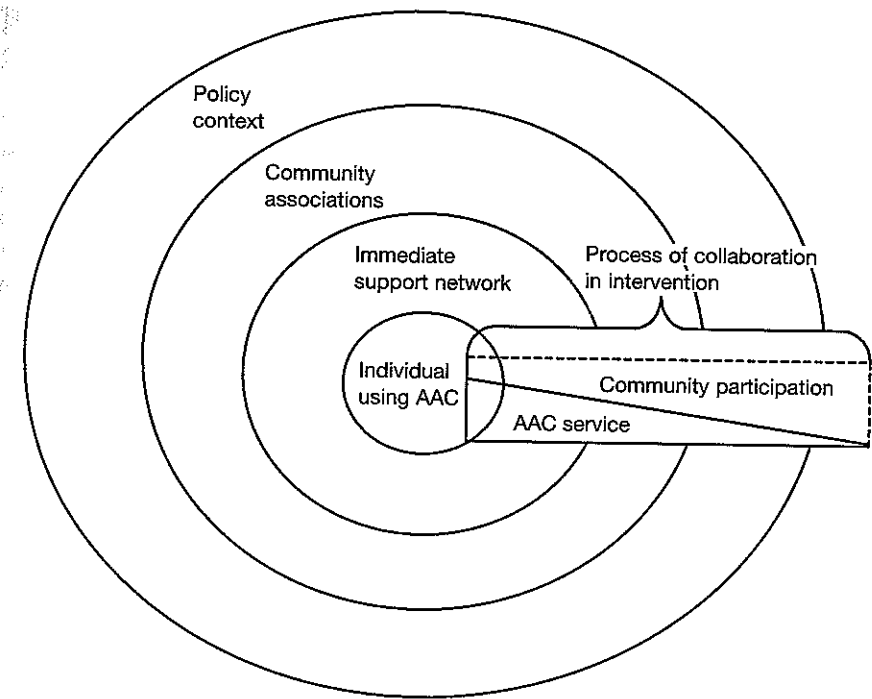
Figure 8.2 AAC intervention within an ecological perspective.

the intervention process on each of the different levels, namely the immediate support network level, level of community associations and organizations, and the broader policy context. The extent of the involvement of the different participants is, however, changing as the AAC interventionists' roles diminish – diagonal line moving downwards towards the right side of the rectangle to the right of the figure. At the final point of the diagonal line, the AAC intervention will be withdrawn for the community support structures to take over the responsibility for the maintenance and extension of behaviour. Also important is that as the community participants gain more understanding and insight into the AAC intervention process, their participation becomes more prominent and the AAC interventionists less prominent.

Clearly this process of less reliance on the professional input over time does not imply that no further intervention can be provided at a later stage, but rather that a particular intervention cycle in the life of an individual or family has come to a logical end. What the criteria for the termination of intervention would be is clearly a matter for discussion early on in the intervention process.

One of the most important aspects of the intervention is identifying the relevant community participants on different ecological levels in the community. These participants need to be representatives of community organizations or programmes and associations that will be in a position to broaden the benefits and scope of the process into the rest of the community. The whole process of community intervention is therefore not the sole responsibility of the AAC interventionists, but is a collaborative process between AAC interventionists and the broader community. The AAC interventionist will have a primary contribution in facilitating the selection of appropriate AAC systems. However, this needs to be done in partnership with the support networks, from where the intervention will be a shared responsibility. As the AAC interventionist's role thus diminishes, so the immediate supportive structures and community take over to ensure sustainability and long-term impact. The identification of community participants on the different levels is thus vital in ensuring a meaningful collaboration between service and community associations as part of a broader social development process. This process might be better visualized by describing what could be the content and process used in typical initial AAC intervention meetings.

Table 8.2 Description of initial AAC intervention meetings within a support-based approach

First meeting:

* A discussion of the reason for the visit of the individual who needs AAC intervention, with as many participants of the immediate support network attending as possible;
* A discussion of the intervention process as an integral part of community development, thus explaining Figure 8.1;
* The identification of people, i.e. support systems and potential resources in the community, that could become part of the intervention process; if people are not aware of who might become involved, this is noted for further exploration;
* The development of strategies and joint responsibility of all present including the AAC interventionist for inviting relevant people to participate in intervention as a strategy for community development; the interventionist as well as the people present during the first meeting will identify specific key people who need to be involved in the process;
* Focus on the individual who needs AAC: initial assessment/intervention procedures can be started with the individual who uses AAC, but the involvement of community support is seen as a vital part of the intervention process;
* The next intervention session will then be scheduled within a convenient time period to allow for these people to come on board.

Table 8.2 contd.

Second meeting:

* Discussion of the aim of the meeting: support-based AAC intervention and its link with community development;
* Identification of present issues with the individual using AAC and immediate support system;
* Comments and ideas from community members in organizations and associations regarding impressions of this individual's difficulties as well as how this involvement could benefit others in the community;
* Joint identification of intervention issues to be addressed during this intervention meeting;
* Focus on the individual who needs AAC: investigation/demonstration or discussion of AAC intervention strategy with individual using AAC;
* Ideas for facilitating the use of intervention strategies/information discussed by all involved in the meeting;
* Identification of criteria for success for intervention goals;
* Identification of who should be involved in the next intervention meeting.

The process of intervention

Although this discussion is presented in different steps, these clearly need not be implemented in any rigid sequence. The intention is merely to highlight the different components that need to be considered as part of this process. The different intervention components would include the following.

1. Definition of problem of the AAC-user

This includes defining the problem and reasons for the consultation.

2. Development of asset-based profile

* *A description of individual capacities:* these include the individual who needs an AAC system, and other individuals who are part of the immediate network. The purpose is to identify existing skills that could be used as a basis for extending resources.
* *A description of the individual who needs AAC's strengths and needs on different levels* (AAC assessment).
* *A description of the broad skills of individuals who form part of the immediate support network* to identify their capacity to take care and be involved in the caring and intervention process. This skill profile would be more extensive in allowing people to form an idea of potential resources in the network as a basis for extending resources. The capability profile is aimed at understanding the skills of the individual

in different areas of living, including health (e.g. caring of the sick or people with disability), office skills (typing, bookkeeping, etc.), construction and repair, maintenance, food preparation, child care, transportation, equipment operation, supervision, sales, music, security and so on. It provides the people themselves with an opportunity to understand their own skills in different areas. In particular, this becomes important as people from within the immediate support network start to realize the strengths or skills they can offer to others in return for assistance or support. For a complete list of what could be included, please see Kretzmann and McKnight (1993, pp. 19–27).

- *A description of the resources available to the immediate network by identifying:*
  - the nature or kinds of supports;
  - the sources of the supports – who supports them in what domain;
  - description of the community resources (community resource mapping) and their location, to provide a basis from where families and immediate support networks can become more actively involved.

3. Building community capacity

From the above resource analysis of the individuals, immediate support networks and the community, one could develop a better understanding of the strengths and resources of communities and families (Kretzmann and McKnight, 1993) in an attempt to increase the capacity of the community in accommodating the needs of community members. This phase involves an integration of the individual capacities of the families and individuals to identify strengths, as well as an analysis of existing support systems in the community. The aim is how to extend existing, or commence new, community initiatives to increase the capacity to address the needs of families. The underlying awareness of 'the potential common nature' of difficulties and challenges experienced among families and individuals with disabilities is a most powerful tool in mobilizing community members to work for the good of all.

Although not traditionally included as part of intervention for people with disabilities, this phase is important in creating an awareness within the immediate context, as well as people with disabilities themselves, of the contribution they could make in strengthening and enhancing the support systems for people in similar circumstances within the community. For example, many support groups for parents of children with disabilities are started by parents who see the need to share their experiences with others in a vision of strengthening support for families in the community who have children with disabilities. Similarly, AAC-users themselves could facilitate exciting groups for people with disabilities

by getting involved in advocacy work for people who use AAC. Mutual benefits for people with disabilities themselves as well as the broader community are well reported in the literature (Kaffman et al., 1996; Winton and McCollum, 1997; Wesley and Buysse, 1997).

According to Trivette et al. (1997), the process of strengthening the community will require three steps:

- identifying strengths of existing community groups;
- demonstrating how these strengths can impact on individual and family to address specific needs; and then finally
- eliminating barriers to the expansion or extension of resources.

Clearly, all families or individuals with disabilities will not be in a position to facilitate community development at specific stages; however, it is important that community responsibility for the strengthening of internal community resources becomes part of the ongoing intervention discourse.

4. The development of suitable solutions

Based on the different assets identified, suitable solutions will be developed around intervention for the individual who needs AAC and the family within the context. Clearly this is not necessarily a separate step, but an integral part of the ongoing processes. The following steps would be included:

- Identification of an appropriate communication system that would be meaningfully used in the contexts.
- Development of strategies for implementation to facilitate more opportunities for interaction with the immediate support network as well as within the broader community.
- Identification and problem-solving of ways of dealing with other problems and difficulties that were identified as part of the process.

After or often during the description of assets and resources within the intervention context, the people involved spontaneously voice ideas or potential solutions. It is thus critical not to see the process of resource description as essentially separate from the process of developing solutions. The two processes clearly facilitate each other as family and community members become aware of their own resources and start thinking about possible solutions.

4.1 Identification of an appropriate communication system

Starting off with the discussion of the capabilities of the AAC-user and existing communication systems will clearly facilitate the development of potential solutions from the participants in the process. As AAC interven-

tion moves away from the medical model and focuses more on participative decision-making in the selection of a system, specific information on costs and the time involved in setting up and expanding the communication system is essential. Most importantly, the availability of professionals or professional support and the conditions required for sustained use of the system need to be discussed. Inherent in the choice of the specific communication system is the issue related to the development of a support system that can facilitate use and daily interaction.

4.2 Development of strategies for implementation on individual, immediate supportive network and community association levels

The importance of sustained involvement on different levels of community participation is a critical part of the AAC implementation strategy. Regular activities and contacts need to be planned in order to keep people informed of activities to facilitate the process.

Another important issue relates to the joint identification of criteria to describe progress of the intervention process (individual, immediate supportive context and community associations). AAC intervention is a collaborative process between service and community. This necessitates a clear understanding of the outcomes of the process and the benefits of it for all involved. Developing an understanding of involvement in intervention as community development, and therefore understanding the concept of 'mutual benefits' of the process, is pivotal to its success. The process of intervention needs to be an integrated effort of service, immediate support and community associations.

4.3 Identifying strategies for other problems identified by the participants

Often, as part of the intervention process, families will identify needs that do not necessarily include AAC intervention for the individual as a priority. It is important that the intervention process be sensitive to the dynamic nature of family needs and assist in problem-solving. Only by acknowledging the priorities and needs of the immediate context can the implementation of an AAC system be sustained.

5. Action–reflection phase

The implementation phase will be a reflection of a specific plan of action in relation to the outcomes of the intervention that will include the immediate supportive context, associational communities as well as the individual with disabilities. The extent of the intervention thus requires obtainable, realistic goals, i.e. small steps – but meaningful realities. The focus is on flexibility to ensure all participants achieve success and stay motivated.

6. Monitoring progress and evaluating outcomes

Outcomes of the intervention need to be evaluated on three levels. Clearly the immediate effectiveness of the intervention is going to be a main concern initially, to ensure that the individual and partners understand the strategies and are able to implement them successfully in the short term. However, as intervention proceeds, the sustainability of it becomes increasingly important. In the final instance, participants need to be sensitive to the accumulated impact of the intervention in facilitating independence and self-determination of the person using the AAC system. Table 8.3 provides some questions that can be used to guide the monitoring of progress of these three levels (see also Chapter 2, where the terms effectiveness, sustainability and versatility are described).

Table 8.3 Relevant questions for monitoring AAC intervention progress within a support-based approach to intervention

Effectiveness of intervention indicators:

(Referring to the specific behaviours of the individual which were targeted)

1. What specific behaviours were targeted?
2. What immediate behaviour changes can one identify as an outcome of the intervention process?
3. Has the frequency of these behaviours increased?
4. Has the quality of these behaviours increased?

Sustainability of intervention indicators:

(Ability to maintain behaviours over time – after withdrawal of intervention)

1. How long is the behaviour maintained without direct prompting?
2. How often does this behaviour occur spontaneously?
3. How dependent is the behaviour on prompting or specific encouragement?
4. How involved is the immediate support network in providing a congenial context for maintaining behaviours?

Versatility of intervention indicators:

(Impact of intervention process on a more distant level for the individual and immediate support context)

1. How is the individual coping in other aspects of living?
2. How has the intervention experience impacted on other skill areas?
3. What other gains can be observed in the individual who uses AAC as well as the immediate environment?

Identification of assets and resources as part of the intervention process

As the identification of resources is an integral part of a support-based approach to AAC intervention, some further discussion on how resources can be identified as part of the intervention process is important. To this end, this discussion will focus on:

- the nature of resources available that can be identified;
- description of the sources of support;
- development of a community resource profile (community resource mapping);
- a case study to demonstrate application.

Nature of resources available to the immediate context

This profile aims to describe the kinds of resources available to a family or immediate living context, in relation to different areas of daily living. Apart from highlighting the resources of the family, it also deepens the understanding of potential stresses the family or immediate context lives with; for example, whether the family has running water available or has to fetch water, whether the family has regular income, and so on. Table 8.4 provides a taxonomy of resources for meeting family needs, summarized from Dunst et al. (1988, p. 83). This table can be used as a basis for discussion with the immediate support network to enhance understanding of the types of support that they are exposed to.

Table 8.4 Taxonomy of resources for meeting family needs

Resource category	Examples
Economic	Money for necessities
	Money for emergencies
	Money for special needs or project
	Money for the future
	Stable income level
Physical and environmental	Clean environment
	Adequate housing (space, safety, furnishings)
	Safe neighbourhood (protection)
	Adequate heat, water, plumbing
	Housing accessible to other resources
	Resources for home repairs and maintenance

Table 8.4 contd.

Resource category	Examples
Food and clothing	Adequate food for two meals a day
	Enough clothes for each season
	Reliable means for laundering clothes
Medical and dental	Trustworthy medical and dental professionals
	Available general or emergency health care
	Accessible medical and dental care
	Means of acquiring medical and dental care
Employment and vocational	Opportunity to work
	Satisfaction with work (in or out of home)
Transportation and communication	Means of getting family members where they need to go
	Means of contacting relatives, friends, and other sources of support
Adult education and enrichment	Available adult education opportunities
	Accessible educational opportunities
Child education and intervention	Accessible child education opportunities
	Opportunities and activities to help, teach, and play with children
	Appropriate toys and other educational materials
Child care	Help in routine daily care
	Emergency child care
	Child care/babysitting for employment purposes
	Respite child care
Recreational	Opportunities for recreational activities for individual family members, couples, whole family
	Available recreational facilities for individual members, couples, whole family
Emotional	Positive intra-family relationships
	Positive relationships outside the family
	Companionship
	Sense of belonging to family or group
	Opportunities to spend time with significant people
Cultural and social	Opportunities to share ethnic or value-related experiences with others
	Opportunities to be involved with community and cultural affairs
	Accessible community and cultural affairs

Source: adapted from Dunst et al., 1988.

Sources of support

After a discussion of the nature of the resources in the context, it is equally pertinent to understand the origins or sources of these supports. It is important to identify the range of people involved in supporting the immediate network, but it can also highlight potential vulnerabilities in the support systems. This analysis aims at identifying the people or associations in the immediate environment and community that are already involved or available within the context. It is focused on present and potential sources of support and can include a broad variety of people. Sources of support identified by Trivette et al. (1997) include immediate personal social networks, associational groups, community programmes, and professionals and professional services.

Immediate social networks (immediate support context)

These include people the family can and do turn to in order to ask for advice and assistance, including spouses, relatives, the clergy, friends, neighbours, co-workers, babysitters, teachers and carpool partners (lift clubs).

Associational groups

The aim of this analysis is to identify the groups the immediate context is already involved in as well as those they can potentially obtain support from. These include potential sources of support that can meet people's needs, for example: parent support groups, youth groups, elderly groups, women's groups, men's groups, health groups, fitness clubs, interest groups (e.g. AA, disability interest), self-help groups, sports groups, study groups, security groups (community security), school groups and outdoor groups.

Community programmes and professionals

These programmes include formal community agents, projects and services that are oriented to address needs in the community. In different countries the sources of these might differ; for example, in the USA these might typically be government-initiated, while in many developing countries non-governmental organizations play a leading role in these programmes. Programmes can include:

* programmes targeting specific populations/needs; for example, those for promoting adult literacy, skill training for domestic workers, programmes for early child care and development, parenting programmes, health promotion programmes (e.g. for the prevention of HIV/AIDS), feeding programmes, Arrive Alive programme, and housing programmes (e.g. Habitat for Humanities);

* institutions, hospitals, schools, child-care centres, universities, community colleges and libraries;
* services that are not necessarily institution-based: police, social work, library mobile units, and health-care mobile units.

Specialized professional services

These include specialized services for the community that could be governmental, non-governmental or private, but are typically provided by professionally qualified staff. These services may be freely available in some contexts, while in others, particularly poorer communities, these may be limited or not accessible to the majority of the people owing to limited availability of professional staff, costs of services etc. Services will include, for example, baby clinics, clinics for children identified as at risk, special educators, therapists, early child intervention specialists and vocational rehabilitation programmes. As an example how an analysis of resources can be done, a case study is presented.

Case study

This is an analysis of the resources of a mother who lives with her three children: a boy of 10 years, a girl of 17 years, and a boy of 12 years with severe physical impairments who is not speaking. Although still married, the father does not live with them and has no stable employment. The mother has full-time employment as a cleaner. The grandmother (87 years) lives with them as well as one of her other grandchildren, a boy of 3 years. This boy is the son of her son, who is deceased. The mother of the young boy is estranged. They were referred by a church worker for AAC intervention. Table 8.5 represents an integration of the resources identified within a specific context while also including the source of the resources, to provide an overview of the supportive system of the immediate support network. Most of the immediate support network were involved in the discussion, including the next-door neighbour.

Table 8.5 Integration of resources and sources of support after initial discussion

Resource	Description	Source (who)	Category
Economic	Money for emergencies	Grandmother (sporadic)	ISN
	Money for necessities	Mother	ISN
	Money for child's education	Father (sporadic)	ISN
	Stable income	Mother	ISN
Physical environment	Adequate housing	Mother	ISN
	Adequate heat, water	Mother	ISN

Table 8.5 contd.

Resource	Description	Source (who)	Category
Food	Food for one meal per day	Mother	ISN
	Food for children (one meal)	Feeding programme	CA
Clothing	Adequate	Mother/aunt	ISN
		Women's group (church)	CA
Medical and dental	Dentist available two days a week: 2 km from home	District clinic	SP
	Nursing staff: 2 km from home	District clinic	SP
Employment	Shops 4 km from home (potential resource for weekend jobs for children)	Community agencies	CA
Care and intervention for individual with disability	Assistance with daily routine	Brother/sister	ISN
	Child care	Day-care mother/ neighbour	ISN
Transport	Mostly walking – carrying child	Immediate network (who is available)	ISN
	Taxi and buses	Local taxi and bus association (for work only)	CO
Recreation	Singing – choir	Church	CA
Emotional support	Positive associations	Sister of the mother who lives close	ISN
		Children at home	ISN
		Employer	CO

ISN = immediate support network; CA = community association; CO = community organization; SP = service programme.

Table 8.5 represents the initial description of resources in interaction with the immediate support context. It is evident that not all resources have been described at this point, but the initial description reflects some trends for further discussion.

The family seem to be able to cope with their basic needs (albeit very humble), i.e. food, shelter, clothing and health, as the mother has a stable income and there is some support from the church for feeding and clothing. They are also using health services in the district although they are far away. What is clear from the sources of the support, however, is that there is very limited involvement from government services or more formal organizations in providing support: even for the day care of the child with disabilities, the mother relies on a neighbour. The focus is on the mother as breadwinner and main support of the immediate support network, with sporadic support from the father. No mention was made of any welfare support for the child with disabilities, or the grandmother and 'adopted grandchild' who are living with them.

The factors that stand out in this analysis are, first, the social isolation of the family within the community and, second, the lack of contact with formal organizations (e.g. government departments of education and welfare) as well as other community associations (other than the church). This profile confirms the social isolation of many families who live in poverty – and particularly those who have a member with a disability (see Chapter 4). The inclusion of a description of this nature as part of the intervention process could provide a meaningful basis for the further exploration of potential support for the family within the community as well as the identification of people who can become involved in supporting the immediate context. This would be particularly important in identifying those who can assist with the programme for the 12-year-old boy, who has limited or no functional speech.

However, to develop a more comprehensive understanding of the resources and access to them, a map of the community resources is important.

Community resource mapping

The aim of this discussion is not to provide a comprehensive discussion of community resource mapping, but rather to provide a synopsis of how this activity can benefit the intervention process. Community resource mapping will include the development of a network map of what is available in the community and, importantly, also the location of these resources in relation to the family or immediate supportive context. The aim of this exercise is to increase awareness of community resources in an attempt to mobilize resources to meet needs. This approach has been used extensively in community development programmes (Daley and Poole, 1985; Hasenfeld, 1983; Kretzmann and McKnight, 1993) as well as early childhood intervention (Trivette et al., 1997), but it has not been used extensively in the development of services for people with disabilities.

Community resource mapping is the development of a comprehensive list of community resources and their geographical location in relation to the family. This needs to be done by the immediate support network of the family or individual to further enhance understanding of the community resources. The facilitation of *the process* of drawing up this map will involve identifying community members sufficiently knowledgeable to provide the necessary information. Typically, this is the kind of activity all members of the immediate support context can engage in to locate resources and potential community members to become involved in the intervention process.

From the above case study it is evident that this is a most important component of the analysis to assist the family in identifying potential resources. Families need to become more aware of the community resources to enable them to use these. The inclusion of community members as part of the intervention process that could provide information on community resources would thus be pivotal.

Principles of an AAC support-based approach

Principles of an AAC support-based intervention process can be summarized as follows:

- Acknowledgement of a reciprocal association between personal (client) and family/community associations, namely the need to view the individual within the support context from the beginning of the contact. Identification of the individual's communication difficulties needs to be a collaborative effort representing different perspectives, to allow for the development of joint understanding and commitment to the process of intervention. The process of developing mutual understanding is pivotal to a sound basis for understanding.
- The 'common good' of the outcome of the process. Dunst et al. (1993) talk about 'enhancing a sense of community' (p. 25), which refers to getting people together around shared values and common needs in ways that create mutually beneficial interdependencies. This is a topic that needs discussion to ensure that all involved are comfortable with their role within this context.
- Acknowledgement of the definition of the problem as a broad basis for asset-based or capacity profiling. Although the process was initiated for a particular reason (an AAC user and their context), it is vital that all participants remain committed to the identification and extension of resources within the immediate network, and also in the broader community. Often, a particular asset may not be immediately relevant but,

over time, people involved gain insights that allow them to move the process forward. For example, a mother may feel frustrated while shopping, as she has no one to look after her young child with little or no functional speech. When the lady selling peanuts down the street was mentioned as a potential asset, the mother started thinking about possibly approaching her to assist. This can then be viewed as another potential interaction opportunity for the young child after one of the participants in the intervention process approached the peanut lady. Mutual benefits of this interaction will need to be discussed to ensure the interaction is not exploitative.

- Acknowledgement that the resources to alleviate the problem lie primarily within the individual/family and community associations. This implies an ability to cope with external resources (e.g. professional input during intervention) to facilitate personal, family and community development. Participants in the intervention process need to understand that they will ultimately need to maintain and sustain the intervention effort. To do this, they need to explore ways to realistically integrate the strategies within their everyday contexts. This requires a sound understanding of what is possible. Implicit within this approach is a feeling of enablement allowing participants to translate or modify suggestions to fit their context.
- Acknowledgement of different perspectives as an inherent part of the intervention process. Involvement of participants in each step of the intervention process implies that diversity of views and solutions will be encouraged and accommodated. While consensus may not be reached, creative synthesis as part of the intervention process becomes pivotal to secure a congenial context for intervention. The challenge for any collaboration process is, however, to ensure that the purpose and outcome of the process are monitored and used to enhance the outcome of the process.

One of the major challenges is the accommodation of integration between specific AAC intervention goals and broader community goals for intervention, namely a delicate balance between specific and comprehensive goals. This reflects the necessary integration between service and community associational skills. Goals need to be set by each sector in interaction with each other. The challenge, however, remains how to maintain the intervention process, particularly in the field of AAC, which often requires long periods of intervention. Maintaining participants' interest and motivation as part of the process is vital to a supportive community-based approach. Gains of involvement in the process shall be explicitly addressed within each phase of the intervention. To facilitate the visualization of the process, the following case study is presented.

Case study

Description of the client and context

Family X lives in a poor, urban context. Although there are many families living together, people are suspicious of each other. It is a relatively high-crime area with sporadic violence. Households are quite isolated from each other.

Njogu is a boy aged seven who has little or no functional speech. Presently he is functioning on a five-year-old level on most development skill domains. Physically he is severely involved although he can walk with a broad base with associated hand and arm movements. He stays with his mother who is a full-time domestic worker, and his father, who is working as a taxi driver. Also living in the house is the grandmother (84 years) and six other children varying from three to ten years. Njogu attends a local school and gets taken there by other children (they walk together). Professional involvement in his case is minimal, except for the district health clinic, which they visit periodically for ailments. Njogu was brought to the AAC interventionist at the district hospital by the grandmother after a friend informed her of speech therapy.

Intervention process

One of the first issues to be addressed is the identification of the people involved in the intervention process. The identification of participants in the intervention process is challenging, as family members are often not oriented towards involvement in intervention and neither are they familiar with the concept of involving the community in the process. They are thus not empowered enough to identify community participants. However, as participants come to understand the approach, they become more at ease with the process. The grandmother, who attended the first meeting with Njogu, was not able to identify any involvement with the community other than church and the child's school. Both parents were working and not able to take time off work to participate. The family support scale (Dunst et al., 1994) was used as a basis for thinking about potential participants in the process.

First intervention meeting: strategies discussed for the inclusion of participants

* The grandmother pointed out the importance of the parents becoming involved, and that this could mean intervention needing to be on a Saturday.
* The grandmother suggested asking the mother to identify other potential participants.

* Including the women's group of the church in the intervention context was discussed. The grandmother volunteered to talk to them, but she felt insecure. It was then decided to involve the priest at the church to discuss the need for involvement with the women's group.
* It was decided to contact the school principal to discuss the intervention and involvement of teachers and students as part of the process. The AAC interventionist volunteered to do this.
* The inclusion of the community health worker and the social worker involved in the service will also be secured for the second meeting by the AAC interventionist.

At the time of the second meeting, which was in the late afternoon to accommodate the parents, most of the above people attended the intervention session (see Table 8.6). The focus of this meeting centred around facilitating the understanding of mutual benefit for all involved in the process. This meant that each representative was encouraged to think about how involvement in a process like this could benefit them and, also, the association or network they are involved with. Exploring strategies to facilitate the extension of benefit to their own associations or networks was discussed as an inherent part of the intervention process.

Description of the second intervention meeting

Attendants:

* grandmother, mother, brother aged nine as well as neighbour (immediate supportive network);
* one member of church women's group;
* Njogu's class teacher and one classmate;
* community worker (district hospital);
* social worker (district hospital).

Table 8.6 Aims and outcomes of the second intervention meeting

Aims	Strategies	Outcomes
Discuss the purpose of intervention process and the involvement of each participant	• Definition of support-based community intervention as a community development process • Discussion of benefits in terms of sustainability of intervention • Concept of mutual benefit to the individual, but also to the community	• Each participant identified initial ideas of how this process could impact on their own context and community association, in terms of skills, attitudes and community development • Participants undertook discussions with their constituencies to identify the involvement of relevant disability or parent or family support groups in the process

Table 8.6 contd.

Aims	Strategies	Outcomes
Discuss the process of intervention	• Agreement on length of initial intervention period • Agreement on how to evaluate the outcomes of the process on the different levels of participation: individual, immediate support network and community associations	• An intervention contract for involvement in 8 intervention meetings was developed • Initial suggestions were made for feedback to the community or constituencies regarding the outcomes of the intervention
Intervention with Njogu	• Discussion of communication difficulties • Identification of strategies already in use • Discussion of extension of strategies • Demonstration of how a communication board can facilitate interaction: practice session with parents and other participants	• Joint decision to use appropriate Picture Communication Symbols (PCS) to facilitate communication, as he is able to identify line drawings • Initial vocabulary of 8 symbols on a communication board • Extension of symbols • Joint discussion on how the communication board can facilitate interaction, and the importance of seeing the communication board as a tool to facilitate understanding and interaction. It is not to be a show-piece, but a tool for interaction
Preparation for next meeting	• Importance of using the communication board in interaction. Importance of exploring ways to use the board to enhance interaction – personal exploration with Njogu • Discussion of how to create interaction opportunities within the different contexts for Njogu to interact – to practise the use of the board to explore interaction • Discussion of who should be involved in the next meeting, e.g. involving the father again and setting the date	• Discussion of report-back on their experiences at next meeting – challenges and gains • Setting realistic criteria for success for this first period • Discussion on feedback, and extension of benefits of first meeting to self and broader community context • Identification and discussion of new or additional issues of importance as part of the process

Table 8.7 provides a more detailed example of the planning for specific opportunities to use the child's new communication system in daily contexts.

Table 8.7 Example of a more specific formulation of goal setting for AAC intervention to facilitate participation of each group in the process

Specific/own goals of AAC-user	Immediate supportive context	Community associations
Use of new communication board with 8 PCS concepts Strategy: attention-getting to initiate contact to talk	Create opportunities for use of communication board Strategy: asking before giving to, or doing activities for, the individual	Enhance understanding of the importance of communication for all. What are the benefits for us all in being involved? Strategy: talking to people at school/church about the different ways of communicating Strategy: teacher to provide information to class; peers to make own communication boards for interaction, for example by drawing pictures Strategy: creating opportunities for increasing interactions with AAC-user
Extending communication concepts – to include more use of multiple meanings in interaction Strategy: practising using one concept to portray different meanings; for example, what else can we say using the picture 'cup'? For example, cup drink, cup empty, cup full/overflowing (grateful)	Using one symbol for different purposes in communication Strategy: getting others in immediate environment to communicate using a particular symbol to initiate communication; for example, can we talk about the symbol 'cup' today?	Class: encouraging different children to use the board in class – how to get people who can't speak to use their communication boards by using multiple meanings Youth group: investigating the involvement of AAC-user in a youth group

Implicit in Table 8.7 are various important issues. The first relates to the relationship between the individual, immediate support system and community associations, and the principle that intervention has to be planned to accommodate different levels of community interactions. If these interaction opportunities do not exist, ways need to be investigated

to extend present interaction opportunities. Interaction with community associations and the immediate support group cannot start 'after' the new communication system has been learned or is in use. The interaction has to be facilitated from the beginning, and problem-solving in relation to strategies to increase these interactions needs to be developed. The communication system needs to be an integral part of real-life interactions from the start. This might mean starting with less content, but more extensive use in different situations.

It is important that the use of communication is demonstrated, but it is emphasized that it is a tool to be used to enhance understanding and human contact. People are, therefore, encouraged to explore different ways of using the board with the individual to assist in developing a communication tool and not a showpiece.

The participants in the intervention are thus many, each representing a particular segment of the individual's world or community. They act as the primary agents in allowing access into the supportive networks within their context. The main concern is, however, to include those regarded as pivotal to assist in integrating the individual AAC-user into the community. This may mean less frequent intervention meetings, but more extended meetings to ensure enough time for sharing and facilitating understanding.

The focus of interaction is the development of meaning between individuals. As discussed in Chapter 2 (Intervention issues), this implies that the individual needs to become involved in the dynamic process of developing meaning in interaction with others. Typically, however, using communication boards, or even voice output devices, the AAC-user has limited vocabulary available to express the rich nuances of everyday communicative interactions. The focus should thus be on making the communication system work, finding flexible ways of adjusting vocabulary by combining new concepts, and training partners to see any indication of symbols (or combination) as an attempt to develop meaning in interaction. Meaning cannot be conveyed; it is developed in interaction between people. This means that access to symbols (participation) is not in itself access to communication, but involvement in the process is most important for sustained interaction (see Chapter 2).

From the above, it is suggested that these goals of intervention outlined in Table 8.7 will take longer to accomplish, but can be more extensive owing to the involvement of community members in the process. Similarly, the focus is on access to vocabulary, but particularly the more creative use of the vocabulary – small steps, but with meaning.

Conclusion

Dunst et al. (1988) discuss some faulty presuppositions in relation to family intervention in early childhood intervention, which can be well applied to the proposed intervention approach. These include the following.

- *That it is often unrealistic to get families to formulate long-term goals, as their needs change and often demands are immediate. Formulating long-term goals is thus not functional in most cases.* This implies that although it is important for individuals and families to have a vision for long-term education and vocational purposes, the focus in intervention needs to be pragmatic in facilitating coping (better use of resources or getting access to new resources) and interaction. It implies that intervention needs to accommodate issues surrounding effectiveness and sustainability of intervention, while at the same time maintaining awareness towards issues related to versatility (Chapter 2).
- *That it is often unrealistic to expect all families to identify child-related concerns as needs and goals for intervention.* Often other seemingly unrelated needs are formulated as priorities and should be dealt with first before needs statements in relation to the child will be relevant. Flexibility is a prerequisite for sustainability of intervention. This implies that intervention, although primarily focused on the AAC-user, will be flexible in accommodating priorities of the immediate context; for example, in the case of Njogu one of the goals during a session was to support a sibling who was not well. This was a need identified by the grandmother, who needed support.
- *It is a fallacy that more exposure to intervention is better: intensity and frequency of intervention are not always important. Informal treatments can have most significant effects.* Frequent intervention sessions often tend to create dependency, which needs to be monitored carefully. More extensive contacts with more people involved at longer intervals could be a meaningful alternative. However, this approach should be balanced with a realization that participants need to experience success; thus their efforts need to lead to tangible outcomes for the process to be sustained. The benefits for the individual, immediate support structures and community associations need to be ongoing as part of the discussions during intervention. As mentioned, the impact of more informal interactions – not professional but community contacts – could be equally meaningful in facilitating communication development. The ease of transfer of skills of the individual and use of the communication system will depend greatly on the nature of the intervention and its appropriateness in relation to the immediate and more extended environment. As mentioned above,

small manageable intervention goals that can be extended in different ways and contexts to allow for creativity from participants can be most beneficial.

- *The potentially damaging role of the case manager as the person 'who will be responsible for implementation of the plan and coordination with other agencies and persons'* (Dunst et al., 1988, p. 131). This statement touches on the basis of a support-based approach to AAC intervention, as the responsibility for the intervention is shared. The AAC interventionist and/or case manager are significant partners and facilitators in the process, but they need to understand the scope as well as limitations of their involvement in relation to long-term sustainability and versatility of intervention. Openness to participants in discussing their views and ideas on developing more extensive networks of support is pivotal to the success of the process.

The above fallacies clearly are most relevant in dealing not only with families in early childhood intervention, but also with the immediate support structures of people with disabilities. The development of trust between partners in intervention form the basis of the intervention process, together with a belief that all partners are working for the good of all involved. Working for the common good is, though, not unproblematic. Families and community members seldom relate to anything but immediate gratification. However, the development of caring environments is at the heart of the asset-based approach (McKnight, 1997), as interventionists also need to work towards the development of safer and more supportive communities.

Challenges of a support-based AAC intervention approach

Clearly, an approach focusing on the development of a partnership between service and community is going to present participants with substantial challenges, not only because of the hesitancy of people from the community to become involved in activities beyond their own immediate interest, but also because of the major shift that professionals need to make in the process as they move towards a partnership model of intervention.

However, what are the alternative models if we want to move towards facilitating community development and empowerment of all involved? The medical model of implementation has relevance within particular contexts, but dealing with communication and its integral relationship to everyday life necessitates a more in-depth consideration of models oriented towards a social definition of disability.

Perhaps the most obvious challenge to this approach is the issue of people not wanting to become involved, or not being able to sustain their involvement as part of the process of intervention. Clearly, uninvolvement

or lack of motivation to participate in the intervention process is not a new phenomenon: lack of time, stress and changing priorities are well-established issues in traditional intervention contexts. The issue remains whose priority is it? If intervention is professionally directed, does it not make sense for communities to feel that the responsibility resides only with the professional and the individual? Perhaps one of the major challenges lies in the mindshift necessary from both professional and community participants to realize that sustainable long-term impact is only possible if the process of intervention is based on mutual commitment towards outcomes.

Integrally related to this is the development of more appropriate models according to which this partnership can be effective; for example, less frequent but more extensive contacts, and a different definition of outcomes – not outcomes related just to effectiveness of intervention, but also related to sustainability and versatility. The development of indicators relevant to the participants as part of the process might be challenging, but is most significant in maintaining the intervention process.

It is important to point out that a support-based approach does not deny the pivotal importance of parents in the intervention process; however, it acknowledges the major problem that parents, particularly those who live in poverty conditions, encounter in dealing with the added stressor of having a child with a disability. The absence of a nuclear family as traditionally defined, as well as the social, emotional and financial stresses imposed, contribute greatly to many parents' inability to become active participants in the process without substantial support from others around them. Caring communities as Kretzmann and McKnight (1993) propose are how we would like to view the communities we live in.

Finally, the biggest threat to any intervention process is the need to standardize too much. The process must remain flexible to accommodate the different needs of the individual, family and community at different stages of the intervention process.

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Chapter 9
AAC technology for development

Erna Alant

This chapter deals with issues surrounding the use of assistive technology (AT), in particular augmentative and alternative communication (AAC) technology within a low-income context. It starts off by describing the problems and exploring issues relating to the integration of technology as part of development within communities, by using the model of Riedijk (1987). The proposed model is based on a support-based approach to intervention (see Chapter 8). A case study is used in an attempt to illustrate relevant issues to implementation within low-income countries. Challenges of assistive technology implementation in low-income countries are discussed and, in conclusion, the need for further debate and research in this field is emphasized.

Over the last decades much effort has been invested, particularly in the USA, to promote the use of AT for people with disabilities, based on the assumption that low and high technology and adaptations would substantially benefit the costs associated with facilitating independent functioning in major life areas (e.g. transportation, health care, rehabilitation and telecommunications). There were therefore statewide technology-related assistance programmes for meeting the needs of people with disabilities. In the Technology Related Assistance for Individuals with Disabilities Act of 1988, the US Congress stated that the provision of AT enables *some* individuals to:

- have greater control over their lives;
- participate in and contribute more fully to activities in their home, school and work environment, and in their communities (Inge et al., 1998);
- interact to a greater extent with non-disabled individuals; and
- otherwise benefit from opportunities that are taken for granted by individuals who do not have disabilities (Wallace et al., 1995, p. 4).

The acknowledgement of the importance of AT in facilitating social inclusion and independence is also evident in the Continental Plan of Action for the African Decade of Persons with Disabilities for 1999–2009 (African Union, 1999). In this document, 'objective 4' focuses on the importance of enhancing support services for people with disabilities in Africa. Support in the design, development, production, distribution and servicing of assistive devices and equipment for people with disabilities, adapted to local conditions and dissemination of knowledge about them, are explicitly stated (African Union, 1999).

Augmentative and Alternative Communication (AAC) technologies form an important part of AT used by people with disabilities, and therefore the use of these devices has escalated during the last decades. However, experts agree that elderly people, people in rural areas and people who do not speak English remain big challenging populations in dealing with AT service delivery. According to Rogers (1995) discontinuers are characterized by less formal education, lower socio-economic status (SES) and less contact with the change agent. These issues and those concerning cultural attitudes towards AT largely contribute to the complexity of issues concerning technological abandonment (Scherer, 1993, 1996) in developed, but also in low-income, countries. The acknowledgement of the importance of technology and training support to facilitate the sustained use of AT as well as the critical importance of the selection of aids appropriate to the needs of the individual, family and community context are reflective of the increasing awareness of the complexity of factors involved in effective service delivery in AT.

Over the past years there has been increasing discourse during International Society for Augmentative and Alternative Communication (ISAAC) conferences in relation to the definition of *appropriate AAC technology* within the international arena, with particular reference also to low-income countries. This issue will be addressed by posing four critical questions.

1. What is meant by appropriate AAC technology within a developed and developing country context?
2. Is a suitable AAC device for an individual child necessarily relevant within the broader social context of the community or country?
3. How do the AAC interventionist, technology distributor and communities go about facilitating the development of an infrastructure for the use of AAC technology?
4. Is it feasible to think of AAC device implementation in contexts where poverty and threats like HIV/AIDS are demanding much of the gross national income?

Clearly, these are not easy questions to answer and the purpose of this chapter is not to attempt to provide specific answers to these questions,

but rather to enhance understanding and insight into issues related to the questions. The chapter will explore a model for facilitating implementation of AT within the international arena, but specifically also in the developing-country context, by integrating the individual, family and community variables into a paradigm which acknowledges the importance of intervention within broader community development. The successful use of AT is not essentially an individual or family issue – it also has to do with a sustained training and technological infrastructure within communities (Chester et al., 1998; Sideman and BenDak, 1997). It is an issue, too, of the prevailing cultural values of the broader society, namely the extent to which AT is viewed as being important, and the extent to which the perceptions and values of the family with regard to AT parallel the values of the broader cultural community. It is not surprising, therefore, that assistive technological abandonment is such a prominent issue in intervention (Aminazadeh and Edwards, 1998; Brotherson et al., 1996; Gitlin et al., 1998; Parette and Angelo, 1996; Wehmeyer, 1998).

A consequence of the realization and acknowledgement of complexities related to the use of technology has been a definite change in approach, from the Western 'expert', 'transplant' and 'consumer' models to the encouragement of a partnership model (Baird and McConachie, 1995, p. 21). This implies that instead of imposing values and technology from specific Western countries or contexts, professionals adopt a more community-orientated, culturally appropriate approach utilizing local personnel and resources with technical support (Lysack, 1997). This approach is also reflected in terminology like *appropriate technology* (Parette et al., 1993; Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), 2001) that reflects a critical awareness of the relevance of technology within a particular context. Appropriateness within the context of AT according to Parette (1997) 'must be interpreted with regard to the extent to which the device or service will help the individual achieve an individual or family goal or function that would not be attained otherwise' (p. 270). Although this definition clearly is oriented towards industrialized countries, 'appropriate' within low-income countries could also be extended to include an evaluation of the transferability of the technology to the new cultural and country context (Kahen and Sayers, 1997). It is thus important to point out that the term 'appropriate technology' is really a misnomer, as the issue does not lie within the technology itself, but rather in the relevance of the technology within a specific context.

According to Kahen and Sayers (1997) health-related technology development in low-income countries faces four major obstacles, including: (1) lack of national policy formulations and organizational style; (2) inadequacies in infrastructure, and ineffective health-care technical services;

(3) shortage of capable human resources (e.g. inadequate experts and ineffective training systems); and (4) insufficient information support and lack of effective information systems. These issues list the major challenges confronting the use of AT, and in particular AAC technologies, in striving for sustained use. According to the WHO, essential health care should meet three criteria: it should be technically valid, economically feasible and socially acceptable (Nakajima, 1995). 'Technically valid' relates to the appropriateness of the supportive infrastructure within a country, and would include training, distribution and maintenance of technology; 'economically feasible' would relate to the affordability of the equipment as well as the funding infrastructure within a country; while 'socially acceptable' would relate to the cultural and social attitudes in relation to the technology and its use. Clearly, the definition of appropriate technology, particularly in developing contexts, needs to take cognizance of the interrelationship between individual and family needs within the broader context of community development.

AT in low-income countries

The realization of the close link between technology use and community development has given rise to the philosophy of technology for development which is based on the use of the most advanced and modern technology in giving a dignified life to all human beings (Riedijk, 1987). The focus is, however, not only on the relevance of the technology for the context but also on the access of these devices to all in need. (The context, in turn, should consider not only the demands of the environment where the AT will be used, user needs/preferences, and technology features, but also the cultural values that operate within both the family and broader culture.) Technology should be implemented in a manner that provides dignity to the individual and promotes opportunities for personal choice by both individual user and family while at the same time being accessible. This approach of broad-based access to AT has led to considerable debate on what should be regarded as basic or essential assistive devices that need to be accessible to all. Lankester (1992) argues that most AT is unnecessary and that a community-based care approach selects essential drugs and technologies and uses them effectively. This approach to AT is, however, quite problematic as it assumes that community needs are homogeneous – that one size fits all. Also the selection of what is essential is a value-driven decision: in some developing communities the ability to communicate might not be regarded as that important, while it clearly would have a major impact on the individual's ability to participate in activities. For example, the decision can be taken that

high-technology AAC devices are inappropriate for low-income countries – thereby placing the focus of the issue on the technology rather than the support structures for the implementation of the devices.

Lankester describes three stages of health care: the traditional health system, which is convenient, affordable but not very effective; the scientific health system, which is inconvenient, expensive but effective for those who can afford it; and community-based health care, which is convenient, affordable and effective. Clearly the focus is on accessibility to all in need, which makes the provision of services more sustainable. Applied to AT, this framework would emphasize the importance of embedding the use of AT within community development. Sanders and Carver (1985) expanded on this concept by pointing out that smallpox vaccination, with its efficacy, is a good example of appropriate technology. They highlighted two vital operational factors which contributed to its success: first, the use of local agents who were familiar with the local geography, conditions and customs and, second, the effectiveness of the technology itself (bifurcated needle) used in the process. The issue is how to integrate effectively a minority need (like communication technology) within this context. Clearly the issues surrounding AAC technology in the broad sense also need to be viewed within the context of accessibility to all (i.e. affordability), familiarity to local agents and the evaluation of the effectiveness of the technology in addressing the communication needs of people within the context.

Issues surrounding people's access to AT include a range of ethical dilemmas relating to financial and social resources. For example, can one prescribe a communication device if the family cannot afford such a device, or if buying the device or paying for subsequent intervention may impact on basic needs by, for example, taking money from housing or groceries? In the chapter by Zinkin (1995) on priorities for children with disabilities in low-income countries she cautions that naive actions of professionals can make it more difficult for a poor family to meet their basic needs. Moral dilemmas in relation to the individual with disabilities also abound, as reflected in the following questions:

- Can one, and for how long, put the development of a child's communication system 'on hold' until the community or family has developed an appropriate infrastructure for its implementation?
- To what extent can the implementation of devices facilitate the development of a meaningful infrastructure for support?
- What is the moral basis for early detection if it cannot be matched by appropriate actions after detection?

Riedijk (1987) emphasized that technology for development is based on the notion of respect for the delicate relationship between needs and

ecology. Individuals are dependent on nature for their physical existence; therefore, technological solutions need to be compatible with the ecological environment of the community. Technology is 'nothing more or less than the expression of the values and lifestyles living within society' (Riedijk, 1987, p. 4). The notion therefore is clearly that no technology is good, bad or neutral. It depends on how it is used to facilitate either economic and political autonomy or dependence. The use of technology is a value-driven process, and communities and individuals might vary greatly in relation to their perceptions and evaluation of the outcomes of the use of technology. Reflecting on the basic tenets for the use of AT within specific context is thus most relevant.

Technology for development is defined as the technology of liberation. This means that technology is an inherent part of the process in which an individual and community grow to self-understanding and management. The key concepts of a development-based technology are thus vital to an understanding of the use of technology. Table 9.1 provides a modified outline of the key concepts for appropriate technology as described by Riedijk (1987, p. 11).

Table 9.1 Key concepts in technology for development

Needs	Process	Tools
Growth	Self-development	Liberation
Relations	Self-management	Organizational
Existence	Self-sufficiency	Technical provisions

Source: based on Riedijk, 1987.

From Table 9.1 it is evident that needs are first identified as a requirement for basic existence, the need to relate to others and to develop interactive patterns with the environment, and to grow, expand and develop. The means or processes through which this is addressed are through self-sufficiency, self-management and one's own development. Self-sufficiency refers to the ability to self-provide, thus the notion that technical provisions need to be easily accessible, close to the community who use them. Maximum use should be made of locally available resources to facilitate economic autonomy. With globalization, however, this notion has become redefined and focuses on the need for interaction and negotiation with global companies to produce and access technology in the most affordable and sustainable way. Technology should be easily accessible and affordable. Self-management, however, is the process whereby the community needs to organize and manage the production or production

networks. Policies and strategies need to be in place to facilitate the structure and processes needed to be effective. Infrastructures need to be developed to ensure that devices can be maintained, serviced and ensured. Finally, individuals and communities need the variety of tools or technology to facilitate the processes. For example, devices need to be provided and distributed, thus organized to become tools for liberation for individuals and communities. This refers to the empowerment of the individual and community and the raising of critical awareness (Freire, 1970) to reflect on and facilitate positive change.

Technology should therefore be an integral part of the growth and development of the community and individuals. Although these concepts essentially describe technology for development in a community context, it is important to stress the relationship between personal development and social development. Burkey (2000) describes human or personal development as the basis for economic, political and eventually social development. This means that issues related to personal development need to be addressed and viewed within the broader framework of social development. The dilemma of implementation of AT therefore lies in the integration between the needs, processes and the tools within a society.

Clearly, this model has some important implications for AAC technology. In the first instance, this model emphasizes the need to ensure sustained access to AAC technology or services as an essential step in the development of infrastructure and management of technology. As the infrastructure for technology becomes more integrated within the country, self-development is facilitated as people reflect on their own context and continue to improve or change the technology to facilitate development to suit their needs. Clearly, there is no linear relationship between self-sufficiency, management and development, as these processes develop within a spiral relationship. The interrelationships between these processes facilitate advancement in all areas. As networks develop between communities, service providers, distributors and other technological support structures, the organizational tools develop that assist in the emancipation of the community and individuals and facilitate the integration of technology as a meaningful part of people's lives. Technology for development is thus primarily concerned with the role of technology within the broader development of the country and the people.

As intervention is essentially focused on an individual and the immediate supportive context of the individual, the challenge for AAC interventionists is how to integrate this development approach with the more focused approaches of AT typical of AAC and other intervention approaches. The association between individual, family and community needs is particularly important, as long-term use of technology does not

solely depend on the individual or family's motivation and skill in the use of the device, but also on the support system available in the community and broader policy context for the distribution, maintenance and repair of devices. This organization or support network within the community and country is particularly important within a context where expertise and resources could be limited.

Life-cycle of AT

Panerai and Mohr (1989) described the life-cycle model of health technologies, which focuses on the intensity of use over time and starts with the innovation stage, which refers to the invention of a new product, or the introduction of a new product within a specific context. This is followed by diffusion, where the technology is introduced into the broader community with high interest and expectations. This is a complex process driven by personal and corporate profit in addition to 'community profit' (Panerai and Mohr, 1989, p. 12). The third stage is incorporation, where service providers recognize the technology as an established technology, which leads to a change in its status. Hereafter the technology becomes routinely used or utilized (stage 4) in services. This typically could lead to broad-based public financing of the devices as well as overuse and abuse. In many low-income countries, technology tends to be concentrated in the private sector in countries where this section is well developed. This leads to unequal distribution of high-cost technology particularly favouring urban areas. The final stage of the life-cycle is abandonment, i.e. where the technology is discarded for a variety of reasons ranging from safety issues, lack of operational infrastructure and maintenance, to the introduction of more effective technology. A considerable number of technologies are, however, being forced out of the market by 'artificial obsolescence' (Panerai and Mohr, 1989, p. 17) which is a strategy used by industries to enhance their sales record. In most cases these innovations are incremental rather than radical new inventions. A good example of this would be the consistent improvements (albeit small) in technology noted in the development of new speech output devices. Clearly issues surrounding artificial obsolescence are a major concern in developing contexts. An AAC device can be acquired only to find that within a relatively short period of time the device is replaced by another, with relatively little maintenance support for the old devices. This obviously poses a major challenge for AAC device implementation, as there are rarely financial resources to secure upgrading of technologies in low-income countries.

Models of AT

As a starting point, it is important to explore some of the existing AT models commonly used in AAC circles. Two approaches to AT technology will be discussed as a basis for the present argument: the home-based approach (family-centred approach) of Brotherson et al. (1996) and the Human Activity AT (HAAT) model of Cook and Hussey (1995).

Parette and Brotherson (1996) as well as Judge and Parette (1998) described a comprehensive approach to involve families in four domains of AT, i.e. the child, family, service system and technology. They emphasize the need for this process to be collaborative to ensure that no mismatches exist between the technology, technology service available, needs, strengths and styles of the family system. They formulated a home-centred approach (based on the family-centred approach of Dunst et al., 1988) to AT provision for children with disabilities which focuses on family problem-solving as an integral part of the selection of AT.

Table 9.2 provides the questions suggested by Brotherson et al. (1996) to facilitate problem-solving for the use of AT in the home. Although cultural factors are included as an important factor in Parette (1997), the home-centred model focuses on the family as central to the process.

Table 9.2 Questions to facilitate family problem-solving in relation to AT in the home

1. What is your desired outcome? (Address priorities and concerns.)
   What have you been told about [AT, etc.]?
   If you could focus your energy on one thing, what would that be?
   Describe what you would like to see happen for your child after using this technology.
   What do you want to accomplish in the next 3 months that will help your child?

2. What can your family and the programme do? ('Brainstorm' alternatives.)
   How do you see this happening in your everyday life and home?
   What are some ways of getting to where you want to be?
   What would a trial use of this device be like for you and your child?

3. Think it over and decide on action. (Examine family values, resources, and impact.)
   Who in your family could help with this device or learn to use this technology?
   How, if at all, will this device put demands on your family?
   How will this device get from home to school and back home again?
   How will your home need to be modified to accommodate this technology?
   What will it cost for you to modify or change your home?
   Describe for me the ideas with which you are most comfortable.

Table 9.2 contd.

4. Take action. (Tasks to do with strategies and activities.)
   What needs to be done to make this happen?
   What specific changes will you see for yourself and your child?
   Who needs to be involved in getting done what you want to do?

5. Are we there? (Criteria and time-lines for evaluation.)
   How will you know when this assistive device is successful?
   How long do you think it will take?
   How will you be able to tell if you (we) are successful at reaching this outcome?
   When will you know that the trial period is completed?
   When will you know if it is time to change?

Source: reprinted from Brotherson et al., 1996, p. 92.

The approach of Brotherson et al. (1996) is focused on assisting the family to identify their own knowledge and resources about AT in an attempt to start where they are at and to develop a joint understanding of the priorities of the family. Priorities and concerns are identified as a basis for further exploration. The second step is the exploration of what the programme or service can do in relation to the priorities and concerns voiced, followed by an analysis of family values, resources and the impact of the AT on the family resources. The fourth section deals with the action and prioritizing that would be the most important action step and who should be involved. Finally, the development of criteria to evaluate progress is discussed. The approach reflects sensitivity to the family and the resources as well as concerns raised by the family, as is typical of the approach of Dunst et al. (1988). Subsequently, this model has been expanded to place greater emphasis on the cultural context of AAC decision-making (cf. Huer, 1997; Huer et al., 2001; Parette, 1998; Parette et al., 2000; Parette and Huer, 2002; Parette et al., 2001; Parette et al., 2002; Soto et al., 1997; Stuart and Parette, 2002). As noted by Parette et al. (in press), an understanding of culture, both in terms of milieus/environments and family perspectives, is integral to more effective AAC decision-making. Payne (1996) argues that people from lower socio-economic levels are often acculturated to accept the absence of technology, and this becomes part of what she calls 'generational poverty' and is deeply engrained in the value systems of the culture – people simply get along without technology in their lives, and it is a function more of values learned than the unwillingness to use or adapt when AT is actually provided along with the appropriate supports to ensure its successful implementation.

The Cook and Hussey (1995) HAAT model is based on the human performance model by Bailey (1989), but was modified to include the

elements of human activity, AT and the context. The activity is seen as the fundamental element of the HAAT model as it represents the functional result of human performance. The human component represents the underlying abilities that the individual uses to perform activities and tasks. These intrinsic enablers are grouped into three categories: i.e. sensory input, central processing and effectors (motor). The third component is the context, which includes the setting (home, school, employment etc.), social context (familiar and non-familiar interactants) and physical context (light, sound, heat). The argument is made that the cultural sensitivity of the model is accommodated within the description of the concepts of activity and social and physical context. Cultural factors that impact on AT delivery are acknowledged and include a broad range of factors: the use of time, the balance between work and play, values regarding finance, knowledge of disabilities and sources of information, beliefs about causality, sources of social support, acceptable amount of assistance from others, degree of importance attributed to physical appearance, and degree of importance attributed to independence.

By identifying these factors, Cook and Hussey (1995) provide pointers for interventionists involved in decision-making in AT with families. These include their orientation towards the role of AT in their lives, social supports and priorities assigned to various aspects related to technology. From this model and the description, it is clear that the HAAT model acknowledges the cultural context and, similar to the previous model, suggests some ways of accommodating it into the process of selecting AT. The AAC model (Fuller and Lloyd, 1997; Lloyd et al., 1990), discussed earlier in Chapter 2, addresses communication with and without the use of AT (i.e. aided and unaided AAC). This model and the related AAC assessment model (Wasson et al., 1997) are relevant to the discussion. They consider many factors but have as their major components the AAC-user, partners, environments and AAC systems.

These models are focused more on the individual and the social context (i.e. family or interactants) than on the integration of these components within the broader community and policy context. Although these models are relevant in countries with established infrastructures for the use of AT, the challenge in low-income countries revolves around how to integrate the above AT approaches with a community development framework. The issue of acculturation is a good example. Parette et al. (in press) argue that it is an important variable in the use of AT. *Acculturation* is defined as the 'extent to which ethnic-cultural minorities participate in the cultural traditions, values, assumptions and practices of the dominant White society' (Landrine and Klonoff, 1995, p. 124). The issue is thus how to accommodate minorities within the broader context of Western societies. The chart contained in the paper by Parette et al. (in press) suggests that there are four different options for AT acceptance or rejection. These options include: first, where AT strategies and recommendations are rejected by the user and family (thus totally separate/different values); second, where the AT strategies and recommendations ignore the needs or preferences of the user and family (thus where the users are marginalized); third, where the AT strategies and recommendations are accepted in part by the user/family (integrated values); and, finally, where AT strategies and recommendations are accepted totally by the user/family (assimilated values). These options are useful in demonstrating that when Western values are imposed on differing value systems, families/users may respond in varying ways depending on a range of forces at work within the cultural context. While the approach of acculturation has some important insights to contribute, the main challenge in low-income countries remains how to support the introduction and use of AT in a situation where the majority cultures have not developed a supportive AT infrastructure.

Integrating AT within a development framework

From the models discussed above it is evident that, particularly within developing country contexts, there is a need to more closely explore the interaction between a broader community-development-based approach towards the use of AT and a family-centred or activity-focused approach. It is against this framework that an adaptation of these models will be explored to include a stronger emphasis on the community and cultural supports for the use of AT intervention.

The triangular focus (see Figure 9.1) points include: the main partners in the process, i.e. the individual who is the primary beneficiary in the process; the immediate supportive context (family and significant others), which is the secondary beneficiary; and the associational community (different social contexts and community associations that the individual and family are directly involved with), which is the third beneficiary in the intervention process. The concept of 'common benefit' is most relevant in facilitating an understanding of the importance of integrating the different components for the good of all involved (see Chapter 8). The sustained and valued use of technology assists in integrating the individual within the context, which in turn benefits both the family as well as the community as the individual becomes a more active participant in community life. Also, as families or immediate support networks become aware of the benefits of AT for themselves, they are more likely to become involved in the
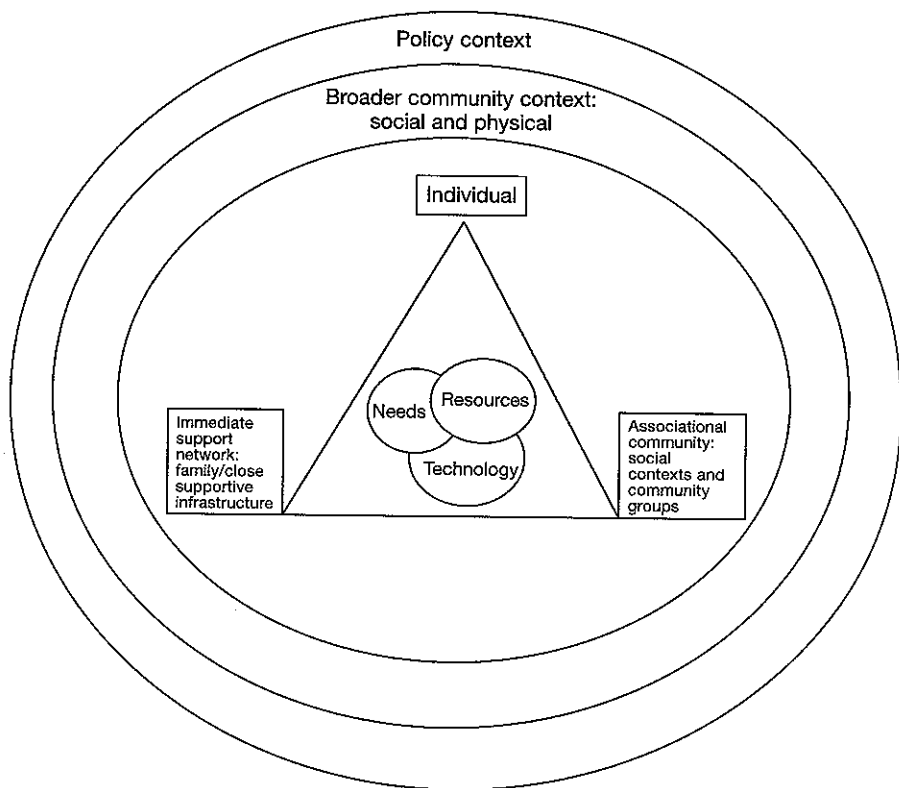
Figure 9.1 AT for development: an integration of individual, immediate support network (including family) and community context.

development of better community infrastructure for technology support and training. The broader cultural context, which includes both the social and physical context, thus refers to the infrastructure for the use of AT which is supportive of the triangular components. These would refer to the availability of AT support networks and maintenance, as well as the general attitude towards the use of these within a country or district. The outside circle represents the broad government and policy framework within which implementation occurs. AT service provision thus will be conducted within a support-based model discussed in Chapter 8.

From the model in Figure 9.1 it is evident that there needs to be a synthesis between the different perspectives (i.e. needs and concerns, resources and technology) to ensure meaningful implementation. The critical issues of such a synthesis are outlined below.

I. The resources of the individual, immediate supportive context and community associations that the individual and family are involved in need to be described. This would involve a description of the following.

A. Present communication styles and functions of the individual, family and community interactions, i.e. an analysis of capabilities and existing interaction patterns.

B. Existing and potential support systems for individual and immediate supportive context in relation to intervention.

C. Physical resources and potential resources in the environment, particularly in relation to wheelchair access and physical resources that can facilitate functioning in the different contexts.

D. General orientation and support systems in relation to technology, namely:

1. experience/exposure:
   • existing range of technology in use by different partners involved in intervention;
   • familiarity/previous experience with different types of technology;

2. general attitude toward the use of technology, both low- and high-tech;

3. general technological know-how and infrastructure for technological support;

4. funding resources for technology and intervention;

5. potential resources accessible to facilitate intervention.

II. The needs and concerns of the individual and family in relation to those of the associational community or broader social contexts with respect to interaction with the individual with disabilities need to be described.

A. Specific needs in relation to present communication styles and functions of the individual, family and community interactions, i.e. an analysis of difficulties that need to be addressed.

B. Specific needs in relation to existing support systems for individual and immediate supportive context in relation to intervention.

C. Identification of barriers in physical environment, particularly in relation to wheelchair access and physical resources that inhibit functioning in the different contexts.

D. General needs in relation to technology:

   • exposure and experience that might be needed;
   • general attitude/knowledge in relation to technology, both low- and high-tech;

- knowledge and skills needed for technological know-how and infrastructure for technological support;
- financial needs to address intervention.

III. Technological considerations: characteristics and resources of specific devices/systems. This refers to a consideration of the different technological options available (low- and high-tech) and the potential matching of different kinds of technologies within the individual, immediate supportive and community contexts in relation to the following.

A. Different technological options that need to be considered (low- and high-tech).
B. Existing supportive infrastructure for training and maintenance of particular devices.
C. Cultural orientations and perceptions surrounding the use of technology.
D. Matching needs and resources with technological options in moving towards decision-making.
E. Training and support needed for implementation of technology and resources to comply.
F. The formulation of criteria for success in the implementation of the device/system.

In addition to the analysis of resources, needs and technology options, however, specific attention needs to be paid to the orientation and resources for the use of technology within the broader cultural and policy context. Interventionists need to assist individuals and families to understand the need for involvement in and support of the technological support system within the community to ensure sustainable use of technology. This would include:

A. Support and maintenance of technology within the broader cultural (social and physical) context.
B. Support structures for mainline computer/electronic equipment.
C. Support structures for dedicated communication devices.
D. Attitudes of distributors and business towards developing further infrastructures for specialized technology.
E. Distance of infrastructures from the user in the community.
F. Availability and know-how of upgrading facilities for users.
G. Specific government policies in relation to AT:

- general policies integrating comprehensive service models with more specialized services (like dedicated AT devices – see Introduction and Chapter 2 about the integration of comprehensive and selective or specialized services);

- policies regarding general funding of devices;
- range of devices and availability of devices to be funded;
- policy in support of the development of support structures for AT.

From the above it is evident that knowledge about the political and social policy and cultural framework in which the three main intervention components function is an essential part of meaningfully integrating communication devices within the lives of the individual and community. This does not mean that individuals with substantial financial means can't continue to buy in expertise from other parts of the world to support an individual family member in a rather isolated way. The point is that sustainable AAC intervention and AT provision require a specific awareness of interventionists of the need to use opportunities in intervention to work for the broader good of the community. There needs to be a definite sensitivity towards the need for regarding AAC technology as part of the personal, social and economic development of a country.

Supportive infrastructure: support within the broader community context

The intervention team needs to consider the existing supports for technological and training support for the use of the AAC system. Available networks need to be identified as a basis for support for the use of the communication system. This implies that the socio-economic status of the clients and community as well as the values and cultural orientation towards communication and technology are key issues in guiding the decision-making process. Families need to be sensitive to the general cultural and community attitudes towards the use of technology (see Chapter 5), as an important step in understanding the demands of the intervention process on the individual and family. For example, a particular family might be interested in and able to afford a specific high-tech AAC device, while the community they live in is totally unfamiliar with this kind of device. In most low-income countries, sophisticated voice generating devices might fall into this category. The family then needs to be guided in understanding the implications and responsibility that surround a decision to acquire the device. Alternatively, if the family might not be in a position to assume the responsibility to access and maintain the device without strong local technological support, they might need to be guided to alternative solutions. The topics to be discussed include:

- an analysis of the existing supportive infrastructure for the use of this particular device – discussion of 'pros and cons' in long-term service of the device;

- the familiarity of the specific technology under consideration within the broader community context, thus the likelihood of the device being accepted by peers and others;
- the potential of a mismatch between what the family or individual wants and support for the technology within the broader community in relation to general attitude and technological know-how; specific ways to deal with this mismatch need to be explicitly addressed and financial and other implications highlighted;
- critical discussion of the sustained implementation of technology within the context, in view of the additional demands placed on the immediate supportive context in taking responsibility for the intervention; specific strategies for coping with these demands need to be developed;
- discussion of strategies of how this particular intervention experience can positively impact on the development of a better infrastructure for the implementation of AAC technology within the broader community context – social responsibility of working towards a common benefit for all (Pierce and Porter, 1996; Turner et al., 1997).

Vignette

Table 9.3 provides some examples of how this analysis could be summarized to facilitate decision-making. Although the focus in this discussion is on AT, it is important to stress that intervention should be seen as an integrated process, as discussed in Chapter 8.

The case study is about a young girl aged five years who is severely physically involved, who lives with her parents in a two-bedroom house in an urban, low–middle-income area. The mother is employed as a teacher and the father is a driver for a drugstore ('chemist's'). The young girl is attending a crèche or preschool during the day, but has very limited interactions with people in the environment.

From Table 9.3, page one can identify various issues that need consideration in decision-making on AAC technology within this context:

1. Choice of system: From this brief description it is clear that the young girl has a limited communication repertoire. This might indicate that starting off with a low-technology system, i.e. a communication board, could be the desired way – to establish first a firmer base of communication interaction, before moving on to more sophisticated technology. Issues in favour of starting with a low-tech system are:

   (a) Building a low-technology basis for AAC implementation has many advantages and should be stressed, particularly as technology can become dysfunctional and necessitates a back-up system.

   (b) A pattern of communication should be established between the child and others in the environment. Time needs to be spent to ensure people understand the concept of communication as development of meaning and contact between people, thus the process of learning to understand and to express as an integral part of human contact. The aids are tools to assist in the process. Parents and friends need to focus on communication and not the tool that is used to facilitate the process. Chapter 2 (Intervention issues) expands on this issue in emphasizing the difference between *sharing messages* and *involvement in communication*. It is important to point out that starting off with a more sophisticated device within the above methodological approach could also be most beneficial. In this particular case, within the context, low technology might be the more appropriate choice – at least for the initial stages of intervention.

   (c) Clearly resources for high technology are limited – and the compromises that might be needed at this point to obtain a digital device might make it less feasible. This does not mean, however, that a device could not be used most beneficially in future. Two issues need to be explored: first, the back-up for the device in relation to training and maintenance support and, second, the need for the immediate support network to be realistic about who are going to be involved in ensuring that the system is used and upgraded on a regular basis. There is thus a preparatory phase that is needed to ensure an optimal environment for implementation.

2. Child issues:

   (a) The child needs to become more involved in communication as a process of making contact, to learn how to develop meaning with people as the basis of intervention. Although the parents used a storybook before, the child has not yet been exposed to a communication board to facilitate her own interaction. The principles of the storybook could be used as a basis for extension to a communication board.

   (b) The child already has access to some adaptive toys – these could be extended to facilitate interaction with peers (Lane and Mistrett, 1996). Issues surrounding mobility in, for example, giving her access to participate in skateboarding activities with peers need to be considered (ibid.).

3. Parental context:

   (a) Parents are keen to obtain the digital device, to provide their child with a voice. While this is understandable, issues surrounding

unrealistic expectations in relation to the device and amount of effort to update and use the device for communication are vital for sustainable implementation. Parents thus need to be exposed to training and guidance to provide a more comprehensive idea of the role of the device in interaction. This is particularly necessary, as they do not at this stage seem to be oriented towards the use of technology in their house.

(b) Funding issues are important, as the parents need to realize that these devices might need upgrading at a later stage. Some guidance will need to be provided in relation to:

  (i) the development of strategies to approach the medical scheme for support, i.e. how to get them to reconsider financial assistance for a device;

  (ii) contact with other parent groups to promote issues relating to AAC devices within the context;

  (iii) investigating with the interventionist options for alternative funding.

4. Community/service issues:

(a) The company providing the digital speaker is rather small, with limited infrastructure. Long-term sustainability of the company is thus not clear. It is vitally important that these issues be discussed within a broader forum of AAC intervention within the community, to ensure systematic thinking and support for the development of a sustainable infrastructure. Interaction between the supplier, professionals and support groups thus becomes vital, to prevent 'there today, gone tomorrow' scenarios which are to the detriment of all involved.

(b) The use of AAC technology needs to be seen within the broader framework of AT within the policy contexts. The partners involved in the process also need to take the social responsibility to promote the development of AAC on a broader basis, to facilitate long-term sustainability.

(c) Parents and service-providers need to realize their pivotal role in assisting in building infrastructure (both social and economic) within a community.

5. Cultural issues:

(a) Although there is an emerging awareness of the rights of children with disabilities, these are still not well integrated within the

community context. For example, issues surrounding independence of young children with disabilities still seem to be inconsistent. The atmosphere for the use of more sophisticated devices might be positive, although the infrastructure and financial support is limited. This situation opens itself up to opportunities whereby parents and people with disabilities can obtain equipment without long-term meaningful support and back-up. These issues need to be most carefully considered by professionals before the acquisition of a device is finally recommended.

(b) The parents of the child are clearly prepared to put in effort in intervention; however, long-term they will need support. Building better support structures for intervention within the immediate and associational community thus needs to be part of the intervention process (see Chapter 8: Support-based AAC intervention).

(c) Building support clearly indicates moving beyond the individual child and family needs. The importance of parent-support groups to unify efforts to build infrastructure is critical.

6. Policy context:

(a) The team involved needs to plan and devise strategies to move beyond the immediate therapy room in facilitating and promoting the use of AAC technology within the community. The intervention with one child should thus be seen as an opportunity to work more actively towards 'common benefit to all by facilitating the development of broader infrastructures for children and parents in similar needs' (Wellman, 1988, p. 19).

(b) Joining lobbying groups on AAC and AT that can make meaningful contact with policy-makers are important.

(c) Influencing policy-makers, however, means going beyond specific interest groups. Interventionists and manufacturers need to realize the importance of influence beyond the small confines of disability groups, to bridge the gap between people with disabilities and the broader society. For too long, disability groups have communicated mainly among themselves; it is vital that these interest groups become stronger partners with other social-interest groups, for example those representing gender issues, human rights and crime prevention.

Table 9.3 Example of a synopsis of the analysis of resources, needs, and technology relative to the individual, family and social context.

Resources/capacities	Individual	Family	Broader associational context
1. Communication	At present the child uses some facial expressions and signs to indicate happiness and rejection.	The family communicates with the child by talking and asking yes/no questions.	She enjoys interacting with friends although communication is mostly restricted to laughing with pleasure when they are around. Few other communication exchanges.
2. Play	The child has a couple of adapted electronic toys that are operated with a single switch. She accesses them with her hands.	The family has developed a picture book that they enjoy reading with her.	She can play card games with them – provided they give her enough time to indicate.
3. Mobility	She walks with difficulty and uses a wheelchair most of the time.	Parents also have a pushchair to facilitate taking her shopping in the community. They find the wheelchair too big for local travel.	She is able to move around during play with her friends, but mostly sits on the side and watches when they engage in gross motor play.

Needs

	Individual	Family	Broader associational context
1. Communication	To express herself so that others can understand: she needs to express more than just basic needs.	To find an easy way to get the child to show what she wants.	To get her to engage in play with siblings and friends.
2. Eating	She eats all foods, but wants to be more independent. She often gets upset if people try to assist her.	Parents would like the child to become independent in eating.	Seldom eats with friends as she needs to be fed.

Table 9.3 contd.

Needs

	Individual	Family	Broader associational context
3. Mobility	She is able to walk, but often falls: she needs mobility support.	Parents place a great emphasis on her becoming more independent and mobile.	Friends are physically active – she needs to participate in skateboarding with her friends.

Technology

	Individual	Family	Broader associational context
1. Communication options	The child could use both a communication board and digital speaker (16 location overlay), which she accesses through direct selection, but she is slow.	Family prefers digital speaker to provide the child with a voice.	Friends are interested and open to the use of the digital device and communication board.
2. Play facilitation	Child uses switches to activate toys – battery operated. Computer games could be introduced.	Family is not oriented towards high technology. No computers at home.	Friends enjoy playing with battery-operated toys – and are keen on exploring technology.
3. Training and support	The child will need regular AAC intervention sessions to facilitate use of system. The interventionist will need to collaborate with educational and home contexts to facilitate implementation.	Parents will need training and support for implementation. Parents are not familiar with the technology, but are willing to learn.	• Some intervention time will need to be dedicated to train peers in interacting with the child. They could also assist in recording messages. • Teacher will need to be involved – encouraged to expand messages for the child. • Need to explore promotion of AAC technology within associational community – to familiarize and expand understanding.

Table 9.3 contd.

Community context	
General description	Average low–middle socio-economic area. Health services are available, although inconsistent AT support from government hospitals. There are companies doing technological support in their community, but these are mainly IT companies. There are existing companies importing technology for the blind, but there is limited back-up support for AAC technology. Generally, technical support for digital speakers is limited, although sophisticated mainline computer technology is freely available in the community. The company importing this particular digital speaker is small, unstable and has limited training and support infrastructure.
Physical home environment: resources and needs	The family home is wheelchair-accessible; however, there is little awareness of issues surrounding making the physical environment more accessible to the child: generally cupboards are difficult to open and not in reach. Independence for the child is clearly defined within specific areas.
Physical community access: resources and needs	The physical environment is reported to be mostly wheelchair-friendly – there are lifts in most shopping centres. Public transport, however, is not wheelchair-friendly. Parents reported difficulties in taking the child to public parks or movies in a wheelchair.
Cultural context	• Independence is valued in certain contexts; for example, the parents are keen to have the child less dependent within the eating and playing contexts. Broader independence within the home environment, e.g. being able to access toys and food from cupboards, is not a priority. • There is a positive attitude towards the use of technology – it is encouraged, although the infrastructure and knowledge about specialised technology is limited. • Attitude towards disabilities reflects a strong emergence of human rights issues within the community, with consequent opportunities for education and training, but infrastructure for support is limited.
Socio-economic context: resources and needs	• The parents do have medical scheme benefits, but the medical aid indicated that it is unlikely that they will be willing to pay for a communication device for the child. The family mostly uses private medical services, which is costly, but they prefer not to use government hospital services, owing to long queues. • They are not aware of any other funding systems in the community for AT. • Parents themselves are not able to afford a device, but want the best for their child. Parents are willing to approach funders to raise money to try and obtain funding for the device, but have never done this before.

Challenges of AT within the context of low-income countries

From the above case it is clear that there are some general issues in implementation of AAC strategies that need serious consideration.

The role of the AAC interventionist in promoting AAC in a more sustainable intervention context

Professionals need to move beyond individual implementation, broadening the intervention process to facilitate the development of a meaningful support structure for the individual and others in similar positions. Professionals, individuals with disabilities, the immediate support structures as well as community associations involved need to plan strategies to address issues surrounding a social definition of intervention. The intricate needs of the different communities and individuals in relation to assistive communication devices need to be understood. These needs also have to be accommodated within a support-based approach and an understanding that is not exclusively based on a deficit model of intervention. Empowerment implies development from a position of strength.

Dedicated and non-dedicated devices

From the above case study it is clear that the community has more infrastructures in coping with mainstream information technology. A PC-based communication system therefore could potentially be accommodated more readily in relation to long-term sustainability. It is not the intention to delve into issues surrounding dedicated versus non-dedicated devices in this chapter; however, it does remain an important issue to consider in the recommendation of AAC technology. The limitations of the recommendation of non-dedicated devices are well known as interventionists try to use a broadened forum to address specific communication needs. This could lead to a device that is used for general educational purposes, but has limited use for personal communication. The philosophy of communication as an interpersonal process needs to be stressed in the application and use of these technologies for AAC intervention.

Balance between 'transferring' and 'local development' of technology

The broad range of needs require an open-minded approach to AAC technology. Transferring Western technologies to low-income countries (Kahen and Sayers, 1997) and the development of local technology are

important. Costs remain important, and clearly in most low- or light-technology options, local development remains a potential solution. Using local resources for maintenance and service is vital to ensure meaningful long-term intervention. Private initiatives or businesses need to facilitate the development of infrastructures for technology in addition to providing assistive devices to individuals.

Potential mismatches between needs and resources of immediate support network and community

As in the above case, the potential difficulties of a mismatch between what parents would like for their child and the existing infrastructure for support in the community should be identified and discussed. Clearly, it is the decision of the parents and young child as to what system they would like to use. It is, however, the responsibility of the AAC interventionist to ensure that they are realistic about the implications and future responsibilities that the decision might bring. Guidance needs to be provided to the parents and young child in addressing issues within the environment to facilitate successful implementation (see the involvement of the associational community in intervention in Chapter 8). This issue accentuates the difficulties in dealing with a needs-based approach to AAC implementation: whose needs are to be addressed and how relevant are they to the community within which the individual is living? (See Chapter 2 on difficulties with a needs-based approach towards intervention.)

Accept heterogeneity in communities

Communities are heterogeneous and this implies that interventionists need to understand the interrelationship between individual and community needs. It is to be expected that what could be meaningful to an individual or family might not be relevant to others in the community. A variety of AAC technology solutions need to be accommodated within countries to allow for diverse needs; however, the focus and priorities need to be one of broad-based development.

Role of professionals/service in developing an infrastructure for technological support

From the above it is indicated that professionals rendering services have a most important role to play in the development of a sustainable infrastructure for technological support in collaboration with the providers, training institutions and policy-makers. This does not mean that they need to take primary responsibility for these actions, but that they need

to realize the importance of their involvement in assisting parents and disability stakeholders in furthering the cause in the community. They need to become more oriented towards the development of strategies with major disability partners in ensuring that intervention is sustainable and appropriate to the local context. Professionals need to understand the relevance of Rogers' (1995) diffusion of innovations theory in AAC implementation (knowledge, persuasion, implementation and confirmation) to plan and develop infrastructure for technology. The level of knowledge and the nature of knowledge that would be relevant need to be considered, together with the kinds of attitudes that prevail in relation to disability and AT.

Collaborative framework

AAC technology needs to be introduced and supported within a collaborative international and national framework. Intervention and development of AAC technology need to be positioned within a framework of facilitating self-sufficiency, self-management and self-development. This requires close co-operation between local associations, disability groups, training organizations and manufacturers. The model of Riedijk (1987) should thus be explored further in assisting low-income countries in developing more sustainable contexts for AAC device implementation.

Conclusion

Clearly the debate surrounding AAC devices and sustainability of use is an important one that needs to be expanded to facilitate a better understanding of the issues involved and to move towards better descriptions of strategies for implementation. To achieve this will require that AAC interventionists, manufacturers and communities as well as policy-makers come together, particularly in contexts with limited technological infrastructure, to engage jointly in strategic development. Although small steps and small actions are important as part of the bigger vision, one needs to ensure that these steps and actions are within a strategic context that moves from purely individual business interests to more long-term sustainable provision and support (see Chapter 15). The benefits of AAC technology have been demonstrated; addressing issues to make the use of it more sustainable, however, requires further research and innovative ideas.

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CHAPTER 10
Family-centred early childhood intervention: new perspectives

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This chapter describes a family-centred early childhood approach to intervention by describing an international as well as a poverty perspective. The different roles of the family within the intervention process are described, i.e. the family as decision-makers, the family as communicative environment, the family as consumers and the family as trainers. The different roles and tasks assigned to the family, as well as the goals for intervention, are discussed in relation to the effectiveness, sustainability and versatility of communication intervention. Finally, the impact of communication intervention on the family system is discussed.

Around the world most cultures have proverbs and metaphors conveying a firm belief that providing early support to young children and their families has a positive impact not only on children's development but also on later development in adult life (Odom and Kaul, 2003). Implicit in this belief is an understanding of the important influence that child–adult interaction and relationships have on all development and thus the importance assigned to family life.

Early childhood intervention constitutes services provided to young children and their families with the aim of increasing the probability that young children at risk or with established physical and/or mental conditions function and develop as well as possible. The age groups included, as well as the target groups for services, vary between countries (Björck-Åkesson and Granlund, 2003). A common age span is birth to start of school (5–7 years). Traditionally, early intervention services focused on the child. In the last decades the family and other environments containing children have been the focus of interventions (Guralnick, 1997).

A common trend in the analysis of outcomes of forms of early childhood intervention has been a change of focus, from interventions aimed at preventing disease and disability toward interventions aimed at promoting health. This general trend is reflected in the World Health

Organization's (WHO) classification system, the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The classification encompasses functioning as universal human experience conceptualized and classified at three dimensions: body function and structure, the performance of personal activities, and participation in close environments and communal life. The facilitating or restricting role of the environment is recognized and forms part of the classification. As a consequence of this shift of paradigm in early childhood intervention, the focus has changed from medical diagnosis to the functional consequence of health conditions in terms of participation and engagement in life situations.

The child's environment changes across the stages of infancy, early childhood, middle childhood and adolescence (Simeonsson et al., 2003). Each change is a product of previous child development, environment and child–environment interaction and affects future child–environment interaction. Child–environment interactions occur at the nodal point between the child and the environment. These nodal points are named *developmental niches* (Super and Harkness, 1999). A developmental niche is characterized by three components: (1) the physical and social settings in which the child lives; (2) the customs of child rearing and child care; and (3) the values and beliefs of care-providers that define parenting practices. A focus on developmental niches in early childhood intervention requires more attention being paid to parents' values and beliefs about raising their children and the typical activities in which children engage. A desired outcome of early intervention is child participation or engagement in the activity settings surrounding the child. Children who frequently engage in everyday activities in their preschool years are perceived as more competent by their teachers in the first years of school than less engaged children (Tudge et al., 2003). The patterns of time children spend in different activities are associated with both poverty and ethnicity (Tonyan and Howes, 2003). The proximal environments of the child such as family context and other care contexts need to be involved in the planning and implementation of early intervention. A review of early childhood intervention programmes (Shonkoff and Phillips, 2000) indicates that programmes offering both a child and a family component are more successful in promoting long-term developmental gains for children from low-income families.

Early intervention in a poverty perspective

The association between poverty and child development is a complex relationship receiving increased attention over the past decade. The number of families living in poverty or relative poverty is on the increase, not only in low-income countries, but also in industrialized contexts (Bradley and Whiteside-Mansell, 1997; Brooks-Gunn and Duncan, 1997). Most studies on poverty and child development are, however, rather unspecific in the description of poverty, and the nature of the poverty – i.e. intermittent (transitory) or persistent (chronic) – is often not well described. The majority of studies use a one-time measure of poverty, which often underestimates economic hardship and poor development (Brooks-Gunn and Duncan, 1997; Philips and Bridgman, 1995). Dealing with families in an early childhood intervention context, however, necessitates a more in-depth understanding of the duration or nature of the poverty, as families living in persistent poverty are demographically different from those living in transitory poverty. One of the main differences between these groups relates to the neighbourhoods they live in and the consequential stresses induced by the environment. Families living with persistent poverty are 'trapped in neighbourhoods that are unsafe for their children. These families experience more conflict and suffer psychological distress associated with long-term stress' (Bradley and Whiteside-Mansell, 1997, p. 18).

The effects of poverty on the health and development of young children are well recognized as the association between persistent poverty and a variety of developmental delays become clearer. Findings indicate a higher probability of infants born prematurely or with low birth weight. Increased in-utero toxicity, a higher incidence of exposure to HIV/AIDS, psychiatric disturbances and maladaptive social functioning are but some of the factors describing the broad impact of poverty on child and family health (Bradley and Whiteside-Mansell, 1997; United Nations Children's Fund (UNICEF), 2001). Clearly these factors are also closely intertwined with the socio-economic and environmental contexts and stresses within which the family resides. In addition to an increase in health-related problems in children reared in poverty, the severity of health conditions are often more pronounced (Parker et al., 1988). The specific impact of poverty on children's health and development is, however, difficult to predict as poverty so frequently co-occurs with other conditions (for example, teenage pregnancies, single-parent families, social exclusion). The specific association between co-occurring factors and poverty is also not easy to describe, as co-occurring factors (for example, disability) can be a cause of poverty just as the co-occurrence of poverty can be a consequence of disability. Chapter 4 discusses this issue in detail.

Families living in poverty experience less control over their lives, as they are more exposed to crime, violence, illness, death and inadequate housing. Thus, the impact of poverty on families and children is partly indirect; in interaction with family resources and strengths it affects the family's ability to handle their life situation (Shonkoff and Phillips, 2000).

These strains not only cause frustrations and stress, but also often lead to social isolation and exclusion (Gracia and Musitu, 2003). Distrust between families within communities and lack of social cohesion contribute to increasing lack of communication between families within communities. The impact of poverty on family life is extensive, as families suffer not only from lack of economic and human resources, but also from lack of social capital or networks that can facilitate access and use of existing resources (Gracia and Musitu, 2003; Hanson and Carta, 1995). One can summarize generally by stating that research indicates that poverty and economic hardship lead to less access to material resources and social services, increased likelihood of encountering other adverse conditions, depletion of psychological resources and a breakdown of connections with other supportive agents (Bradley and Whiteside-Mansell, 1997).

The impact of poverty on families and children emphasizes the need for partnerships between the family or community context and the interventionists as part of the intervention process (McConkey, 1995; Thorburn, 1987). The intervention partners must develop not only a sound understanding of the young child with special needs, but also of the resources and stressors within the family and environment to facilitate the development of appropriate intervention strategies that will benefit all involved. Multiple difficulties, poverty, severe tensions and sheer exhaustion make parental involvement a difficult proposition in low-income countries. In these communities, there may be little surplus energy or compassion to spare. McConkey (1995) expands on this by pointing out that early intervention schemes are often constrained by what the family has to cope with, rather than possibilities envisaged by the service workers.

For early childhood intervention to work, particularly within poverty contexts, the family and other participants in the process must understand the mutual benefits of the process, and focus on expanding the family's capacity to access and use internal and external resources. Only by acknowledging the role of social networks and family structure as part of the intervention process can interventionists facilitate long-term impact.

The model of family-centred intervention potentially provides the interventionist with a framework flexible enough to venture into diverse social contexts to facilitate the development of more congenial environments for young children to grow up in. Different ways in which families can participate in this process will be discussed in more detail.

Family-centred intervention

In early childhood intervention a trend away from professional-centred intervention towards family-centred intervention can be observed (Guralnick, 1997; Osher and Osher, 2002). There is, however, no clear consensus on what constitutes a family or on what constitutes family-centred intervention.

Osher and Osher (2002) reviewed North American literature on family-centred intervention. They conclude: 'a family is defined by its members' and 'can include biological or adoptive parents as well as foster parents and their partners, siblings, extended family members (kinship care-givers), and friends who provide a significant level of care and support to a child or primary caregiver' (p. 48). That is, a family can only be defined in relation to the context in which it is embedded and in relation to the functions it is meant to fulfil. In an ecocultural framework the basic unit of analysis is the *activity setting* (Gallimore et al., 1996; Harry, 2002). By attending to activity settings – family events, attitudes, physical setting – of families in relation to social and cultural practices, sustainable communication interventions can be designed. According to Harry (2002) the pattern of findings in reviews of studies concerning early childhood intervention outcomes for children from culturally diverse families points to greater familial and religious support within ethnic-minority families characterized by extended family systems. The results indicate the positive consequences of adopting other definitions of family than the traditional Euro-American nucleus family (father, mother and children). A comparison between poverty settings and middle-class settings probably will reveal that children in poverty spend more time in a family setting (including informal kinship care) while children in middle-class settings spend more time in formal child-care. Thus the impact of the family setting on child development is seen as relatively greater in poverty.

Concerning family-oriented services, Dunst et al. (1991) conducted a meta-analysis with a multimethod and multisource approach to bring clarity to how family-centredness is expressed. They used a classification system of concepts in which family-oriented services are a super-ordinate concept for describing four types of services, from professionally centred to family-centred, see Figure 10.1 (from Carlhed, 2003, adapted from Dunst et al., 1991). The four terms represent different degrees of family involvement on a continuum of family influence.

In Figure 10.1 the arrow describes the degree of family control. For example, the family-centred model is consumer-driven and the interventions are almost entirely designed to increase the family's strength and competence. Professionals are seen as change agents. On the other side of the arrow (the professionally centred model), professionals are seen as

FAMILY-ORIENTED SERVICES

family-centred	family-focused	family-allied	professional-centred

High   degree of family ascendancy   Low

Figure 10.1 Models of family-oriented services in conjunction with degree of family ascendancy. Adapted from Dunst et al., 1991.

experts who determine the needs of the family. The family-centred model is most consumer-driven, whereby professionals maximally promote family decision-making to encourage the family's own strengths and empowerment. The concept of *empowerment*, in this context, means supporting families to increase their involvement in and their control over the intervention process. There seems, however, to be a lack of consensus in defining the empowerment concept (Dunst, 2000). A basic question is whether empowerment is to be seen as an outcome of family-centred intervention or as a description of family-centred practices (Carlhed et al., 2003).

Bailey et al. (1998) argue that relationships between families and professionals are all addressed in isolation – without reference to the process–outcome distinction. Although some studies address desired outcomes, very few focus on the specificity of outcomes or on measuring pathways to different desired outcomes in early childhood intervention. Documentation of different ways to implement family-centred practice is more common, but there is still a need for knowledge about how they relate to measurable outcomes (Dunst, 2002).

In an effort to understand the construct family involvement in intervention, many studies emphasize different aspects of building good relationships between professionals and parents (e.g. Bjerre, 1998; Carlhed et al., 2003; Dinnebeil et al., 1996; McWilliam et al., 1998; Stenhammar and Ulfhielm, 1998; Weston et al., 1997). Some of these studies aim to evaluate outcomes of family-oriented services, family orientation or family-centredness in early childhood intervention. The family orientedness itself is sometimes regarded as the result of the collaboration process (e.g. Bjerre, 1998; Wadsworth et al., 1994). In fact, these evaluations are dealing only with the process in parent–professional collaboration. Outcomes are assessed with parent satisfaction measures, which can be seen at first glance as appropriate and easily accessible. However, the meaning of the responses is difficult to interpret because parents have minimal ground for comparison (Simeonsson, as cited in

Bailey et al., 1998). In addition, desirable outcomes in relation to satisfaction must be explained. If professionals work in a family-centred manner, parents may become active in the process, but that does not indicate parents perceive the relations with professionals as good. Neither does it indicate that the family fulfilled family needs or gained more knowledge about their child (Carlhed, 2003).

In relation to early childhood communication intervention, the different roles and missions assigned to the family, different models for service delivery, and possible outcomes of communication intervention are important to discuss. In Table 10.1 different focuses, desired outcomes and methods of early childhood communication intervention are displayed, and related to the roles and tasks of parents and professionals in intervention (adapted from Granlund et al., 2001).

Table 10.1 The function of communication intervention in the family system

Focus	Goal/ objective	Professional role in intervention	Role assigned to family	Family task
Family as decision-makers	Family perceive control over the intervention process	Provide opportunities for control; teach problem-solving strategies	Decision-maker, service co-ordinator	Define problem; design goals and methods; select from service options; evaluate
The family as communicative environment	The child interacts optimally with persons and objects within the close environment	Family members are given advice, adapted toys etc. and interaction coaching	Providers of 'rich environment', interaction partners	Adapt environment to needs of child with disabilities
Family as consumers	Fulfilled family needs	Assess needs; fulfil needs	Recipient of services	Identify needs; use available services
Family in crisis	Family have a normal family life-cycle and 'accept' actual child, e.g. cope with grief reactions	Crisis therapy; help family redefine behaviour of child with disabilities	Patient, client	'Solve/cope with emotional reactions'; interpret and interact with child in a realistic fashion
Family as trainers	Increase in child skills within specific area	Teach training programme; supervise parents	Student, trainer	Implement programme designed by professionals

Family as decision-makers

In communication intervention services the active participation of the family in the decision-making is stressed. The family and the child with disabilities can experience a sense of forming their own life (life projects, lifestyle etc.) and continuity in the services obtained (Gallimore et al., 1996). Professionals must view families as equal partners, help parents develop positive prospects for the future and have pertinent information available (Knox et al., 2000). However, these professional skills must be performed in a manner enhancing the cultural fit between family and services. Harry (2002) states that working within a family's zone of proximal development means 'finding out that family's stand on a given issue, such as the goal of independence for the member with a disability, and working to enhance independence in the family's terms' (p. 137). Professionals must be aware that parents of children with disabilities have positive perceptions of their life situation (Hastings and Taunt, 2002), some of which are not at all related to the child or the disability. Positive perceptions function as strategies helping families to adapt or cope with the experiences of raising a child with disability.

Family as communicative environment

Families organize and shape their members' activity, function and development through daily routines. In creating and maintaining routines, families respond to sometimes conflicting circumstances. This process is called family accommodation (Gallimore et al., 1993; Leskinen, 1994). The everyday routine does not exist in a social vacuum: it is shaped by surrounding eco-cultural features. Such features are: family subsistence and financial base, accessibility to educational and health services, home security and convenience, domestic task and chore workload of the family, care tasks related to family members, social leisure activities, marital role relationships, social support and sources of information and goals (Gallimore et al., 1996). Accommodation of these features is a process common to all families. Accommodations made depend on many factors including ecological constraints and resources, cultural beliefs, and customs. Intervention is aimed at the construction and maintenance of daily routines containing interactions through which the child develops and functions. That is, intervention recommendations include how the parents should interact with or train the child in conjunction with everyday routines (Granlund and Olsson, 1999). Such interventions are of low intensity and long-term duration. They must be sensitive to other types of adjustments made by the family over time. Specific interventions not implemented or sustained are probably not well fitted to the existing daily routine and the many adaptations the family are already making (Parette and Brotherson, 1996; Singer, 2002).

In a review of the findings from early intervention for families with low socio-economic status, Allen et al. (1984) identified factors that reduced the effectiveness of intervention: (a) professionals' emphasis on verbal skills in interacting with children; (b) mother having less 'teaching style' in the mother–child interaction in comparison to professional–child interaction; (c) parental beliefs being less positive regarding the effectiveness of early intervention; and (d) the negative perception of the disability. They conclude that early intervention promotes a middle-class-style interaction; therefore, mothers of lower socio-economic status have to make greater (maybe too-great) changes in their behaviour when implementing recommendations. This conclusion is supported by the findings from an evaluation of early intervention made by McDowell et al. (1995). They found that within a subgroup of low-income families, formal support was related to increased levels of stress. Only higher income was significantly related to decreased levels of stress.

Family as consumers

In adapting to their circumstances, families tend to express needs – they ask for possible solutions to the problems they are experiencing (Bailey and Simeonsson, 1988; Granlund and Roll-Pettersson, 2001). Professionals must be careful not to make the family dependent on them for solutions. To avoid dependency, four characteristics of need identification must be taken into consideration (Dunst et al., 1994): (a) the family must decide something is not as it ought to be; (b) the family decides that the discrepancy is or will influence the family's or the child's function; (c) the family must know there is a resource that will reduce the discrepancy between what is and what ought to be; and (d) the family must recognize that there is a way of procuring a resource to meet the need. Families tend to ask for solutions they have knowledge about (e.g. speech therapy) rather than describing the problem they are experiencing and allowing professionals to identify the desired solution as the problem (e.g. not enough speech therapy) rather than as the solution (Carlhed et al., 2003). Professionals, as well as families, must be skilled at defining the problem by reasoning backwards, from asking for a solution to expressing the problem in terms of the difference between how it is and how it ought to be. Professionals must also be skilled in how to convey information to parents in an efficient manner (Singer, 2002).

Family in crisis

The birth of a child with disabilities may be an affliction to members of the family, and an adaptation process is then started. Different families and individuals within families tend to cope with the adaptation process in ways of varying competence: for some family members it is a burden

while for others it is a crisis leading to positive changes in life (Grant and Whittel, 2000). The degree of 'crisis' experienced by the family tends to vary over time, depending on personality and life history of individual family members, life circumstances and critical events (Ferguson, 2002; Roll-Pettersson, 1996). A long-term follow-up of families with children with disabilities and those without children with disabilities revealed that no differences in terms of family well-being were found between these families when the children were 30–40 years old. Families with children with disabilities reported a smaller and less-supportive social network (Mailick-Seltzer et al., 2001). Probably culture and acculturation are strong predictors of parental reaction to having a child with disability in the family. In attempts to delineate coping strategies, degree of emotional distress and acceptance of the disability of a family member have been compared between families of different ethnic origin. According to Harry (2002) the reviews reveal that North American parents from minority groups (Mexican-American and African-American) are more accepting than European-American parents. Over time, the family and the individual family members develop coping mechanisms that help them when 'crisis' is experienced, i.e. versatility. With experience most families change their coping strategies from stress-reducing strategies toward cognitive and problem-solving strategies (Grant and Whittel, 2000).

Communication intervention with a crisis focus is aimed at redefining (explaining and interpreting differently) the behaviour of the child with disabilities, thereby changing the way family members respond to and interact with the child. Thus the active participation of parents in defining interactional problems and in assessing the communicative skills and resources of the child is important. Research shows that redefining interventions focused on child–parent interaction have positive effects only when the parents state a need for help with interacting with their child (Affleck et al., 1989; McCollum and Hemmeter, 1997). Services will be a burden if the fit between family preferences and services provided is poor (Ferguson and Ferguson, 1987).

Family as trainers

When family members are assigned the role of trainer, the professional's task is to teach training rationale and training skills to the family member, who then applies the learned skills in training the child with disabilities. In implementing training recommendations the parent must adhere to a set of training methods for which the outcome is predetermined. The professional is seen as an expert who defines the goals and methods for intervention. This often requires considerable adaptation of family routines and parental/spouse commitment for extended time periods. In

communication intervention, the outcome of such training programmes seems to be positive on the child's language development but the effects on the child's interaction skills and actual interaction patterns are not well documented (McCollum and Hemmeter, 1997). The effects of commitment to a training programme on family functioning are reported as both positive and negative (Ketelaar et al., 1998). In outcome studies of positive behavioural support interventions, a lower degree of success is reported for families from diverse cultures and families who experience multiple risk factors (Forehand and Kotchick, 1996). This may be because efforts to sustain a functional family routine drain the system of resources otherwise used for training the child.

In summary, the focus chosen for intervention has consequences for both the desired outcome of intervention and the role assigned to the family. Accordingly, the impact of communication intervention on the family's system will vary depending on the focus for intervention and the family's perception of needs for support.

Effectiveness, sustainability, versatility and family-centred intervention

The different roles and tasks assigned to the family, as well as the goals for intervention, will relate to the effectiveness, sustainability and versatility of communication intervention (see Table 10.2).

Table 10.2 Effectiveness, sustainability and versatility in family-centred communication intervention

Focus	Goal/ objective	Professional role in intervention	Role assigned to family	Family task
Family as decision-makers – the basis for developing *versatility*	Family members are actively involved in and perceive control over the communication intervention process over an extended time period	Provide opportunities for involvement and control in intervention planning Teach problem-solving strategies Give advice regarding resources available	Decision-maker Implementer Service co-ordinator	Identify and explain problems, design goals and methods Identify resources and select from pool of resources, depending on type of problem Evaluate outcomes and revise intervention

Table 10.2 contd.

Focus	Goal/ objective	Professional role in intervention	Role assigned to family	Family task
The family as communicative environment – the basis for *sustainability*	Family members have knowledge about goal–method relationship and can revise goal and/or method when circumstances so requires	Parents/spouses are given advice, adapted toys etc. related to identified problems; supervision and interaction coaching in implementing method	Providers of 'rich environment', interaction partners; revise method depending on changes in child or family competence	Stimulate child with disabilities; adapt environment to changing needs of child with disabilities; use necessary resources to sustain effect
Family as trainers – the basis for *effectiveness*	The family has good knowledge and skills concerning how to train a specific skill and how to evaluate behaviour change in relation to intervention goal	Design intervention method after goal decisions have been made; teach training programme to family members; supervise parents in implementing programme	Student Trainer	Implement programme designed by professionals; evaluate outcomes in relation to pre-set standards

Effectiveness relates to the demonstration of behaviour changes as a direct consequence of intervention (Schlosser, 2003; Schlosser and Braun, 1994). In relation to family roles and responsibility, effectiveness primarily implies that the family is assigned the role of trainer. The outcome at family level is defined as gains in knowledge and skills concerning how to implement and evaluate a specific communication intervention (Carlhed, 2003). Effectiveness requires a certain amount of professionally or expertly focused service provision as well as a good cultural fit between the recommended intervention and family activity setting.

Sustainability refers to the length of time the change in behaviour of the individual or family is maintained when direct intervention is not provided (see Chapter 2: Intervention issues), i.e. when professionals are not involved. It relates to the infrastructure available to encourage the use and extension of the specific individual's skills when direct intervention is withdrawn. For sustainability at the family level, family members must be knowledgeable about goal–method relationships and the skills to revise goal and/or method when circumstances so require. To reach this outcome the family must have pertinent information readily available

(Knox et al., 2000), control over the intervention, and continual access to necessary resources (Dunst, 2002). For professional sustainability professionals must build a partnership with the family and support family members in decision-making (Carlhed et al., 2003) within changing circumstances.

Versatility refers to the relevance of intervention in relation to building individual and community skills in coping with change that forms an integral part of the process. It is the ability to manage change over time, and use past experiences in problem-solving new or different problems. The issue of changing needs and circumstances of the individual and family over time is central to this component, and relates to the ability to address changing needs (see Chapter 2: Intervention issues). When family members are actively involved in and have control over the communication intervention process over an extended time period, they develop skills to identify and explain problems, design goals and methods for intervention, identify resources necessary to solve the problem, evaluate outcomes, and revise intervention (Grant and Whittel, 2000). Critical for the development of versatility are family members' ability to identify and delimit problems (Coulehan et al., 1998) and identify resources necessary to solve the problems (Bennet et al., 1998). It is also critical for professionals to allow families to play an active part in all steps of intervention circles, and to provide support fitting the families' knowledge base and values.

Versatility and communication intervention based on collaborative problem-solving

The empowerment theory (Rappaport, 1987) addresses such complex realities of life as identifying everyday problems to be solved and the resources necessary to solve them. According to Björck-Åkesson et al. (1996) empowerment theory implies that:

- many competencies are already present or at least possible – given niches and opportunities;
- what one sees as poor functioning may be the result of the social and physical structure of the environment as well as lack of personal resources, which make it impossible to use existing skills to reach desired outcomes;
- to increase an individual's competence, changes must be made in a context of real-life activities rather than in artificial settings (Rappaport, 1981).

In early childhood intervention, identified problems as well as their solutions are divergent. It is possible to identify many different problems for

the child and the family as well as several solutions for each problem (Rappaport, 1981). To reach consensus regarding intervention plans it is important that all significant persons in the close environment of the child participate actively in all steps of the intervention process. An intervention circle involves eight steps recurring over time: problem description, problem explanation, problem-ranking, goal-setting, intervention design, implementation, evaluation of implementation, and outcome (Björck-Åkesson et al., 1996). By repeatedly participating in these steps family members will develop skills in how to manage change following from child development and life circumstances, i.e. they develop versatility. The eight steps of the intervention process must be clearly declared and allow for mutual information exchange and knowledge transfer between family members and professionals (Björck-Åkesson et al., 2000).

A problem is defined as 'the perceived difference between the existing state and a desired state within a specific context' (Björck-Åkesson et al., 1996, p. 328). In parent–professional collaboration, defining the problem can be described as a negotiation phase (Stewart et al., 1991) aimed at finding a usable problem definition co-constructed between professionals and family members. How the problem is defined often determines the interventions applied. Thus, the professional must be attentive to everyone's view of the problem and translate the views into a working definition everyone agrees upon. Under the course of intervention (i.e. from entering to leaving early childhood intervention) the problem undergoes considerable change. As the problem is continuously redefined so are the causes and, as a consequence, the methods of intervention. One can say problems and causes become virtually indistinguishable (Friedlander and Heatherington, 1998). The first identified problem (e.g. Down syndrome) may be used to explain a second problem (i.e. delayed language development). This delay, in turn, may be used as an explanation of a third problem (e.g. low frequency of peer interactions). With the passage of time, parents tend to change perspectives on what constitutes the problem. The child's body and impairment are often considered the problem for parents with infants (e.g. 'my child has a motor disability'). For parents with preschool children, functional consequences of the impairment (e.g. 'my child can't participate in outdoor activities with peers') are often considered the problem (Carlhed et al., 2003). Therefore what constitutes a problem is partly defined by the context and timeframe in which the child lives (Wachs, 2000). For this reason, defining the problem is an ongoing process and short-term goals are probably more functional in the long run both for the child and for the family.

Problem explanations can be defined as information about factors hypothetically increasing or decreasing the probability of a certain

outcome (Björck-Åkesson et al., 1996; Wachs, 2000). According to modern developmental psychology most outcomes of child development processes have several causes that are structurally related (Sameroff and Fiese, 2000). The number of factors pulling the developing system (i.e. the child) in a certain direction is a better predictor of the outcome than any single factor. Since communication is a transactional process, it is more important to identify several factors that can be manipulated in intervention than it is to establish specific cause–effect relationships. In addition, results from attribution theory research indicate that external, unstable and specific causal attributions increase the probability of psychological well-being for adults (Seligman and Csikszentmihalyi, 2000). Results from family therapy research report that a common positive outcome of family therapy is a reframing of problem explanations from internal stable (impairment) and personal characteristics to interpersonal/ interactional (environmental) and caregiver characteristics (Coulehan et al., 1998). In conclusion, to reframe family members' causal attributions for child communicative problems, it is important that the family members participate actively in the assessment of child-care interaction as well as in the assessment of environmental factors. Relatively few assessment instruments focusing on communication interaction and/or environment are structured in a manner that stimulates parents' participation in the process (Olsson and Granlund, 2003).

Following the identification of several possible communicative strengths and problems to address in early childhood intervention a decision is made regarding the ranking of problems in the order they need to be solved. Dunst et al. (1994) describe four characteristics of need identification that need to be considered in ranking:

- There must be a concern that something is not as it ought to be.
- The recognition of a discrepancy between what is and what ought to be is not sufficient unless family members make a personal judgement that the discrepancy is worth intervention.
- There must be an awareness that there is a resource available that will reduce the perceived discrepancy.
- There must be a recognition that there is a way of procuring the resource necessary to meet the need.

The identified characteristics suggest that parents' ranking of problems in the order in which they need to be solved are based on parents' earlier experiences and skills in solving child and family problems, as well as on expectancies for the future and the information about resources readily available. Thus, professionals need to relate to parents in a manner that is sensitive to parental expectations, and provide the necessary information on the resources available for solving problems.

Goals set for early childhood communication intervention should ideally be equal to the desired outcome as stated in the difference between the present state and the desired state (Granlund and Blackstone, 1999). The goal is preferably phrased in terms used by the family members and should be short term (Björck-Åkesson et al., 1996). Long-term goals tend to be diffuse and too general in scope (Granlund and Olsson, 1999). A key issue for professionals is the relationship between specific intervention and practice from a lifespan perspective. Desired outcome of action tends to vary rather quickly over time for all human beings. All the different desired outcomes do, however, tend to apply to certain themes depending on personality, interests and life situation. In research focusing on social cognition, concepts like *lifestyle* are used to describe such behavioural themes; another related concept is self-determination (Wehmeyer, 1997). Early childhood communication intervention should strengthen the lifestyle of the child and the family (as displayed in personality, interests etc.), providing continuity and deep affectionate relationships over extended periods of time (Granlund, 2001). Short-term, goal-focused interventions are needed from time to time. These interventions will vary in focus and content but will adhere to the lifestyle of the family, that is, they should make a good fit with family niches.

Intervention methods encompass actions by people, adaptation of the physical environment and provision of assistive technology. The professionals contribute ideas about important key principles of the method (i.e. the principles of incidental teaching). The family provides information about how and when the method can be implemented without affecting family routine too much (Gallimore et al., 1996). The generation of method strategies focuses on enhancing already-existing competencies and resources in the close environment. If possible, the intervention strategy should assimilate explanations given to the problem by the family and extend the use of existing resources. If the family members cannot explain the relationship between goal and method, or between explanation and method, it is difficult for them to sustain the intervention when life circumstances change or the child changes (Björck-Åkesson et al., 1996).

To evaluate the intervention process and the outcome, it is necessary for the professional as well as the family to have access to information about the intervention implementation and the outcome. This is only possible if the goal and the intervention method are clearly declared and delimited. Continuous evaluation of treatment implementation offers a learning opportunity for family members by allowing them to evaluate their own behaviour in relation to the desired outcome. Such discussions constitute the basis for sustaining the effects of communication intervention for extended time periods (Noell and Witt, 1999). Outcome

evaluation includes evaluation of the desired outcome of a specific intervention as well as consideration of unexpected outcomes. By explicitly discussing unexpected outcomes, the knowledge and skills families need in order to develop versatility are enhanced.

Conclusion

From this chapter it is evident that the developmental niches or nodal points of interaction between child and environment as well as between family and surrounding society are important in understanding child and family functioning. Social settings, cultural customs of child-rearing and care, as well as the values and beliefs of caregivers are central to understanding child development. Patterns of interaction between the child and the family and the broader social context are critical in enhancing understanding of processes closely intertwined with the general development of young children.

The impact of poverty on the developmental niches is particularly evident in research identifying a complex set of socio-economic and psychological stressors imposed on family life. Not only do these adverse conditions directly affect the psychological and social well-being of the child and family; they also severely limit their access to resources within their own environment.

To account for the diversity of family needs, the discussion focused on different degrees of family involvement in the intervention process. Depending on the level of understanding and the nature of engagement of the family, different functions of communication intervention can be indicated. These different functions vary from where the family is more dependent on professional support, to where the family is able to make decisions independently, with the professional acting as a facilitator for problem-solving. Clearly these different roles and functions in the intervention process also have implications for sustainability of intervention. As the professional's role changes from being more direct to indirect and supportive, the likelihood is that the impact of intervention changes from being effective and sustainable to facilitating versatility – and in this way to facilitate coping, not just short-term but also long-term.

Central to an intervention process that facilitates family versatility in communication intervention is a collaborative problem-solving process in which family members actively define and explain problems and goals, design and implement intervention methods, and evaluate intervention. This demands that professionals have good knowledge of the problem-solving process and the roles of families, and also act both as facilitators and experts in their respective professional area.

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CHAPTER 11

Multiskilling in AAC intervention

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This chapter focuses on multiskilling as a means to equip people working in the health and educational context to function in a transdisciplinary manner when performing augmentative and alternative (AAC) intervention. Issues discussed include defining the concept, the need for multiskilling and a discussion of potential problems/challenges posed by it. Finally, there is a description of two programmes: a beginning communication intervention protocol that was implemented in training community health nurses, and a play package that was implemented and validated for multiskilled professionals.

Multiskilling is a form of role diversification and refers to the cross-training of professionals and/or support-level practitioners to perform procedures and functions in two or more disciplines (Allerton, 1997; Salvatori, 1997). It can therefore be seen as the vehicle by which individuals who already possess certain skills (e.g. primary health care nurses, teachers, etc.) are equipped with transdisciplinary skills to deal with the issues that confront them when attempting to deliver high-quality sustainable services to people with severe disabilities and their primary caregivers. It is thus a redesign strategy driven by the public and private health sectors' concern for cost control, aimed at enhancing cost-effectiveness, efficiency, quality and co-ordination of services owing to reduced intervention time and fewer professionals delivering services (American Speech-Language-Hearing Association (ASHA), 1996; Foto, 1996; Landry and Knox, 1996). Improved morale has also been noted as a result of greater job satisfaction (Basker and Husband, 1982), as is heightened quality of care owing to continuity and co-ordination of services as professionals share a common body of knowledge (e.g. general intervention principles), set joint intervention goals and reinforce skills (e.g. all activities are viewed as a therapeutic opportunity to continue treatment) (Foto, 1996). In cases where there is a lack of trained professionals who are equipped to provide services to all in

need, multiskilling can be viewed as a way in which this shortage can be addressed (Johnson, 1999). Multiskilling also eliminates role demarcation, thereby reducing hierarchical supremacy via interprofessional competition (Foto, 1996; Hurst, 1999), and helps professionals to advocate on behalf of their clients (ASHA, 1996).

Multiskilled health professionals can be defined as:

persons cross-trained to provide more than one function, often in more than one discipline. These combined functions can be found in a broad spectrum of health related jobs, ranging in complexity from the non-professional to the professional level, including both clinical and management functions. Traditional functions (skills) added to the original health care worker's job may be of a higher, lower or parallel level. (ASHA, 1996, p. 54)

Cross-trained, multiskilled professionals are sometimes referred to as *generic workers* (Hurst, 1999). However, multiskilling is much more than simply transforming professionals and/or support-level practitioners into 'jacks of all trades' (Salvatori, 1997). It offers opportunities for job expansion and job enrichment in the shape of new or expanded roles and responsibilities, skill sets and job titles, and it usually implies in-service training rather than formal education (as illustrated by two programmes discussed in this chapter). It does not mean the loss of one's professional identity, nor does it imply the demise of specialists. Opportunities exist for all service-providers to maintain their speciality skills and at the same time develop or expand roles and skills sets without giving up their professional identity (Salvatori, 1997).

Service-providers with skills and competencies in more than one area are likely to be regarded as more cost-effective and more employable than their traditional single-skilled counterparts (ASHA, 1996; Landry and Knox, 1996).

Multiskilling is part of the worldwide health reform which uses a primary health care approach, implying an increased focus on population health versus individual health, community-based care versus hospital-based care, and holism in intervention (Salvatori, 1997). It also promotes a client-centred rather than task-centred approach to intervention that is said to counter the previous authoritarian relationship between clients and professionals (Bolton, 2001). Individuals are taking more interest in their own health and in general prefer to interact with fewer service-providers. Health care suggests two major thrusts in the future – collaborative practice (not a new concept, but one that will be promoted because quality care and client-focussed care are its corner stones) and multiskilling (Salvatori, 1997). Multiskilled professionals thus stand in stark contrast to compartmentalized and overspecialized professionals who work to custom and practice (Hurst, 1999).

To pursue multiskilling as a training strategy, professionals trained in the traditional specific disciplines have to make three important mind shifts. First, they have to recognize that not every aspect of intervention requires the knowledge, judgement and skills of their particular area of specialization (Edwards, 2001; Foto, 1996). Second, they have to identify which of their services are skilled and which are non-skilled and could therefore be provided by someone else (Foto, 1996). Third, they have to identify what makes their profession truly unique and what competencies they share with others (Salvatori, 1997).

Multiskilling dimensions

As the precise dimensions and the suitability of what aspects should be addressed during multiskilling vary according to the specific professional discipline, the setting in which the intervention will be conducted, the aim of the intervention (for this purpose, service delivery to people with severe disabilities) and the resources already in place, it is difficult to provide distinct responsibilities. However, current viewpoints about multiskilling classify four main levels (ASHA, 1996; Johnson, 1999; Pietranton and Lynch, 1995), which are:

1. *cross-training of basic client care skills*, e.g. routine, frequently provided, easily trainable, low-risk procedures, such as monitoring vital signs, transferring and positioning clients, etc.;
2. *cross-training of professional non-clinical skills*, e.g. skills and services such as client education, team dynamics, communication skills, leadership, technical writing, etc.;
3. *cross-training of administrative skills*, e.g. programmatic activities such as quality improvement, case management, management of clinical services, systems design, etc.;
4. *cross-training of clinical skills*, e.g. obtaining skills from across multiple traditional disciplines to function in a truly transdisciplinary manner.

Although these four levels have been outlined in order to provide a platform from where to discuss multiskilling it is imperative to remember that they do not provide distinct categories. If, for example, prevention is discussed, it cuts across at least three of these levels. First, prevention can be viewed at level 2 where clients are educated about possible causes of disability (e.g. alcohol abuse), at level 3 where formal prevention programmes are administered and at level 4 where clients receive direct services (tertiary prevention). Additionally it is important to note that the additional skills added to the original list may be of a higher, lower or parallel level (Pietranton and Lynch, 1995).

Implications of multiskilling for AAC intervention

When looking at the intervention needs of people with severe disabilities, the interrelatedness and complexities of these needs as well as their dynamic nature have to be acknowledged. In an attempt to address these needs within the medical model, the various specialist professions evolved (Foto, 1996). This implied that a physiotherapist was needed to address positioning, an occupational therapist to assist with activities of daily living and a communication pathologist to implement a communication system. However, the sea of faces in this model underlines its fragmentation and inefficiency and the notorious poor communication between the different professionals (Edwards, 2001).

Consequently, the social model of intervention advocates transdisciplinary functioning of all professionals. Not only will the quality of care be enhanced if professionals are multiskilled; intervention will also be personalized as the people with severe disabilities interact with fewer professionals (Hurst, 1999). If multiskilled professionals work together, they can reinforce or intervene with each other's goals in mind (Foto, 1996). They can also respond with the people with severe disabilities' needs in mind and respond appropriately (e.g. when a wheelchair user wants to go to the bathroom during therapy, the communication pathologist can use this as a functional activity and not wait for the nurse).

In delivering AAC intervention, multiskilling is, like transdisciplinary functioning, characterized by role transition. This implies the crossing of traditional disciplinary boundaries, where professionals can work together, share their expertise and exchange certain roles and responsibilities to develop new ideas and strategies for service provision (Chapman and Ware, 1999; Lloyd et al., 1997; Orelove and Sobsey, 1996). This would mean that the skills associated with one profession could be taught to others who work with the specific client, e.g. the communication pathologist can train primary health care nurses or teachers to provide communication opportunities (deliberately) to people with severe disabilities when teaching them the concept of 'requesting help'. All professionals delivering AAC intervention need to be equipped to play each of the following four professional roles during the role transition process: trainer/educator; expert/prescriber; negotiator and collaborator (Parette and Brotherson, 2000). Transdisciplinary functioning of multiskilled professionals will lead to less fragmented services, and will provide people with severe disabilities with more opportunities to practise this communication function. Role transition is a process and consists of six separate but related processes (Orelove and Sobsey, 1996; Parker, 1994). Role transition and its application to multiskilling are described in Table 11.1.

Table 11.1 Role transition and multiskilling as realized in AAC intervention

Role transition process	Multiskilling level	Realization in AAC intervention
Role extension Increasing theoretical knowledge and clinical skill in own discipline	Level 1	Professionals expand knowledge and skills about AAC as it pertains to their own discipline, e.g. occupational therapy on switch access, communication pathologist on different communication means, nurses on medication, teachers on curriculum accommodation, etc.
Role enrichment Development of a general awareness and understanding of the terminology and basic practices of other disciplines	Level 2	Communication pathologists should understand motor patterns and reflexes; occupational therapists and physiotherapists should become aware of different communication means (aided and unaided); nurses should be able to explain some of the basic concepts related to AAC intervention and severe disability to people with severe disabilities; teachers should be able to maintain correct positioning of a child with cerebral palsy in her classroom.
Role expansion Acquiring information to make knowledgeable observations and recommendations outside own discipline	Levels 2 and 3	Intervention for people with severe disabilities involves a whole array of services, ranging from activities of daily living to literacy. Sensitising all professionals involved (e.g. doctors, therapists, nurses, teachers) and primary caregivers to all the issues pertaining to people with severe disabilities, and enabling them to make informed recommendations while also providing support, is essential. This aspect needs to be re-addressed for each new life event for people with severe disabilities, e.g. transition from toddler to childhood, attending school, etc.
Role exchange Learning the theory, methods and procedures of other disciplines and beginning to implement the techniques	Levels 3 and 4	Equipping professionals (e.g. nurses and teachers) with the necessary knowledge and skills to provide basic services to people with severe disabilities and their primary caregivers, outside their traditional roles. Basic AAC aspects should be addressed, such as the different communication means (aided and unaided), the range of communication functions and how to create deliberate communication opportunities (Reichle et al., 1992).

Table 11.1 contd.

Role transition process	Multiskilling level	Realization in AAC intervention
Role release Using newly acquired skills in consultation with a professional from the discipline responsible for those practices	Level 4	After initial multiskilling training, professionals should be visited in situ to assist them with the implementation of the intervention (e.g. whilst the nurse is teaching the use of gestures, or at lunch time whilst the teacher is feeding a child, etc.) and also to assist with problem-solving. Intervention effectiveness at this level often depends on whether this type of support is given, and caution should be taken not to terminate training without this process.
Role support Informal encouragement and back-up support from professionals from another discipline	Level 4	A cadre of professionals from the same primary discipline should receive multi-skilling training (e.g. nurses and teachers) in order to provide an infrastructure for inter-vention to people with severe disabilities in the particular setting. In addition, the professional who conducted the training should be available to the multiskilled professionals for an extended time.

Components of successful multiskilling

The success of any multiskilling programme is dependent on a number of factors. First the commitment of both the professional who is conducting the multiskilling programme and the multiskilled practitioner should be firm (Johnson, 1999). Questions as to the necessity of the multiskilling programme and if it is in the best interest of all parties involved (profes-sionals, support-level practitioners, client, family, community, etc.) should be answered. Although the benefits of being able to function as a cross-trained multiskilled practitioner have already been discussed, personal preference should also be kept in mind. Not all support-level practition-ers might have the aptness to work in the field of severe disability.

Second, the co-operation and support of administrators have to be ensured prior to the implementation of any programme (Johnson, 1999). As multiskilling will create a greater diversity among practitioners in terms of knowledge and skills, issues of credentialing and liability come to the forefront. Therefore it is imperative to consult the legal framework (e.g. code of ethics, licensure requirements, scope of practice) and other

existing professional guidelines. All multiskilled practitioners should receive contracts in which their specific roles and functions are outlined, as well as the in-service training they will be required to partake in, in order to obtain these skills. Guidelines for supervision also have to be included. Care should be taken never to assume that support-level prac-titioners know what to do without training and that they can operate independently without any mentoring and supervision (Johnson, 1999). Finally, the effects and effectiveness of the programme has to be under consistent scrutiny and ongoing review (Johnson, 1999).

Implementing multiskilling as an intervention strategy is compounded owing to a paucity in the literature on the specific skills that should be included in this type of training. Indeed there is little empirical data to support the nature and purpose of multiskilled professionals (Hurst, 1999). Two multiskilling programmes that have been implemented, one in the health sector and one in the educational sector, will be described to elucidate the multiskilling principles discussed earlier.

Training programme 1: Beginning Communication Intervention Protocol (BCIP)

Many changes have taken place in nursing practice over the past 20 years. Up until the early 1980s the medical model for intervention prevailed, implying that nursing practice was medically orientated and concentrated on curing individuals of disease. Today, with the social model widely accepted, nurses take a holistic view of a person's life and world, and have to express their expertise in a way that is versatile and innovative (Naumanen-Tuomela, 2001). Within the social model, primary health care is seen as the strategy whereby health care (intervention) could be made universally accessible to all individuals in the community by means acceptable to them, through their full participation and at an affordable cost (Rifkin, 1986).

Currently, primary health care is the focus of rural clinics in the South African context, with a supermarket approach (one-stop approach) for at least eight hours a day, five days a week, where individuals with a wide range of health problems visit (Lequerica, 1997). At these clinics a seam-less system, i.e. a care system that provides primary, secondary and tertiary services in order to ensure continuity, is promulgated. Although rural primary health care clinics only deliver primary level services, serv-ices at the other levels must be initiated from this level (Roberts et al., 1998). It is mostly primary health care nurses who staff these rural clinics, and defining their roles is difficult, owing to the fact that this depends on

the changing needs of the communities they serve (Clark, 1996). However, primary health care nurses at these clinics:

- must be expert generalists because of the diverse skills they need when working with individuals across the age range with a variety of health conditions (Clark, 1996; Hamel-Bissell, 1992; Tiffany and Hourigan, 1992);
- need to be independent and self-reliant, since they make on-site decisions at clinics that can be some distance from support (Thobaben and Biteman, 1999);
- should have community ties and relationships, which provide close family contact and potential for continuity of care, and must be able to tap local resources (Eayrs and Jones, 1992; Hamel-Bissell, 1992; Thobaben and Biteman, 1999);
- have a high social visibility (leading to relatively little privacy), with their social and professional roles intertwining to such an extent that inadvertent breaches of confidentiality are a concern (Hamel-Bissell, 1992);
- have a positive community visibility that has been linked to professional pride, self-esteem, and a potential role in shaping health policy at the community level (Tiffany and Hourigan, 1992);
- require a broader mix of knowledge and skills because fewer service options are available (Hamel-Bissell, 1992; Thobaben and Biteman, 1999);
- display certain personal attributes, including a higher level of emotional maturity and a greater desire for autonomy (Hamel-Bissell, 1992).

In order to meet the diverse demands placed on primary health care nurses (e.g. professional isolation, limited support services, insufficient continuing education opportunities, limited peer contact, excessive workloads and time demands) and to be compatible with the new health care environment that requires more flexibility in the deployment and management of health resources, interesting trends in service delivery are seen (Gordon, 1994; Salvatori, 1997; Tiffany and Hourigan, 1992). One of these is multiskilling. A core of generic nursing tasks and roles at each multiskilling level, as well its application to disability, is depicted in Figure 11.1 (ASHA 1996; Dublinske, 1983; Freeman and Heinrich, 1981; Hurst, 1999; Mast 1983; Pietranton and Lynch, 1995).

The role of *nursing practitioners* is generic, and primary health care nursing includes both personal and public health (Thomas, 1999; Wilkey and Gardner, 1999). This refers to the *first multiskilling level*, namely cross-training of basic client-care skills. As the activities at this level generally refer to traditional nursing tasks based on the basic nursing curriculum, it will not be discussed any further.
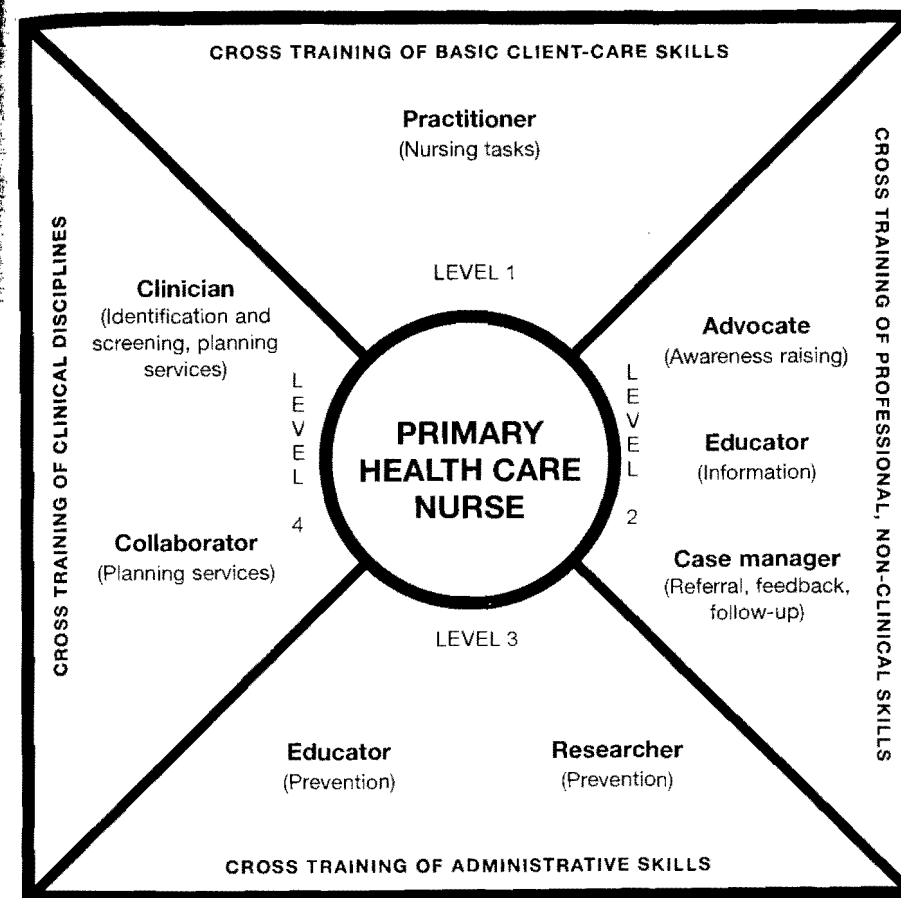
Figure 11.1 Roles and tasks of primary health care nursing within multiskilling levels.

The *second multiskilling level* depicts three major nursing roles for primary health care nurses, namely that of advocate, educator and case manager. The *advocate* role requires speaking out or acting on behalf of individuals who may be unable to speak for themselves (e.g. people with severe disabilities) (Clark, 1996; Glassman-Feibusch, 1984). This may be due to a lack of knowledge, difficulty or inability to articulate needs or ideas, fear, perceived lack of power, and/or intellectual/physical disability (Wilkey and Gardner, 1999). However, advocacy also entails empowerment of these individuals (e.g. by introducing them to disabled people's organizations) (Clark, 1996), and raising community awareness about disability issues. Linked closely to the advocacy role is that of *educator*. Health teaching and the provision of information are viewed as essential

nursing responsibilities. This can be conducted at the individual level (assisting people with severe disabilities and primary caregivers to make informed decisions about intervention) or at a community level (e.g. health talks about disability) (Wilkey and Gardner, 1999). Third, the nurses act as *case managers*, implying the co-ordinating and allocating of services for individuals who cannot manage alone (Lerner and Ross, 1991; Wilkey and Gardner, 1999). Regarding severe disability, this will entail identification of people with severe disabilities, referral when needed and highlighting the importance of feedback and follow-up in an attempt to monitor progress.

The *third multiskilling level* highlights primary health care nurses' role as primarily educators and researchers. At this level, the *educator* role is specifically related to the prevention of disability (at primary, secondary and tertiary levels) (Naumanen-Tuomela, 2001). In order to enhance this prevention function, the primary health care nurse also has to act as *researcher* (Wilkey and Gardner, 1999). This may include tasks such as identifying problem areas, collecting, analysing and interpreting data, applying findings, and evaluating, designing and conducting research (Griffith, 1994; Wilkey and Gardner, 1999). Research is an excellent tool for addressing the complex issues pertaining to prevention.

Finally, the *fourth multiskilling level* depicts the primary health care nurse as clinician and collaborator. The *clinician* role at this level is broader than on level 1, encompassing a rehabilitation function, which implies that nurses act as transdisciplinary professionals, moving beyond the traditional boundaries of their discipline. It requires that these nurses identify, screen and plan services for people with severe disabilities. The exact nursing tasks for specific populations, e.g. a child with Down syndrome, have been documented (Grebin, 1981). These include determining aetiology (to provide genetic counselling), assessment and management entailing counselling/prevention, follow-up, providing medication, collaboration and referral. The *collaborator* role is closely linked to some of the other roles (e.g. clinician, advocate and educator), as these nurses are required to help individuals understand their disability and to make informed decisions about their own intervention.

When looking at these four multiskilling levels, it is important to note that these tasks and roles cannot be viewed as distinct categories and that extensive overlapping occurs. They are also dynamic in nature and may therefore change over time, or according to the needs of the people with severe disabilities and the primary caregivers, which in turn are influenced by, amongst others, the specific disability type (Bornman, 2001; Bornman, Alant and Lloyd, in press). However, in an attempt to clarify specific nursing tasks as they pertain to disability, this distinction amongst levels was made. Questions also remain unanswered regarding the

application of multiskilling to various health care settings (e.g. would multiskilling be applied differently in primary, secondary and tertiary health care settings?), geographical areas (e.g. rural vs. urban) and clinical disciplines and professions (e.g. nursing and AAC) (Pietranton and Lynch, 1995). Another grave concern of multiskilling is that it might add to the workload of already overburdened primary health care nurses. Professionals working in the health care arena are diverse regarding education, experience, training, autonomy and level of client contact, and therefore a single approach to multiskilling seems undesirable.

Implementation of the Beginning Communication Intervention Protocol (BCIP)

A group of 20 primary health care nurses from a rural area were trained in using the BCIP. This training was a direct result of a needs analysis that had been conducted in the area in which nurses expressed a need for knowledge and skills that would equip them to deal with people with severe disabilities, as they felt inadequate about the way in which they were providing services to this population (Bornman and Alant, 2002).

Training was conducted over five consecutive days, Monday to Friday from 8.30 a.m. to 4.00 p.m. Each day started with a brief revision of the previous day's work. The nature of the training was problem-based (case studies were shown on video), as research has indicated that adult learners are more satisfied with learning if it applies to everyday life and is practical and current (Barrows, 1985). This methodology also enabled nurses to extend and improve their knowledge (in particular regarding disability and AAC), to remain contemporary in their field and to provide care to the unique problems they face in their work (Jacobs, 1997). As they were expected to work independently following the training, the value of this approach is evident. Role-play elicited rich personal accounts and concerns that, through facilitation, led to the development of problem-solving skills (Bornman, 2001). After the initial training, three follow-up sessions were conducted, two weeks, six weeks and five months post-training. These follow-ups were all conducted in situ for logistical reasons and aimed to assess the nurses' skills, identify possible problem areas and assist with problem-solving.

The nurses that were trained (n = 20) were all female and generally tended to be mature, with ages ranging from 28 to 54 years with 50 per cent being in their forties (Bornman, 2001). Qualifications covered a broad spectrum ranging from no formal training after leaving school (40 per cent) to nursing diplomas (45 per cent) and nursing degrees (15 per cent). Only 25 per cent had less than three years' experience (including one with less than a year's experience) while 15 per cent had more than 20 years' experience (Bornman, 2001).

The aim of the BCIP training is to provide primary health care nurses with the basic knowledge and skills regarding beginning communication skills (for children with severe disabilities) and how to involve their primary caregivers actively in providing opportunities for interaction (Bornman, 2001). It is based on five principles:

1. *Use the ICF* (World Health Organization (WHO), 1999) to determine an individual's functioning. This implies that the focus of intervention should always be on the individual's *abilities* as opposed to their *dis-abilities*, and how this can be used optimally to ensure full and active participation in everyday activities.
2. *Use a milieu teaching approach.* This is a naturalistic strategy for teaching functional communication skills within daily occurring routines, with logical, naturally occurring real consequences as reinforcement. Specific teaching techniques include time delay, incidental teaching and the mand model (Kaiser, Yoder and Keetz, 1992).
3. *Use activities of daily living.* The environment in which the beginning communicator learns, lives and functions could be adapted to provide opportunities for participation. Research has indicated that individuals with severe disabilities spend significantly more time performing these activities than their typically developing peers (Light and Kelford-Smith, 1993).
4. *Use an integrated communication approach comprising communication functions, means, content and partners.* Communication means (the *how* of communication) include objects, photographs, gestures, Picture Communication Symbols (PCS) and a simplified four-option digital speaker, while communication functions (the *why*) include requesting more, requesting help, protesting, indicating surprise and greeting. Communication partners (the *who*) refer to both adults and peers, and the content (the *what*) to the environment and the activities the child is involved in.
5. *Use deliberate communication opportunities.* Beginning communicators are often passive recipients in interaction. This could be due to a number of reasons, including the fact that few communication opportunities are given by speaking partners. This is, however, a complex task, as a delicate balance must be found between the elicitation and pre-emption of communication behaviour.

Table 11.2 depicts the specific aspects that were included during the initial one-week training, and how they relate to the four different multi-skilling levels and the various nursing tasks.

Results regarding knowledge were obtained using a knowledge-based questionnaire administered at three different intervals: pre-training, directly post-training and five months post-training (post-withdrawal).

Table 11.2 BCIP training aspects

Multiskill level	Nursing task	Application to disability	Outcome
Level 1 Cross-training of basic patient care skills			The current training protocol does not address this level of multiskilling
Level 2 Cross-training of professional, non-clinical skills	Awareness	• Create community awareness regarding the needs of people with severe disabilities • Discuss community awareness with other professionals (e.g. school nurses and teachers) • Make caregivers and teachers aware of the importance of adequate, effective and appropriate communication skills	• Increased awareness of people with severe disabilities at both personal and community levels • Increased community understanding of needs of people with severe disabilities and the importance of providing them with appropriate effective communication means • Reduced stigmatization in community
	Information	• Provide information regarding people with severe disabilities • Provide information regarding expectations • Provide information regarding further communication needs (long-term plan)	• Demystify disability concept • Empower caregivers of people with severe disabilities by providing information about expectations and realistic goals; caregivers should feel supported
	Referral	• Initiate referrals to therapists • Initiate referral for further medical management • Assist therapists and teachers (particularly school nurses) in determining when a medical referral is necessary	• Increased understanding amongst professionals regarding the value of early referral and intervention of people with severe disabilities • Establishment of a clearer referral line that will not waste time, money and/or effort

Table 11.2 contd.

Multiskill level	Nursing task	Application to disability	Outcome
Level 2 contd.	Feedback	• Make caregivers aware of importance of providing feedback to referring nurse • Encourage other professionals to provide feedback to referring nurse • Provide feedback to caregiver regarding the changing communication skills after BCIP implementation	• Encourage regular feedback from caregivers to monitor progress and meet changing needs and abilities of CSDs • Provide feedback to caregivers and other professionals • Establish feedback as a reciprocal activity
	Follow-up	• Encourage caregivers to bring their children for regular follow-ups to monitor progress • Assist caregivers to monitor the quality and quantity of communication	• Regular follow-up visits • Caregivers become active observers of their children's progress • Increased motivation of caregivers as progress is noted
Level 3 Cross-training of administrative skills	Prevention	• Educate community on causes of disability and aversion and prevention, e.g. pre-natal care, good nutrition etc. • Refer high-risk mothers • Educate on compliance with appointments (doctors, hospital, therapists, etc.), medication (e.g. epilepsy), periodic health visits (growth chart) and follow-up	• Appropriate information and/or referral of mothers who are at risk of producing CSDs (e.g. women >38 years or teenage mothers) so that early and informed decisions regarding childbearing can be made • Lower incidence of disability • Decreased impact of the disability on the child's functioning
Level 4 Cross-training of clinical disciplines	Identification and screening	• Identify children who are at risk of disability (e.g. twins, very low birth weight, poor nutrition, etc.) according to health history	• Obtaining relevant information about child in collaboration with caregiver to determine presence of disability so that child can be referred

Table 11.2 contd.

Multiskill level	Nursing task	Application to disability	Outcome
Level 4 contd.		• Conduct health assessment on identified children (at-risk and established risk) • Use 'Progress Checklist' to obtain baseline data • Assist in obtaining necessary medical evaluations	• Analyse and discuss results from progress checklist with the caregiver • Explore presence of risk factors further

Results regarding skills were obtained from a demonstration when nurses were asked to, for example, 'Show me what you would do for Busi.' A different but comparable case study was used for each of the research periods. These demonstrations were video-recorded, and the researcher and an independent rater scored all the interactions. The inter-rater agreement averaged 96 per cent across all measurements (Bornman, 2001).

Research results on multiskilling of primary health care nurses

Research was conducted in order to provide evidence on multiskilling as a strategy, whereby primary health care nurses could be trained to function as true transdisciplinary professionals when providing services to people with severe disabilities and their primary caregivers (Bornman, 2001; Bornman et al., in press). Only results that pertain to the different multiskilling levels will be discussed. These results are shown in Table 11.3.

During the BCIP training the focus of the training was mostly on the fourth multiskilling level, which revolves around service provision. This was necessitated by the fact that this was the nursing task where primary health care nurses required the most input, as service delivery pre-training mostly focused on direct referral despite the fact that appropriate places to refer to were mostly unavailable or inaccessible. Consequently, the emphasis of the BCIP training fell on the provision of knowledge, which was intertwined with skills. As expressed so aptly by Bruner, 'It matters not *what* we have learned. What we can *do* with what we have learned; this is the issue...' (cited in Brewer, 1985, p. 3).

In conclusion, results point to the value of multiskilling as a strategy through which primary health care nurses can be trained to function as true transdisciplinary professionals when delivering services to people

Table 11.3 Results following BCIP training

Aspect	Measurement	Results
Multiskilling level 1		
Not included in training		
Multiskilling level 2		
Advocate (raising awareness) *Educator* (providing information) *Case manager* (referral, feedback and follow-up)	• Knowledge-based questionnaire conducted at 3 different intervals, viz. pre-training, post-training and post-withdrawal • Descriptive statistics	Nurses became more aware of the importance of demonstrating to primary caregivers how to communicate with their children by using the BCIP principles, e.g. 'using real objects to communicate', 'demonstrating communication means and functions' and 'providing communication opportunities'. Pre-training, the skills mentioned were vague and general, e.g. 'teaching people with severe disabilities' and 'facilitate a positive attitude by giving advice'. Generally this trend continued during the post-training and post-withdrawal periods. Pre-training, 90% of the nurses requested more training in 'training primary caregivers and siblings', but it became clear that the BCIP training addressed this need, as a noticeable decline was observed post-training. It was also interesting to note that nurses' initial request of 'categorizing people with severe disabilities according to disability types' was no longer an issue post-training. This is possibly due to the fact that the social model for disability (in accordance with the WHO's classification system), where the emphasis is placed on participation rather than disability types, was used (WHO, 1999). Post-training, nurses identified a whole new set of needs, with 'teaching families to communicate with people with severe disabilities by using demonstrations' as the most pressing. This could possibly be attributed to the emphasis placed on social inclusion during the training. The other training needs revolved around the specific issues addressed during training, e.g. expanding communication means and functions and creating communication temptations. During the post-withdrawal period the highest reported frequency was for 'using different communication means'. This could possibly be because they were already successfully using some manual signs and wanted to expand their current vocabulary

Table 11.3 contd.

Aspect	Measurement	Results
Multiskilling level 3		
Educator and *researcher* involved in secondary prevention – early identification and referral, providing information, acting as role model by modelling appropriate behaviour (Clark, 1996; Freeman and Heinrich, 1981; Roberts et al., 1998)	• Knowledge-based questionnaire conducted at 3 different intervals, viz. pre-training, post-training and post-withdrawal • Descriptive statistics	Nurses became more aware of advice that could be given. Pre-training advice tended to be general, e.g. 'counsel caregivers on acceptance'. Post-training and post-withdrawal, the advice given tended to become more specific in nature, e.g. 'increasing communication means' and 'increasing social interaction'. Generally they also tended to become more aware of the importance of referral to a mainstream school (referral to special schools decreased). The decline in 'referral' over the various research phases is also interesting. This could possibly be due to the fact that nurses became more empowered and confident in their service delivery to people with severe disabilities
Multiskilling level 4		
Clinician and *collaborator* involved in planning services. In remote rural areas nurses are often the only persons available to provide services (Clark, 1996). Therefore they should be able to provide comprehensive holistic services 'on the spot' (Lequerica, 1997)	• Knowledge-based questionnaire conducted at 5 different intervals, viz. pre-training, post-training, 2 weeks post-training, 6 weeks post-training and post-withdrawal • Friedman test to determine statistical significance • Demonstration of skills (video-recorded and rated by two independent raters) • Friedman test to determine statistical significance	A Friedman test indicated that the knowledge increased statistically significantly over time (p=0.0001 thus p<0.05), and multiple comparisons indicated that this increase was between the pre-training phase and the post-training phases, the 2-week follow-up, the 6-week follow-up and the post-withdrawal phases respectively A Friedman test also indicated a statistically significant increase in skills over time (p= 0.0001), and multiple comparisons yielded the same results as for knowledge. In addition, results also indicated a statistically significant increase between the post-training phase and the 6-week follow-up and post-withdrawal phases respectively. This implies that skills increased statistically significantly during the follow-up periods compared to pre-training and post-training. This emphasizes the importance of follow-ups in skills development

with severe disabilities and their primary caregivers. Conducting the BCIP training (based on multiskilling principles) significantly impacted on primary health care nurses' acquisition of knowledge and skills in the field of severe disability. However, the relationships between multiskilling and job satisfaction, between multiskilling and overburdening, and between multiskilling and the motivation to work with people with severe disabilities and their primary caregivers should be further investigated.

A second training programme was developed to be used with multilevel skilled professionals and support-level practitioners.

Training programme 2: an Early Intervention Play Package (EIPP)

The EIPP, an intervention package for the observation and facilitation of communication and its related behaviours, was developed and tested for reliability and validity. This programme was intended for use by multilevel support practitioners and targets children between the mental ages of 12 and 36 months. The EIPP consists of two sections: play activities and assessment measurement. The Daily Multiple Measurement Instrument (DMMI) was developed to assess emerging behaviours of young children (Uys, 2003a).

The play activities

Five play activities were selected because of their proven effectiveness in facilitating skills development: battery-operated toys, finger-paint, pop-up toys, sand play and storytelling (Uys, 1997). See Table 11.4 for a description of each activity.

Procedures used for EIPP

Analysis of the constructs and behaviours included in the EIPP

Adaptation and play are the premises upon which the play package was based. In determining the scope and content of this package, specific domains relating to communication development were identified, i.e. the sensorimotor, cognitive, communication and social–emotional domains (Arnsten, 1990; Dunn, 1991; Linder 1993). These domains formed the constructs (areas to be assessed and facilitated) included in the presentation of the play activities as well as the measurement instrument (DMMI). However, constructs are abstract concepts and, while only observable behaviours can be measured, these constructs were operationalized, that

Table 11.4 Activities in the play package

Activity	Description	
Battery-operated toys	Brightly coloured battery-operated toys were selected. This included an elephant, a car, a worm, and jumping fish. Different switches (a joystick, large and small pressure switches, and a pinch switch) operated these toys. Corresponding 2-dimensional pictures were used	
Finger-painting	A mirror was set up and shaving foam was used as the paint medium. Three different paint colours were introduced in the session. Imitation of certain movements was required	
Pop-up toys	Three different pop-up toys were used, e.g. jumping jack, 'piano' keyboard with hidden animals popping up after pressing a key, and a multimethod pop-up toy where different actions released different hidden animals. Corresponding 2-dimensional pictures were used	
Sand play	The following objects were used: a sandpit of approximately 1m², different tools (spade, cups, bucket, rake, sieves), wooden blocks, a sand wheel, and plastic animals. Hide-and-seek games were played as well as operating the sand wheel. Construction play was introduced with the wooden blocks	
Storytelling	A story was told, using the different objects functionally in the process. The objects included a train, a car, an aeroplane, a doll, and a telephone. Corresponding 2-dimensional pictures were used at the end of the story	

is, the behaviours representing the components of the construct were identified (Uys, 2003b). These behaviours should be targeted in assessment and treatment. An excerpt is presented below, for clarification:

(i) Communication behaviours:
  • Expressive skills – natural gestures, pointing, head-shaking, imitation, eye-blinking, vocalization, verbalization.

(ii) Sensorimotor behaviours:
  • Motor skills – visual tracking and scanning, gross and fine co-ordination, bilateral integration, motor control, visual–motor integration.

(iii) Cognitive skills:
  • Attention – active, passive, visual, auditory.

(iv) Socio-emotional skills:
  • Social closeness – eye contact, enjoyment, active participation, greets partners.

Strategies for facilitation of development of skills related to communication

The principles and strategies to facilitate communication-related behaviours were identified (Beukelman and Mirenda, 1998; Lloyd et al., 1997; Musselwhite, 1986) and are presented in Table 11.5.

Presentation of the EIPP

An important advantage of the EIPP is that it can be applied in a variety of natural settings by different multiskilled professionals and/or support-level practitioners. As such they can use any play activity in a natural setting to observe and facilitate the development of childhood behaviours, e.g. a teacher can use play activities involved in the curriculum to achieve this development.

In planning the presentation of this programme the multiskilled individual should first identify the steps involved in the presentation of the activity. These steps should be written down as guidelines for the presentation. It is advisable to practise these steps before application in the intervention with the child. Based on these steps the interventionist should be able to identify the behaviours to be facilitated and observed.

Once these behaviours have been identified, it is possible to select specific strategies to facilitate the corresponding behaviours. These strategies are pivotal to the success of the intervention. However, it is not only the careful selection of appropriate strategies which is important, but also the efficient application – requiring practice – before implementation in intervention.

Table 11.5 Principles and strategies to facilitate communication-related behaviours.

Behaviour	Strategies and principles
General strategies to facilitate communication (Constable, 1983; Olswang et al., 1982)	• Requesting • Commenting on objects • Commenting on actions • Denying and protesting • Obstacle presentation • Time delay • Nurturance • Sensitivity • Sequence experiences • Fading • Shaping
Prompting (Lloyd et al., 1997)	• Verbal/gestural/physical/visual • Natural prompt: 'What do you want?' • Minimum prompt: 'You need to tell me what you want' • Medium prompt: ' You need to tell me what you want. You want____' • Maximum prompt: 'What do you want? You need to tell me. Say _____.' Used with gestures, and physical and visual cues
Visual tracking and scanning (Musselwhite and St Louis, 1982)	• Stimulus: size, colour, complexity of activity • Location: distance – near to far • Range: grade to 180° visual range • Cues: verbal, vocal, gestural • Speed: slow, medium, fast • Path: horizontal, vertical, diagonal, circular, random
Choice-making (Porter et al., 1985)	• Child should have a preference before initiating choice-making • Child should have a means of communication • Increase the number of opportunities • Choice should be followed by a natural consequence

Joint activity (MacDonald and Gillette, 1984)	• Adult first follows the child's lead
	• Structure for give-and-take situation
	  – Optimal eye contact
	  – Sustain interaction
	  – Routine back-and-forth action and then break the routine
	• Animation
	• Imitate behaviour
	• Initiating
	• Receive requests
	• Maintain eye contact
	• Touch

Table 11.5 contd.

Behaviour	Strategies and principles
Activation (Musselwhite, 1986)	• Different planes • Different speed • Tone of voice • Reciprocity • Animation • Surprise element

Object interaction (Musselwhite, 1986)	• Exploratory
	  – accessibility of toys
	  – increase duration of play
	  – increase opportunities for manipulation
	• Conventional
	  – non-threatening area
	  – appropriate toys
	  – allow self-directed play
	  – functional object use

Learning (Bandura, 1977)	• Repetition/practice • Association, assimilation and accommodation • Trial and error • Reinforcement • Motivation • Imitation • Insight • Multisensory experience • Methodical instructions
Social learning (Bandura, 1977)	• Observation and modelling • Continuous reciprocal interaction with the environment • Reinforcement, self-reinforcement • Rapport between the adult and child
Adaptive response (King, 1978)	• Ensures active participation • Opportunity for goal-directed participation • Sub-conscious integration • Self-reinforcement through experience of success
Level of activity (Kramer and Hinojosa, 1993)	Grade level of activity according to: • Kinaesthetic • 3-dimensional • 2-dimensional

Table 11.6 is an excerpt from the presentation of one activity from the EIPP in which a battery-operated toy is used. In this table the steps, behaviours and strategies are described.

Application and results of the EIPP

A group of five children with comparable intellectual impairments (four female and one male) were included in the training programme. Their chronological ages varied between 5:0 and 7:3 years (average = 6:0), and their mental ages between 1:6 and 3:0 years (average = 2:3). The training programme was conducted over an eight-week period. During the first

Table 11.6 Planning of presentation of the play activities.

What/how to facilitate	Behaviours	Strategies
1. *Look, this is an elephant.* Guide the child's eyes to the toy. Make the gesture for elephant	Attention	Guide eyes. Activation: tone of voice. Good positioning for eye control
2. *I am going to make him dance.* Multiskilled individual imitates dance with body language and makes gesture for dance. *Can you dance?* Wait for response	Attention	Activation: tone of voice, movement in horizontal plane, make eye contact. Commenting on 3-dimensional objects and concepts by indicating similarities and differences
3. *Look, I am pushing the joystick*	Visual tracking; Cause–effect	Describing the actions. Activation: tone of voice. Initiating actions
4. Multiskilled worker pushes the joystick to activate the toy. Stops after 5 seconds. *Ooh, what happened? The elephant danced!* Multiskilled individual makes gesture for *What?*	Visual tracking and scanning; Understands short sentences; Attention; Cause–effect	Surprise element. Multisensory media. Animation of the actions and objects. Incidental learning
5. Repeat the above 3 times		Repetition to learn
6. *Do you want to play with the elephant?*	Understands instructions; Turn-taking	Establish reciprocity. Maintain eye contact. Use simple/elementary sentences. Indirect teaching model

Table 11.6 contd.

What/how to facilitate	Behaviours	Strategies
7. *Make the elephant dance!* Make the gesture for dance. Wait for response	Understands instructions; Gross co-ordination	Time delay. Requesting. Use simple sentences
8. If the child does not respond, prompt: hand-over-hand push the joystick. *Push the stick to make the elephant dance*	Gross co-ordination; Visual tracking; Cause–effect; Understands instructions	Object interaction – allow manipulation. Physically holding the child. Feedback for cause–effect. Horizontal tracking. Auditory and/or visual cues

week, information on the children's level of performance was obtained (*pre-intervention phase*). The actual training with the play activities was done on an individual basis, 45–60 minutes per child, and for three consecutive weeks (*intervention phase*). The nature of the training was functional and took place in natural settings. The children's level of performance was assessed after one-week and three-week withdrawal periods (*post-intervention phase and post-withdrawal phase*; see Uys, 2003a). This methodology allowed it to be established whether newly acquired behaviours were integrated and became internalized (Kielhofner, 1992).

The aim of the training was to establish outcome validity of the play package by determining and comparing the levels of performance of the children on the sensorimotor, cognitive, communication, and social–emotional behaviours during the pre-intervention phase, intervention phase, post-intervention phase and post-withdrawal phase, using three authentic assessment tools – the DMMI (Uys, 2003a), the Transdisciplinary Play-Based Assessment (TPBA) (Linder, 1993), and the Symbolic Play Scale (SPS) (Westby, 1980). Figure 11.2 shows the performance of the group on the DMMI over the eight-week period.

In this figure the group's performance on the DMMI is presented on a weekly basis and it clearly shows the increase in performance on the four different developmental domains (constructs). Distinctive patterns occurred; for example, communication trails all other constructs, making it the most difficult behaviour to acquire. However, little or no difference between the other three constructs across the eight weeks was observed. A definite pattern of gradual acquisition of behaviours occurred from week 1 to week 4, but a plateau was reached from week 4 to week 8. A statistically significant difference was found on the behaviours
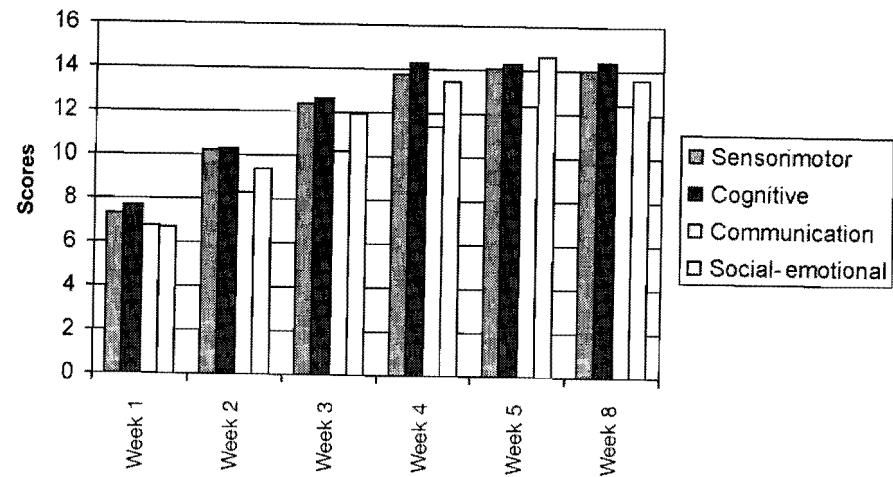
Figure 11.2 Mean performance of the children on the DMMI.

representing all the constructs (behaviours) between weeks 2 and 3, weeks 2 and 4, and weeks 3 and 4 (the *intervention phase*) at the 5 per cent level (p < 0.0001), indicative of development (Uys, 2003a).

Evidence of the effectiveness of any intervention programme depends on its reliability and validity (Mouton and Marais, 1985). The effectiveness of the EIPP was established by utilizing a variety of reliability and validity measures during different phases of the research. The play package (DMMI) was externally compared to the TPBA (Linder, 1993) and the SPS (Westby, 1980), and a significant correlation between these tests was found. Five different types of validity were determined. Face and content validity was determined during the pre-experimental phase, involving six experts in the field who evaluated the description, definitions and content of the play package. During the experimental phases outcome validity (Kazdin, 1982; Wolf, 1978), construct and convergent validity were described. From the data the EIPP can be regarded as a reliable and valid early intervention programme. See Uys (2003a) for more detail on the process and outcomes of validation.

Over the past decade, service provision to people with severe disabilities has undergone many changes, moving from traditional discipline-specific intervention to transdisciplinary services. Multiskilling can be seen as a process to support comprehensive, transdisciplinary intervention services. This, however, highlights a few pertinent issues, namely who should be involved in multiskilling within a particular context, the

extent to which multiskilled professionals can support intervention in other areas and, finally, setting guidelines for quality control.

It is evident that cross-training and multiskilling of transdisciplinary professionals are still in their infancy. Although the success of training of multiskilled professionals has been described in the case of the BCIP, and research findings indicated the validity and reliability of the EIPP, creating a basis for training in early intervention in a multiskilling context requires much more systematic research not only to validate training programmes, but also to monitor quality. Planning of intervention services, especially in low-income countries where there is a paucity of professionals, requires critical reflection to ensure that processes are in place so that intervention programmes may deliver the desired outcomes. Only by evaluating outcomes in relation to programme effectiveness, sustainability and versatility (see Chapter 2) can intervention make a more lasting impact.

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CHAPTER 12
Peer learning and participation in AAC intervention

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This chapter discusses the importance of peer learning and participation in augmentative and alternative communication (AAC) intervention, by describing the importance of social interaction and, in particular, the need for children who use AAC to be involved in peer interactions. Peer training in AAC research is discussed and a training programme for the facilitation of peer interaction is described. The programme describes pre- and post-measures and provides some data on the outcomes of the study. Challenges of peer training are discussed and research implications are highlighted.

The importance of collaborative learning within the educational context

Collaborative learning in schools has become widely practised in both developed and low-income countries and is inherent in educational policies involving outcome-based education. In collaborative learning, children work together in small groups towards a common goal, with individual children being accountable for their contribution – resulting in positive interdependence. The interactive tasks that form the basis of collaborative learning spontaneously stimulate the cognitive, linguistic and social development of the children. Diversity within the group has a positive influence as different interpretations result in a more active exchange of ideas during discussions.

The interest level of children involved in collaborative learning is higher, with improved academic performance and enhanced social functioning cited as outcomes. Effective collaborative learning fosters teamwork, problem-solving abilities, and critical-thinking skills such as

analysis, formulating explanations, synthesizing and elaborating. Group processing activities as well as tasks to develop interpersonal and social skills such as constructive conflict-resolution are important aspects of collaborative teaching methods. Most importantly, the peer-support system that results from co-operative learning strategies helps children not only to accept and respect diversity among their peers, but also to understand and connect with one another. Children involved in collaborative learning give and receive emotional and academic support within the group, and develop valuable interpersonal skills. It has facilitated the acceptance and interdependence between children of different cultures, languages and ethnic groups as well as students with learning disabilities (Slavin, 1989). It is important to ensure that children with severe disabilities, including those who require AAC, also benefit from interdependent peer interaction within the classroom. This will contribute towards ending the social isolation and exclusion that are so frequently the experience of children who require AAC, particularly in low-income countries.

The primary goal of AAC is to enable children or adolescents with limited functional speech to communicate effectively in their daily interactions with others. The child or adolescent who uses AAC needs to successfully interact with both familiar and unfamiliar partners, including peers, in everyday situations within the natural contexts of home, school and the community. However, those who require AAC often have extremely limited social networks and many only communicate with immediate family or caregivers and with those who are paid to communicate with them. They often have no real interaction with peers despite the implementation of multimodal AAC systems and intensive training to promote communicative competence.

As AAC professionals and researchers, we have to make sure that children requiring AAC are involved in the natural, interactive contexts that are created by inclusion and collaborative learning practices, with resulting optimal learning opportunities for all children. There is a need to focus both on the skills to promote communication competence of the child using AAC as well as on equipping peers with the necessary skills to interact effectively with their peers who use AAC. Addressing the social participation of children who require AAC should be viewed as an integral component of AAC assessment and implementation processes (see Chapter 9: AAC technology for development).

Communicative competence for a person who uses AAC was defined by Light (1989) as consisting of linguistic, operational, social and strategic competence. However, the communicative competence of the child or adolescent who uses AAC is only part of the equation for successful interactions with peers. Calculator (1999) discusses five sets of variables that may influence interactions between a child who uses AAC and a peer partner:

1. Features of the AAC system or device.
2. The characteristics of the student who uses AAC, including abilities, personality, motivation and attitudes.
3. The characteristics of communication partners, including their attitudes, perceptions, knowledge, style of interaction and motivation to interact with students who use AAC. In addition, the character, experience and the familiarity of the peer partners as well as the level of the support they have received are important.
4. The quality and content of the instruction given to both the student who uses AAC and the peer partners.
5. Additional associated variables such as opportunities and reasons to communicate.

Thus it can be seen that achieving successful communication for children and adolescents who use AAC is a complex and demanding process that is directly determined by both the children who use AAC and their peer partners.

The need to involve communication partners is substantiated by the fact that both empirical research and clinical experience have proved that intervention directed solely at the person who uses AAC is not sufficient to ensure social competence (Light et al., 1992; McNaughton and Light, 1989). Sack and McLean (1997) have pointed out that professionals in the field of AAC must conceive an expanded role that includes training and supporting the daily communication partners of people who use AAC, in addition to teaching new interaction skills and communication strategies to the person who uses AAC (see Chapter 8: Support-based AAC intervention). This suggests that best practice in AAC intervention for children and adolescents needs to be twofold: (a) addressing the needs and building the competencies of the person using AAC and (b) instruction and training of significant communicative partners including parents, teachers, facilitators and peers. Although partner training is widely recommended in current AAC literature, there are few studies describing partner training and even fewer studies on child or adolescent peer-partner programmes. A barrier to implementing peer training is that peer-training programmes and models are not available, and thus the development of training programmes for the peers of children and adolescents who use AAC is essential.

Some of the difficulties experienced by children who require AAC in industrialized countries are documented and will be discussed later in this chapter. The difficulties experienced in low-income countries appear to be similar but, in addition, are exacerbated by limited or minimal early intervention services or access to therapy and education for children with severe disabilities. This is particularly true for children in rural areas. No

governmental or medical insurance funding for AAC devices, and limited knowledge, skills and expertise in AAC, are additional barriers. The large ratio of students to teachers in classrooms and inadequate support services further complicate the inclusion of children with disabilities into mainstream schools in low-income countries.

A child's social development is inextricably linked to his or her development in areas of language, cognition, sensorimotor skills, play and personality. More advanced skills are based on earlier skills and experiences, and we need to consider the influence of early social development when evaluating the peer-interaction skills of the older child or adolescent.

The early social development of the child who is likely to require AAC – the risk of learned helplessness

The child with severe disabilities is frequently described as at risk for developing learned helplessness – a condition in which a child does not initiate interactions or readily respond to communication attempts by others. The child neither attempts to ask, nor do things, for him/herself. It describes a state of excessive passiveness that is basically caused by repeated experiences in which the child has not been able to have an effect on other people or the environment, i.e. he or she does not have an effect on what happens to him/herself. According to the learned helplessness theory, supplying rewards that are not dependent on the performance of an action can also lead to passivity (also see Chapter 3).

Children with severe physical, sensory or cognitive disabilities, who are by the nature of their disabilities dependent, are at risk for learned helplessness due to two reasons. First, because primary caregivers or family members are not able to interpret or respond to the child's early communicative attempts, the child does not discern a relationship between his or her own actions and a response from people or the environment, eventually giving up. Parents and caregivers often do not respond contingently to early communication attempts by the child with disabilities, as these are often ambiguous or abnormal. Second, they are given free rewards, as adults seldom expect them to do or ask for anything, and so try to satisfy all of their needs regardless of any specific initiation or response from the children. A child with delayed social and communication development is at most risk for learned helplessness, because adults do not expect the child to indicate his or her needs and wants. In addition parents anticipate, and frequently misinterpret, the child's needs. As a result, the child may relinquish any attempt to make his or her desires known, is extremely passive and does not develop the necessary skills to

interact with peers (see Chapter 4, particularly the section on social exclusion).

In addition, concomitant motor, sensory and/or intellectual impairments may impede the young child's ability to act effectively on people in the environment. Many young children who will require AAC do not have independent mobility or functional manipulation skills to independently access their environment – resulting in an impoverished experiential base for the development of language, communication and peer-interaction skills. The ability to use vocalizations to express likes and dislikes does not develop and opportunities for choice-making are frequently absent or far more limited than with the typically developing child. Parents and caregivers frequently underestimate the child with little or no functional speech (LNFS) and may assume responsibility for the child, significantly reducing expectations of the child.

The social interaction of the preschool child who requires AAC

Many children who have severe disabilities and require AAC lack opportunities to participate in dyadic interaction. The result is that they do not develop social contingency awareness and may not develop social signals, develop them far more slowly or develop unusual signals (Schweigert and Rowland, 1992). Social control and development by the child is further compromised, as the parent frequently does not recognize the signals, and without feedback from the child to the parent's initiations the parent may become less responsive, resulting in the child having even fewer opportunities to interact and develop social contingency awareness (ibid.). Additional social development in gaining attention of other individuals, requesting an object, expressing needs, expressing an interest in another person or an object, expressing preferences, or making choices – may present difficulties for children with severe or multiple disabilities who require AAC.

There appear to be few studies involving peer interactions of preschool children who use AAC. In their studies of the communicative interaction between young children who used AAC and their primary caregivers, Light et al. (1985a, b, c) noted that:

- the patterns of interaction were highly asymmetrical, with the children taking few turns and exerting minimal control;
- part of the reason for few initiations by the children was the lack of time given to them to do so;
- the children were dependent on the caregiver to expand their messages;

- the interaction patterns of the caregivers with the children did not encourage the independence or communicative competence of the children;
- the children lacked attention-getting and initiation strategies;
- the range of communication functions used by the children was extremely limited, mainly being confirmations and denials.

The researchers also highlighted the difficulty young children experience in developing competence in using augmented modes to communicate when they are primarily exposed to spoken models (Light et al., 1985a, b, c).

Schweigert and Rowland (1992) have described an instructional sequence to teach social contingency awareness to children with dual sensory impairments and severe motoric disabilities. The children were aged from 10 months to 10 years, and when they began the study none of the children had any clear intentional communication. In many cases the use of microswitches was necessary to establish social contingency awareness, often resulting in the development of further communicative behaviours that were not reliant on switch use (Schweigert and Rowland, 1992). By the end of the study all the children had learned new communicative skills, from gaining attention to indicating choices (ibid.).

Janice Light (1997a), in her excellent article '"Let's go star fishing": reflections on the contexts of language learning for children who use AAC', defined clearly the various interrelated contexts that make up the language-learning environment of the young child, and discussed the implications for the child using AAC. The contexts she described included the physical, functional, language, social and cultural, and within the discussion of the functional context, she highlighted findings that children with LNFS spent far more time in activities of daily living and routines, and that this severely restricted the time they spent in play and emergent literacy activities such as listening to stories. The importance of peer interactions in language learning was also discussed (Light, 1997a).

The value of collaborative interaction as the context for learning language in young children with severe physical disabilities and limited speech was suggested in a study by Letto et al. (1994).

The importance of social interaction for school-aged children and adolescents

Relationships with peers not only contribute to the social, cognitive, emotional and academic development of children, but also are extremely important in a child's life, contributing to feelings of happiness and self-worth (Cartledge and Milburn, 1995). Generally the school-age years

result in a major change in the social context for most children. The size of the peer group is usually much larger and more diverse. Peer interactions also make up a far larger proportion of interactions than previously and are less closely supervised than during the preschool years (Rubin et al., 1998). The pattern of typical development clearly demonstrates that interactions with peers become increasingly important as the child matures, and are considered of utmost consequence during adolescence. Competent social interaction in adolescence is based on social and communicative skills that are learned in childhood through peer interaction (Romaine, 1984). Peer relationships in adolescence are more complex and differ in both quality and quantity from those of childhood (Meyer et al., 1998).

In early adolescence small groups of friends function as the primary base of interaction with peers and allow for regular interaction that is more spontaneous and relaxed than that with adults (Nippold, 2000; Whitmire, 2000). Early adolescent groups are generally composed of only one gender and these peer groups give adolescents the opportunity to develop social skills, share personal problems, support one another and develop mutual intimacy, allowing the adolescents to develop autonomy from parents (Nippold, 2000; Whitmire, 2000). As they develop, adolescents spend significantly greater amounts of time socializing with friends (Nippold, 2000; Rubin et al., 1998).

The goal of communication, which aims to develop interpersonal relationships, is particularly relevant to the adolescent phase, compared to the goals of expressing needs and wants, exchanging information and meeting social etiquette or norms. It is in meeting the goal of developing social closeness that people communicate to initiate, develop or sustain personal relationships and friendships (Light, 1988). The focus of the communication is on the interpersonal relationship – the content of the interaction is not significant (ibid.). Thus, in considering the relative importance of the four objectives of communication at different stages of life, communication to develop social closeness with peers is of increasing importance as the child matures and of supreme importance for adolescents (Light, 1997b). Social closeness is critical for adolescents, as it is during this life period that peer relationships and peer acceptance assume prominence and take priority over family relationships (Fine, 1980; see also Chapter 2, which describes the difference between *sharing messages* (participation) and *involvement* in the communication process).

The development of social-competency skills and mature social behaviours in typically developing adolescents is dependent on peer interactions and relationships (Bigelow and La Gaipa, 1980; Cartledge and Milburn, 1995). Both friendships and peer group acceptance are

important influences on the development of social competence and on the self-esteem of the adolescent (Azmitia et al., 1998). The ability to be outgoing, to amuse peers, to participate actively in peer activities as well as the content and use of language all determine the social competence of typically developing adolescents (Cartledge and Milburn, 1995).

The social participation of children and adolescents who use AAC in school settings

Educational service delivery

Children with severe physical and/or intellectual disabilities are frequently not accommodated in either mainstream or segregated schools (schools for learners with special educational needs) in low-income countries. In South Africa students with disabilities have experienced great difficulty in gaining access to education. The Education White Paper 6 (2001) on special-needs education indicated that in 2001 an estimated minimum number of 280,000 learners with disabilities did not have access to either special or mainstream education. The report based this figure on World Health Organization (WHO) projections that between 2.2 per cent and 2.6 per cent of learners in any school system could be identified as disabled, and that only 64,200 learners with disabilities or learning impairments were enrolled in the 380 special schools in South Africa. The results of a lack of education and vocational training are self-evident but clearly, the impact in terms of limited social and community participation on the quality of life of these children is immense.

The movement towards inclusive educational systems whereby children with disabilities are accommodated within mainstream schools or 'least restrictive environments' has gained momentum in many low-income countries. Current educational policies in South Africa, as in many other low-income countries, are committed to a unified educational system of equal access that will 'cater for the needs of all learners within an inclusive environment' (White Paper on Integrated National Disability Strategy, 1997, p. 38). Yet few children with little or no functional speech (LNFS) are admitted to mainstream schools, and children who require AAC are frequently excluded admission to school for learners with special educational needs in South Africa. This problem is exacerbated in the rural areas where minimal intervention and schooling, special or otherwise, are available for children with multiple disabilities including those with LNFS. In these contexts AAC implementation plans may need to be structured to include not only the provision of suitable AAC systems, family and caregiver training but also peer training programmes with

community peers. A study conducted by the authors on the attitudes of typical students towards a peer who uses AAC, demonstrated that programmes focused on the training of peers are necessary to facilitate understanding between peers (Lilienfeld and Alant, 2002).

Participation of students using AAC

Despite a history of inclusive educational policies in industrialized countries, studies of children who use AAC seldom describe communication between individuals of equal status. Generally, the partners described were adults and were familiar to the child who used AAC. The social relationships of the dyad were thus usually asymmetric, with the partner being of a higher status (Light, 1988). Kraat (1987) also holds this contention and stated that, in most of the interactive research studies of children using aided systems, the children communicated in a dyad with a staff member or caregiver. In addition, the communication attempts of children with LNFS are frequently misunderstood or ignored by teachers and caregivers – with resultant communication breakdowns (Calculator and Dollaghan, 1982).

Children and adolescents who have disabilities and LNFS have been described as having limited opportunities to interact in peer groups and that this negatively influences the development of communicative and social abilities (Beukelman and Mirenda, 1992). Learning of communicative and social processes can only take place by regularly interacting with and by developing friendships with peers. Furthermore, to enable children and adolescents who use AAC to generalize communication skills, it is essential that opportunities exist with varied peer partners in natural settings. Thus communication and social-skills learning cannot be considered as goals in themselves but as interactive processes essential to social participation (Butterfield et al., 1995). Adolescents and young adults who use AAC have described feelings of isolation, barriers in getting to know peers, barriers to meeting and making friends, frustrations with respect to initiating and maintaining relationships with peers, and profound frustration with negative experiences related to attempts at peer acceptance and socialization (McCarthy et al., 2002).

With respect to the participation of students who use AAC in inclusive classrooms in America, Calculator (1999) observed two possible outcomes: (1) little or no evidence of social inclusion of some students using AAC, despite good operational competency skills, and (2) students using AAC who were active participants in academic and other activities and who interacted by initiating and responding to varied partners including peers (Calculator, 1999). It is clear that we need to facilitate the latter outcome in both developing and industrialized countries.

The influence of partners in interactions involving AAC

The importance of the communication partner or partners in influencing the success or failure of the interactions of persons who use AAC has been found to be decisive by many researchers (Bedrosian et al., 1992; Light, 1988). Some partners are instinctively far more competent in adapting to the distinctive requirement of interacting with a person who uses AAC, whereas other partners need to receive effective training in strategies to improve communication with persons who use AAC (McNaughton and Light, 1989; see also Chapter 9). There is an interactive effect between the competence of the peer partner and the competence of the person using AAC, each impacting on the other. The development of communicative competence is therefore inseparable from socialization and partner interaction (Butterfield et al., 1995; Whitmire, 2000).

Peer training within AAC research

One of the few resources for peer training with children who use AAC is PACT (Partners in Augmentative Communication Training) by Culp and Carlisle (1988). The programme was developed to facilitate the interaction of children who use AAC and their communication partners (ibid.). Communication partners addressed by the PACT programme include parents, teachers, siblings and peers (ibid.). Topics include priority communication behaviours, communication assessment guidelines, communication intervention guidelines, and psychological considerations, all of which include behaviours for both the child who uses AAC and the partner (Culp and Carlisle, 1988).

With respect to creating opportunities for communication for students with severe developmental disabilities, Sigafoos (1999) highlighted the importance of developing training programmes and support for peers. A communication opportunity was defined as a situation in which a partner would deliberately intervene and require an appropriate response from the child or adolescent who had a severe developmental delay and limited communication. Besides training teachers and staff, the crucial need to train and support other communicative partners who may be less familiar with AAC, such as peer partners, was noted by Sigafoos (1999).

Five typically developing adolescents acted as peer facilitators in a study by Hunt et al. (1988) to encourage the conversational interactions of three adolescent students with severe cognitive disabilities and limited speech. The students, two 16-year-olds and a 14-year-old, attended the same high school as the peers but were accommodated in a separate class. The training took place in a variety of the high-school campus and community settings with peers, five regular high-school students who worked as peer tutors and a university student doing a practical session

(Hunt et al., 1988). Communication books of pictures were developed for each student as a means of promoting conversation and the peers supplemented their verbal comments by pointing to the pictures in the conversation books. The results of this programme of training included a decrease in inappropriate social behaviours and improved conversational skills of initiation and turntaking. Subjective data from the peer tutors, parents and teachers indicated generalization of gains to other settings (Hunt et al., 1988).

In a later study, the same authors trained regular-education peer students as peer tutors to facilitate the conversational exchanges of three children, two of whom were ten years old and the other six years old (Hunt et al., 1991). The training included strategies to promote generalization of specific conversational skills. Brief instruction was given to the peer partners, who were regular education students at the same school and had volunteered to take part in the study (Hunt et al., 1991). The training of the peer partners took less than five minutes and was done singly or in pairs; it consisted of a demonstration with oral instructions on how to use the conversation book, and a short role-play with the instructor (Hunt et al., 1991). The researchers concluded that peer training appeared to be an essential component of the conversational training programme for the students with severe disabilities.

An interesting approach, adopted by Buzolich and Lunger (1995), was to train a 12-year-old girl, who used AAC, to train her partners. The intervention programme primarily focused on training the AAC-using girl to identify the interaction styles of three peer partners and to adopt strategies to gain greater conversational control, including topic direction, speaking-turn control and communication-breakdown management (ibid.). Following awareness and role-playing phases of training, five different peers took part in 30-minute conversations with the girl who used AAC, who was cued during the conversations by the AAC interventionist without influencing the peer partner (ibid.). Another approach proposed by Van Tatenhove (1992) was to use persons who were competent in their use of AAC as peer trainers and mentors.

Thus, although widely advocated, training of peer partners of children and adolescents has received limited attention. One study that focused exclusively on training peer-partner skills to increase the interaction of four children (three five-year-old boys and a girl of nine years of age) was conducted by Carter and Maxwell (1998). The intervention programme did not address the communication skills of the children who used AAC. During their baseline observations the peers seldom waited for a response from the child using AAC and frequently ignored the communication initiations of the child using AAC (ibid.). The training consisted of an orientation session during which the reasons for the study were explained and questions of the

peers relating to both the disability (cerebral palsy) and the AAC systems of the participants were addressed (Carter and Maxwell, 1998). In addition, two peer instruction sessions were held lasting between 15 and 30 minutes per session. During the first session the peers were informed of the difficulties in communication without the use of speech, and the communication boards of the appropriate participants were discussed. The peers then role-played an interaction in pairs using the communication board (Carter and Maxwell, 1998). During the second lesson peers were taught four specific interaction strategies to apply with the AAC-users: making eye contact, asking questions, giving time for a response, and responding to initiations (ibid.). The researchers reported that the frequency of social interactions of the children who used AAC increased during intervention and also that there was an increase in the use of the taught intervention strategies by the peers (ibid.). Given that there was no training offered to the children who used AAC the researchers suggested that the increase in the communication interactions of the children who used AAC may have been due to one or more of the following reasons:

1. increase in the number of opportunities for interaction;
2. imitation of the peers who demonstrated the interaction strategies they had been taught;
3. as a process of natural peer reinforcement that occurred when the children using AAC attempted to communicate (Carter and Maxwell, 1998).

No further training was instituted but intervention effects were noted for between six and ten weeks for participants. Implementation of peer intervention programmes was suggested as a worthwhile method of increasing the social interactions of children who use AAC (Carter and Maxwell, 1998).

Butterfield et al. (1995) emphasize three aspects related to partner skills: (1) attitudes, (2) knowledge/information and (3) increasing opportunities to communicate. These three aspects are interrelated, as providing information and knowledge about the peer who requires AAC has a positive effect on attitudes towards the individual (Gorenflo and Gorenflo, 1991). Providing information and knowledge of how peers can improve their ability to communicate with a peer who requires AAC will generate increased opportunities for interactions (Butterfield et al., 1995).

Additional characteristics of conversational partners mentioned by Calculator (1999) that could be addressed in peer training include familiarity with the AAC system, motivation to communicate with the peer who uses AAC, and the nature of the messages including the verbal input of the partners. It would appear essential to address all of these issues in the peer training component of AAC intervention with children or adolescents who use AAC and to increase the peers' awareness of the value of their own skills as communication partners. In developing training

programmes for adolescents who use AAC it is imperative to identify the requirements of training and to ensure the training as well as the training procedures have a sound theoretical basis. A peer training programme, including the involvement of an adolescent who uses AAC, was conducted by the first author as part of her doctoral study (Lilienfeld, 2003) and relevant issues to this topic are briefly described.

Discussion of a peer programme aimed at training the peer group, including the adolescent who uses AAC, in communicative skills

The adolescent

The adolescent who uses AAC, Simon, was 15 years 2 months old at the onset of the peer training programme. He had severe athetoid cerebral palsy and was the only student in the class who required AAC. He steered his power wheelchair independently by operating a joystick with his left hand but utilized a head pointer to directly select the keys on both his computer keyboard and DeltaTalker.

Simon was a multi-modal communicator whose preferred method of communication was his natural speech, despite the fact that his speech lacked intelligibility. He was operationally competent in using a DeltaTalker with Unity 128 software.

He had mastered a core vocabulary of approximately 2000 words and short phrases using Unity 128. This software encodes words and common phrases by using sequences of pictures (icons). He understood the rationale of how the vocabulary was organized and was able to customize the software by storing specific vocabulary according to his individual needs. His rate of communication was slow, as he made frequent errors in accessing the keys with his head pointer. If he had forgotten a specific sequence of icons for a word or phrase he readily changed to the alternate spell mode and spelt out the required words, letter by letter.

His teachers described his personality as positive, very friendly, warm, affectionate – a likeable person who was fond of jokes and who had an excellent sense of humour. Although he stated that he particularly enjoyed interaction with peers he was perceived by his teachers and parents as having poor peer relationships and no friends within his school peer group.

The peer group

Simon and his peers attended a school for students with physical disabilities. At the school there was only one Grade 8 class, consisting of 14

students including Simon. There were eight boys and six girls in the class and the mean age of the class was 14 years. The medium of instruction at the school was English. Five of the children were from Zulu-speaking families, two were from homes where both English and Afrikaans were spoken, and the remaining seven were from homes where English was the first language. Twelve members of the class were ambulatory and two learners, including Simon, used power wheelchairs.

The training programme

1. The aims of the training programme

The goals of the peer training were determined by the difficulties Simon identified in his interactions with his peer group. The identified difficulties were matched with the desired interaction behaviours of peers, as in the examples presented in Table 12.1.

Table 12.1 Examples of the communication issues and desired behaviours of peers

Difficulties identified by the adolescent who used AAC	Desirable interaction behaviours of peers
i. Inadequate time was given to him to formulate what he wanted to say during small group discussions, especially when using the DeltaTalker	Peers to be more aware of the time taken to interact using AAC strategies and to allow time for the adolescent who uses AAC to formulate messages, especially when using the DeltaTalker
ii. Insufficient opportunities to initiate interactions about topics of concern	Increasing awareness of their behaviours that block conversations with the adolescent who uses AAC. Improved listening and negotiation skills
iii. Peers often addressed the adolescent who uses AAC and asked him a question but left before he could answer their questions	Peers to learn the strategy of waiting for a response from the adolescent who uses AAC
iv. Peers pretended to understand his message when they had not done so	Increase peers' awareness of how frustrating it is for a person not to be understood. Peers to learn importance of telling the adolescent who uses AAC that they have not understood him and to learn methods to assist in clarification of his messages

2. *The communication workshops*

The peer training programme consisted of eight workshops of 50 minutes' duration. The objectives were grouped according to specific goals and themes so that each workshop formed a cohesive unit. The units included:

- conversation (turnabouts);
- behaviours that block communication;
- listening skills;
- conversation maintenance;
- group consensus;
- feedback and clarification;
- rate enhancement and negotiation.

The final workshop included activities to recall and review aspects of the previous seven workshops.

Using games is an effective tool to increase rapport with adolescents and to improve their effort in learning social skills. For this reason games were used frequently during the workshops to reach specific objectives, e.g. 'the common pool', a game devised by Malouff and Schutte (1998) to increase peer co-operation, and 'What is my future?', a panel discussion game used to teach peers the rate-enhancement strategy of asking yes/no questions in appropriate settings.

Social modelling is the principle involved in the practice of teaching a behaviour by presenting a model to be observed and imitated. Excerpts of the videotape 'Face to Face: Facilitating adolescent communication experiences' (Hess, 1993) were used to model the use of contingent questions and comments. Adolescents also learn and maintain behaviour better when cognitive understanding is engendered. Throughout the training sessions there were group discussions to facilitate metacommunicative skills and to encourage the peers to attach relevance to specific skills. This seemed to increase the participants' motivation. Circle seating with the technique of 'rounds' being used during group discussion times promoted cohesiveness and facilitated interactions.

Behaviour rehearsal is considered crucial to ensure that social skills are learned effectively (Cartledge and Milburn, 1995). Activities were structured to enable the peers to practise skills. After introducing conversational turns (turnabouts), for example, a game using topic cards was played that facilitated the peers' interaction with Simon.

All the materials, including fun worksheets, topic cards, unfinished sentence cards, emotion cards etc., were carefully designed, multi-coloured, attractive and suitable for use by all the peers, including those with visual impairments.

3. *Development of pre- and post-measures*

Communication is a dynamic, complex process. The interactive behaviours of the individuals concerned constantly affect the understanding and behaviours of the other individuals involved in a process that is primarily managed by the codes of social interaction. Interactions involving a person using AAC are inherently multifaceted by virtue of the multimodal nature of AAC and the effect of the AAC system used on the interactional process itself. Some of the factors that impact on the communication process include:

- the attitudes and beliefs of the communication partner;
- the behaviours of the speaking partner;
- the multiple modes of communication, some used simultaneously;
- the use of a device and the characteristics of the device;
- the format of the message formulation and transmission;
- issues of positioning and mobility;
- context.

Observational data are described in this chapter although the perceptions of the peers, teachers and parents with regard to the interactions and social skills of Simon were measured before and after the intervention using qualitative measures. These included peer-referenced assessment strategies, sociometric measures, and qualitative analysis of interviews with teachers and parents. Additional qualitative pre- and post-measures included standardized self-concept scales and self-evaluation procedures that were completed by Simon.

Observational data were obtained from extensive videotaping in the natural context of the classroom during the normal school timetable. Videotaping was selected, as it recorded verbal and nonverbal information, provided an accurate portrayal of interactions taking place between Simon and his peers, and provided evidence that was accurate and verifiable. Filming was carried out during the teaching periods of three teachers across four school subjects – English, drama, human social studies and science. This strategy allowed for varied peer interaction opportunities that were representative of typical interaction opportunities throughout the normal school programme. The videotapes were then viewed repeatedly, and transcribed verbatim according to previously defined notation and transcription principles.

The transcription principles included that the transcription should provide a functional perspective of the interactive behaviours, that the context was an important and integral part of the interaction, and that the coding of each message should provide an adequate and systematic description of each message. Notational principles stated that equal

prominence should be given to the child using AAC and speaking peers, that equal value be given to verbal and nonverbal interactive behaviour, and that interactive behaviours be shown as integrated and complementary. Additional viewing of the videotapes resulted in coding procedures being applied. Any interactions not readily understood by the researcher were then shown to Simon who clarified the content and intent of ambiguous interactions.

In order to compare effectively the interaction of Simon with his peers pre- and post-intervention it was necessary to determine contexts that reflected differing levels of opportunity for communicative interactions within the classroom setting. The pilot study established that only three different contexts allowed for varying densities of communication opportunities. These were defined as follows:

(i)   *Teacher-directed time* included periods of teacher instruction as well as periods when the students were engaged in independent academic tasks. Teachers expected that during these times students would not speak, with peer interactions discouraged. This context allowed for minimal peer interaction.

(ii) *Outcome-based educational (OBE) small-group discussion context*, during which the class was divided into small groups. Group members were expected to contribute suggestions and comments with respect to specified tasks. This context encouraged peer interactions related to the task at hand.

(iii) *Informal time context* included times when no teacher was present. This context allowed students to choose whether they wished to interact or not. Students also had relative freedom to choose with whom they wanted to interact, about what, and how they wished to interact.

4. The effects of training

Changes in Simon's interaction included the development of friendships, interaction out of the classroom and changes in the communication functions of his interactions with peers. Changes in his psychometric status and self-concept as well as changes in the responses of his peers were among the parameters observed and analysed.

Of interest was whether there was any change in the frequency or extent of Simon's interactions with his peers. Changes in the frequency of interactions (number of messages per hour) and in the extent of interactions (number of messages per interchange) were quantified using descriptive statistics. An *interchange* was defined as a coherent segment of interaction that was made up of one or more *messages*. Messages constituted the basic unit of analysis and these could be classified as initiations, responses or follow-ons. Additional parameters of the observed

interactions that were of interest and were analysed included the discourse functions, communication functions and modes of communication used by Simon as well as the responses of the peers.

The increase in the frequency of the messages between Simon and his peers is graphically represented in Figure 12.1; context 1 refers to teacher-directed time, context 2 refers to OBE small-group time and context 3 refers to informal times within the classroom.
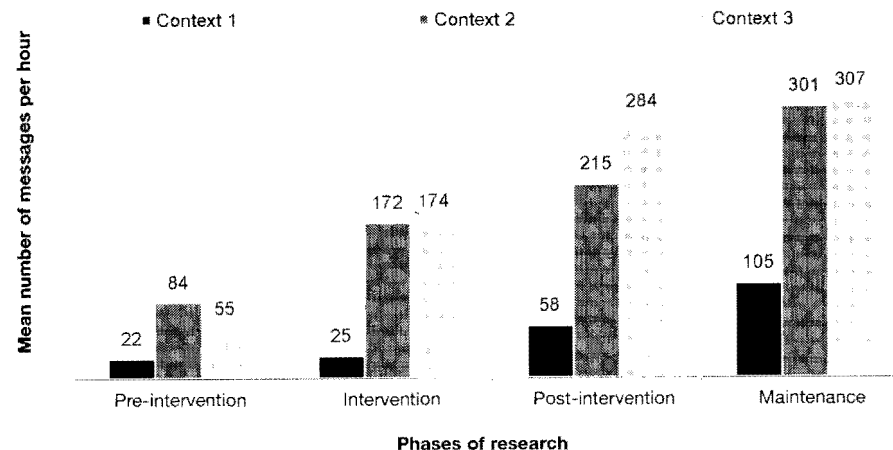
Figure 12.1 Mean number of messages per hour.

As can be seen the increase in messages was not uniform across contexts. The greatest increase was during context 3 (informal times), with a difference between pre-intervention and maintenance phases of 252 messages per hour. The next largest increase was in context 2 (OBE small groups), where the difference between pre-intervention and maintenance phases was 217 messages per hour. The smallest difference was during context 1 (teacher-directed time), which reflected an increase of 84 messages per hour from the pre-intervention to the maintenance phase. The principal increase in the informal time (context 3) was significant, as it is during this context that peers can choose with whom, to whom and for how long they wish to communicate and this would appear to indicate a definite increase in the social interactions of Simon with his peers, as measured in messages per hour. It is interesting to note that the number of messages per hour is virtually the same during the maintenance phase in both the OBE small-group time (context 2) and the informal time (context 3). This is a positive finding, as these contexts do offer different opportunities for interactions and the results could have been disparate.

In OBE small groups (context 2) all the participants in a group were expected to offer opinions and to contribute to the group, whereas in informal time (context 3) the adolescents were free to choose whether or not they wished to communicate with peers.

The mean number of messages per interchange between Simon and his peer partners was also of interest, the hypothesis being that, should the peer training programme result in an improvement in the interactions between Simon and his peers, this would be reflected in not only more messages per hour but also the interactions increasing in extent. The extent of interactions was not measured in time but rather as the mean number of messages per interchange. These results are reflected graphically in Figure 12.2.
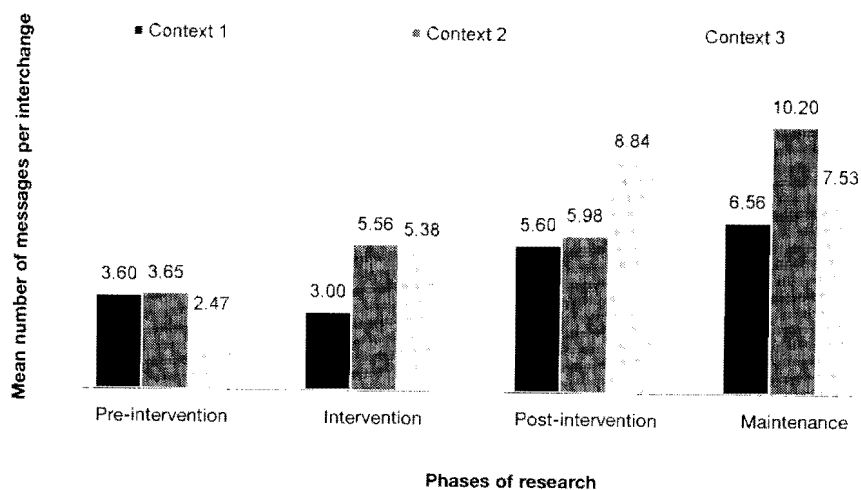
Figure 12.2 Mean number of messages per interchange.

Considerable increases in the mean number of messages per interchange indicated that interactions were maintained to a greater extent than at pre-intervention.

The increase in the number of messages per hour (frequency of interactions) with peers following peer training was consistent with the findings of other research studies during which peer training was implemented (Calculator and Luchko, 1983; Carter and Maxwell, 1998; Hunt et al., 1988; Hunt et al., 1991). The low number of messages per hour of the adolescent with peers at pre-intervention was also consistent with findings that children who use AAC have few interactions with peers in school (Harris, 1982; Kraat, 1987; Light, 1988).

Results of the additional evaluation of the incidence of each of the defined types of discourse analysis, communication functions, modes used by Simon and the responses of his peers indicated the following:

(i) The most significant increase in the discourse functions monitored was in discourse maintainers supporting the evidence of an increase in the extent of interchanges. This was evident in all three contexts.

(ii) The most obvious increases relating to the communication functions of requesting or asking questions, and teasing, pretending, and using humour/sarcasm, were noted within the context of teacher-directed time. During the OBE small-group context the most obvious increases were the communication functions of answering contingent questions, requesting, expressing feelings/emotions and teasing. During informal times Simon showed the largest increases in the use of answering yes/no questions, requesting, as well as teasing and expressing feelings.

(iii) At no time during the study did Simon successfully interrupt the conversation of his peers. This was in contrast to most of his peers, who readily interrupted the conversations of other students.

(iv) The use of his natural voice remained the most preferred primary mode of communication by Simon with peers. However, his use of body movements also increased, particularly in the context of OBE small-group discussions.

(v) A positive factor of the peers' responses was a marked decrease in the occurrence of the peers ignoring Simon.

Challenges of peer training: issues and reflections

1. Lack of validated peer training programmes in AAC

The lack of validated peer training guidelines, procedures and materials was a significant barrier. There was a need for the development of peer training programmes as the peer partners needed to develop attitudes, knowledge and skills to assist their understanding and ability to be effective partners when communicating with other children who use AAC (Light, 1997). It may also be possible to adapt existing programmes that target social interaction skills. In their review, Cartledge and Milburn (1995) listed numerous studies that documented the effectiveness of peer-mediated intervention to train social skills with speaking children who have social-skill deficits. For peers to be influential in maintenance and generalization of behaviours the following parameters should be met:

• the skills targeted must conform to skills demonstrated by the peers;
• the peers must receive instruction and be included in the training sessions;

- conditions to improve group cohesion and co-operation should be instituted (Cartledge and Milburn, 1995).

Peer groups are widely used in life-skills training and psychological skill training, including training in interpersonal communication skills with speaking children and adolescents. One of the benefits of using peer groups to develop skills directly related to the appropriate age of the students is that of mutual reinforcement. This is an important consideration in training the peers of children who use AAC to promote normalization.

It was also important that the training should focus on the quality of interaction and communication and not merely focus on parameters such as the number of exchanges.

2. Limited interactions between children who use AAC systems and peers

As discussed the social integration of children and adolescents who use AAC is frequently problematic. For many of these children both the quantity and quality of their interactions with peers are negatively impacted upon by the inherent disadvantages of using AAC, including the reduced rate of exchange and different expressive mode. Additional factors related to the AAC system may include limited or inappropriate vocabulary, limited range of communication functions, increased demands on the peer in understanding or even co-constructing messages, and the increased physical effort required. Individualized training programmes that include both the children who use AAC and their peers are one possible solution to this issue. Other strategies have included what Musselwhite and Burkhart (2001) have referred to as a Communication Circle, in their description of co-planned social scripts. The Communication Circle is a group of friends or peers of a child requiring AAC who are directly involved in the development of sequenced scripts with the child who uses AAC. The objective of co-planned sequenced scripts is to facilitate greater involvement of the child or adolescent who uses AAC with peers. The script categories described include action scripts, class/work participation scripts and conversation scripts (Musselwhite and Burkhart, 2001).

One practical guide to improving interaction between children that use AAC and their classmates is the handbook *Children Using Communication Aids and their Classmates* by Clarke and Price (2001). Three themes targeted by the manual include improving the attitudes and expectations of speaking peers, building interactional skills with both the children using AAC and their peers, and the development of the knowledge of the peers of the communication aids. Key components of the themes of 'attitudes and expectations' and 'building interactions' are identified, and games and activities suggested for each component. The

activities for the theme of knowledge of communication aids are presented in quiz format in two sections: peer and staff knowledge, and peer and staff responsibilities.

3. Increasing opportunities to interact with peers

The strategy of increasing opportunities for communication is well grounded in the literature of both assessment and implementation of AAC. Greater emphasis needs to be placed explicitly on increasing the opportunities to communicate with peers for children of all ages. At critical times of risk for peer interaction, such as at times of change when a child who uses AAC transfers to a new class and, specifically, at adolescence, the peer interaction of students who use AAC needs to be carefully monitored. Even a child using AAC who has interacted well with peers and had many friends at elementary school may find that this changes at adolescence. Peer training may need to be considered at this stage for a child who, previous to this, was considered socially competent and socially accepted by peers.

4. Lessons from inclusive educational models

Models of educational practice need to be carefully considered to provide the best fit at a particular time for the individual child or adolescent who uses AAC. In low-income countries where mainstream schools do not have support for special-needs students, have very high learner-to-teacher ratios, and are frequently not accessible to people with physical disabilities, total inclusion could be detrimental to the child. However, low-income countries need to carefully review the lessons learned from industrialized countries and then adapt solutions to their own specific circumstances.

In their review of the 'Critical issues in the inclusion of students who use AAC: an educational team perspective', Soto et al. (2001) referred to a number of *key indicators of successful inclusive programmes*. Key indicators included:

- natural support from peers;
- social interaction between the student using AAC and peers both in the context of the classroom and out of school; and
- participatory membership of the student using AAC.

The latter included themes such as that the child using AAC had friends, was happy, not physically marginalized and that the school community accepted diversity and advocated for the students who used AAC. Significantly, another key indicator was that the classroom structure supported participatory learning, including the use of co-operative

learning and activities that built a sense of classroom belonging and community.

Participants from the focus groups in their study included general education teachers, inclusion support teachers, instructional assistants, parents and speech–language pathologists. They all noted the benefits of full inclusion for: the students who required AAC, their peers, the parents of students requiring AAC, the parents of peers, the teachers, and the overall classroom programme. Positive outcomes for the students who required AAC included increased academic expectations, increased social opportunities, receiving the same peer support as typically developing peers, improved communication and language skills, and a greater degree of independence (Soto et al., 2001). Several positive outcomes for the peers included increased academic achievement, learning by teaching and the ability to communicate with peers who used AAC (ibid.). Of additional interest was that the parents of children who used AAC were as, or more, concerned about the social inclusion of their child as they were about the academic inclusion.

Inclusive education using collaboration, co-operative learning, social-skills training and peer tutoring was an effective strategy to advance relationships between children with severe disabilities and their typically developing peers (Jackson, Ryndak and Billingsley, 2000). Peer-mediated instruction or peer tutoring was noted to have the dual outcomes of promoting learning and encouraging peer relations and friendships (Jackson et al., 2000). In their study on useful practices in inclusive education, Jackson et al. (2000) also refer to establishing a sense of community in the classroom, using techniques such as teaching children to advocate for each other, children sharing their similarities and differences, facilitating appreciation between students, finding valued functions for students with, disabilities, and entrenching disability-related topics in lessons. Techniques to allow children with severe disabilities to participate as fully as possible with typically developing peers included using peer–buddy systems and adaptations to promote communication (ibid.).

The significance of focusing on improving the social and communicative competence of students who use AAC with peers is substantiated by the results of studies of mainstreaming in other countries. Communicative and social skills have been found to be better predictors of success in integration of children with disabilities than academic achievement (Goodman and Miller, 1980). Social interaction has been recognized as crucial to successful integration (Ostrosky et al., 1993) and is regarded as the essential criterion with which to measure the success of inclusive programmes (Halvorsen and Sailor, 1990).

5. Criteria to assess the effectiveness of AAC programmes

The effectiveness of AAC programmes with children and adolescents should be determined by how well the child or adolescent is able to meet the social and academic requirements of the classroom (Calculator and Jorgensen, 1991). As AAC clinicians and researchers we need to observe and understand the interaction opportunities and challenges faced by the person using AAC in their natural settings. We need to gain knowledge of how to improve the effectiveness with which children and adolescents who have disabilities and use AAC manage their daily interactions and discourse with peers.

6. The viability of peer training

The persistence of the intervention effects following what was a relatively short period of intervention in the study described earlier suggest that peer training is a viable option to include in the intervention of children and adolescents who use AAC. This is substantiated by the maintenance for two to three weeks of interaction gains noted by Light et al. (1992) after intervention of four 1-hour sessions with facilitators. Similarly, the respondents in the final field trial of the partner-training programme Developing Communicative Interactions (Sack and McLean, 1997) indicated that partner training had a positive ongoing impact on the interactions of persons who used AAC and who had severe developmental disabilities.

Conclusion and implications

Communication is essential for participation in daily life situations. Studies have shown that the implementation of multimodal AAC systems for children requiring AAC resulted in an increase in their interactions with adults, developed their language abilities and had positive effects on literacy development. However, the provision of an AAC system cannot guarantee increased social interaction, the main goal of AAC.

Implementation of peer training programmes, in addition to training the child or adolescent who uses AAC in social skills and strategies, should result in increased social interaction with peers. As mentioned, there have been few studies describing the effects of peer training on the interaction of persons who use AAC. Research studies are required to identify instructional and motivational factors that are essential for the success of peer training programmes and how these factors would differ in importance according to the age of participants. It is necessary to define which variables are relevant to the peer training process and the impact of each on the interaction skills of the child or adolescent who uses AAC. Additional

research to determine the effectiveness of different techniques in peer training would assist in determining which techniques are most effective. A comparison of peer training programmes would be instructive where one programme included activities in which peers have to communicate using AAC in simulated interactions, and another programme did not.

An important contribution would be to establish whether extending peer training to include more natural settings, such as the playground, would result in greater generalization of the social interaction gains. Further studies may identify how the child or adolescent who uses AAC could facilitate the competence of peers in interactions. Speaking persons differ in the way they interact with persons who use AAC and it may be of value to identify and define which strategies used by speaking partners improve interactions. The evaluation of peer training programmes when included as part of inclusion programmes for students who use AAC would usefully explore and compare the experiences and perceptions of the student, peers, teachers and parents. Of additional interest would be the impact of peer training on the interaction of siblings with the child or adolescent who uses AAC.

In the same way that it is now expected that literacy is an essential component of any AAC intervention programme with children who have LNFS, it should be expected that no AAC programme is complete without the successful facilitation of social interaction with both familiar and unfamiliar peers.

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CHAPTER 13
Training teachers for classroom AAC implementation

SHAKILA DADA AND ERNA ALANT

This chapter aims to investigate issues relating to the use of augmentative and alternative communication (AAC) strategies within the classroom context by focusing on the benefits of using aided language stimulation, a description of a teacher training programme on classroom intervention using aided language stimulation, and finally an evaluation and critical discussion on the implementation.

Issues surrounding AAC intervention in the classroom have received significant attention in the literature as teachers take on the challenges of engaging with the complex set of variables influencing learning within group contexts. Even in industrialized countries where financial resources and professional services and expertise are more available and accessible, difficulties surrounding AAC intervention within the classroom context are well known (McCarthy and Light, 2000; Jorgensen and Calculator, 1996). These difficulties (Alant, 2003) include:

* accommodating the individual who uses AAC within the physical context;
* making adaptations to the curriculum for AAC-users;
* access to a communication system;
* managing the communication system and thus updating relevant information;
* facilitating participation in the classroom – role of facilitators;
* training teachers in using the AAC system interactively.

In low-income countries the challenges are increased by various factors including the lack of personnel trained in AAC, attitudes towards AAC devices (Dada and Alant, 2001; Dada and Alant, 2002) and a lack of devices (Alant, 1996; see Chapter 7: Service delivery in low-income countries). However, the need for AAC in low-income countries is great, owing

to the high percentage of persons with disabilities (Bornman and Alant, 1996; Alant, 1999).

In discussing AAC intervention it is vital to acknowledge the important role teachers play in implementing AAC in a classroom. Their commitment and support are vital to the successful implementation of AAC (Alant, 2003; Soto, 1997). Supporting an AAC-user within a classroom context is a complex task. These teachers are faced with the primary responsibility of facilitating learning for the AAC-user as well as other students in the classroom. They need to identify appropriate curriculum goals and determine how an AAC-user can meet these goals (Kent-Walsh and Light, 2003).

However, often teachers do not have special training in working with children with disabilities and have little or no exposure to AAC, indicating the need for teacher training. Furthermore, they may feel threatened by AAC, particularly technology, and therefore may not feel confident when interacting with an AAC-user (Baker, 1993). Teachers' skills in training students, particularly students with disabilities, are diverse. 'Relatively little attention is paid to the task of assisting teachers in developing skills to engage in dialogue with children using augmentative and alternative communication' (Alant, 2003, p. 336).

Teacher training should address the needs of diverse classroom contexts. The characteristics of these classrooms are that teachers have to cope with multi-level teaching not only in relation to various levels of competency of students, but also in relation to diverse languages and special needs. This chapter aims to investigate issues relating to the use of AAC strategies within the classroom context by focusing on:

* the use of aided language stimulation in the classroom;
* a description of a teacher training programme on classroom intervention using aided language stimulation;
* an evaluation of the training programme with respect to teachers' training;
* a critical discussion and recommendations for future consideration.

Aided language stimulation

Aided language stimulation is an intervention approach focusing on the use of pictures and graphic symbols to enhance interaction with individuals with little or no functional speech (LNFS). Graphic symbols are used to supplement verbal communication in order to enhance the comprehension of speech for children with LNFS. These also serve to increase their participation by allowing students to point to graphic symbols, thereby communicating. Aided language stimulation aims therefore to teach the use of picture symbols through modelling interactive use of

these picture symbols in a meaningful context. It operates under the premise that modelling of interactive use is necessary to promote the interactive use of an aided communication system. This process requires a facilitator, who could be a teacher, therapist, parent or aide, who points to picture symbols on a facilitator communication board (Figure 13.1) in conjunction with ongoing language stimulation (Goossens', 1989; Goossens' et al., 2000). Children with LNFS could participate expressively through the use of the facilitator communication board or alternatively through pointing to symbols on their personal (smaller) version of the facilitator communication board.
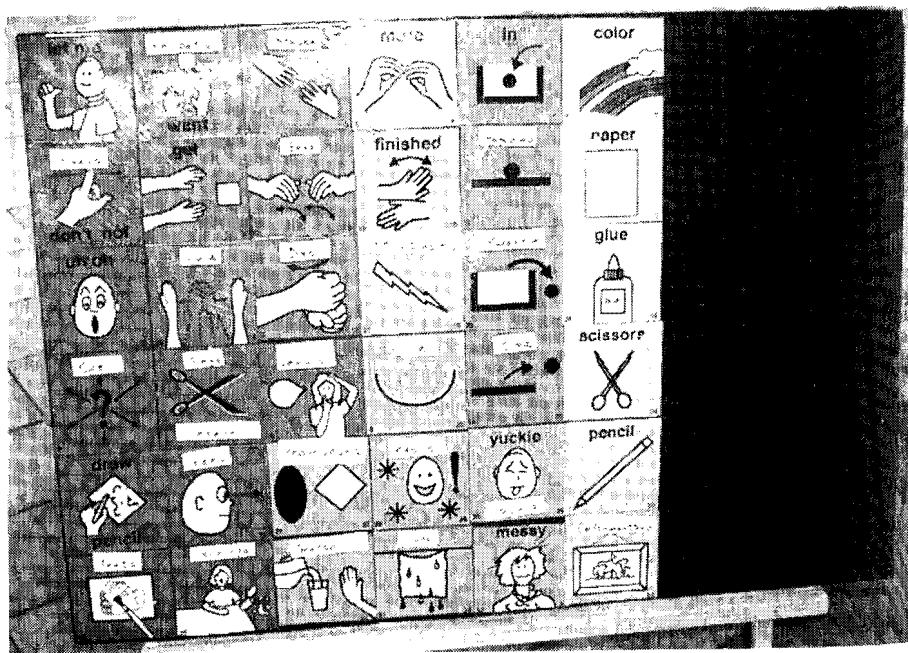
Figure 13.1 The translated arts and crafts activity board.

The approach of aided language stimulation is similar to that of total communication approaches used in the population with hearing impairment. For example the facilitator may say 'Put the jelly in the bowl' while pointing to the symbols 'put', 'jelly', 'in' and 'bowl' on a board, vest or electronic device or other display (see Chapter 3, as well as Wasson et al., 1997, p. 128). It is therefore imperative that the displays must be accessible to the facilitator, and this requires the facilitator to prepare in advance the vocabulary items for the students for each activity.

Aided language stimulation has a variety of instructional techniques that facilitate the use of the communication displays. Various techniques can be used to augment input by pointing or highlighting the graphic symbols as spoken input is provided. The highlighting can be done using the index finger, torchlight or a squeaky toy to draw attention to the symbols being used. The techniques are based on the way natural speakers learn to understand language, and therefore are intended to teach language to an AAC-user in a natural way. The use of a naturalistic setting implies that the instructions are embedded within the activities of daily life. There is an opportunity for joint experience in a routine that can facilitate the development of communication (Beukelman and Mirenda, 1998).

Benefits of aided language stimulation

The benefits of using aided augmentative and alternative strategies as a visual support has become increasingly important in a variety of interventions in children and adults with LNFS, including those with autism (Cafiero, 1988; Quill, 1997; Mirenda and Ericson, 2000; Rowland and Schweigert, 2000; Johnson et al., 2003). Other benefits include prompting joint attention in children (Quill, 1998), establishing conversational referents with children with multiple and severe disabilities (van Dijk, 1966; Hunt et al., 1990; van Dijk and Nelson, 1998), increasing the comprehension of linguistic concepts in children (Quill, 1997), and facilitating social interaction and communication intent with children with severe disabilities (Mirenda and Santogrossi, 1985; Jolly et al., 1993; Krantz and McClannahan, 1993; Bondy and Frost, 1994; Zanoli et al., 1996; Schwartz et al., 1998).

Those with LNFS can also benefit from aided language stimulation by improving their expressive and receptive language abilities (Hodgson, 2000; Goossens', 1989; Romski and Sevcik, 1992; Romski and Sevcik, 1996; Romski et al., 1994; Romski et al., 1996). It can also serve to facilitate interaction between teachers and the learner as well as between students. As aided language stimulation is a group strategy it is congruent with the outcomes-based education philosophy used in schools. The group strategy enables teachers to engage many students simultaneously and move towards facilitating learning across students with various abilities. The use of graphic symbols is beneficial to a variety of students. Students can benefit from the memory cue the symbols can serve, by facilitating story-retelling or cueing the steps that are required for an activity. A further advantage of aided language stimulation is that it is a technology that is appropriate for classroom contexts, as it uses laminated cardboards. This low-technology option would be familiar to teachers.

Furthermore, the cost implications for further development of boards for instruction or students would be relatively affordable. It is against this background that aided language stimulation could be a significant contribution as a strategy within the classroom.

A pilot project to investigate the application of aided language stimulation within special-education classrooms in one province in South Africa was initiated and will be discussed in more detail.

Description of a teacher-training programme on classroom intervention using aided language stimulation

Background to the schools and training

The classroom context within the South African context is diverse. The diversity extends to both teachers and students. Teachers have variations in their teaching skills and academic qualifications. A study conducted in special schools in the Pretoria region indicates that teachers' qualifications range from university degrees while other teachers have not completed their secondary school qualifications (Alant, 1999; Alant and Emmett, 1995). This diversity in teachers' skills impacts on the students who vary in their abilities. The ability of teachers to teach students with differing needs can be facilitated through training programmes.

In order to address the need for teacher training, a programme was developed; it was aimed at addressing two critical needs; first, encouraging a strategy that could be used with diverse students and could therefore assist with multi-level teaching. Second, the training was aimed at increasing teachers' self-reflection on their teaching strategies with children with diverse needs including those with LNFS.

The teacher-training programme that was developed included some activities that were common to the academic programme of the schools. This would allow integration of the programme into the existing academic programme. An aided language stimulation programme was developed, as it is able to address issues in classrooms that have diversity in terms of students' languages, skills and ages.

Training phases

The training approach included two main phases as illustrated in Figure 13.2. The first was to familiarize the teachers with communication boards and their use in the classrooms. This was conducted during two full-day

training workshops in which all teachers working with students with special needs in the province were trained in aided language stimulation. The second phase focused on specific teachers who were supported in implementing the training in the classroom context. Three in-situ training sessions were scheduled over a six-week period. A contract between the school principal and teachers as well as the Centre for Augmentative and Alternative Communication (CAAC) was entered into to serve as a joint commitment to the project. Carol Goossens' highlighted the need for contractual commitment during her visit to South Africa in February 2001. She uses a similar method with her consultations with schools in New York and found a contract a useful method of enhancing commitment.

Figure 13.2 Schematic representation of the structure of the training.

Phase 1: Formal two-day training workshop

A formal two-day training workshop for all the teachers in the province was conducted. The workshop focused on various topics including the importance of participation in learning for children with LNFS, government policy regarding education of students with LNFS and special needs, aided language stimulation and finally evaluating and monitoring teachers' and children's progress. Role-play and modelling of techniques were used to demonstrate important concepts. A total of 130 teachers were trained during the two-day workshop. The workshop was received positively, with 84 per cent of the teachers rating the training as 'very good'.

Training objectives

The training objectives for the formal two-days' training were:

- to familiarize teachers with the philosophy of communication boards in the classroom;
- to assist teachers with identifying relevant content for communication boards for use in the classroom;
- to develop a monitoring system for use by teachers to monitor progress;
- to assist teachers in developing skills in using communication boards in interaction within a classroom context.

Outcomes for phase 1

The outcomes of the training were that capacity in terms of dealing with diverse students was developed in the province among special-education teachers. In addition, teachers in the province were able to have a common vision and understanding of facilitating participation of students in the classroom. They also had the opportunity to develop communication boards and observe demonstrations of their use. Finally teachers were able to identify resources within their province and surrounding areas to cope with the diversity of students.

Phase 2: In-situ training in schools

Trainers went into the classroom at the selected schools to support the teacher in implementing aided language stimulation.

Training objectives

The training objectives of the in-situ training in the schools included:

- selection of particular curriculum activities to be targeted and video-taped for monitoring purposes;
- self-evaluation by the teachers in relation to their interaction patterns with students in the classroom using the tool developed;
- demonstration of activities that enhance interaction in the classroom;
- re-evaluation of teacher interaction at the beginning of every follow-up visit;
- videotaping of teacher interaction during the final follow-up visit and discussion of further development in the classroom.

Two teachers at three different schools in the province were identified for the in-situ training sessions. These schools were involved in the in-situ training sessions and were diverse, with two schools having resources for teaching in an urban and peri-urban context and one school with very few resources in the same area, made up of tin structures that functioned as classrooms. The teachers' skills also varied. Four of the six teachers had teaching degrees and two had teaching diplomas. The teachers' experience in teaching children with special needs varied with each teacher having a minimum of four years' experience. The ages of the teachers varied from 28 to 40 years of age. The teachers all taught in primarily pre-primary or primary school classrooms.

Figure 13.3 The translated food preparation board.

Each school was provided with the following training materials:

- two wooden display boards;
- four communication boards (facilitator boards) for the teacher to use for instruction;
- loose symbols for facilitator boards and for teachers' own boards;
- checklist of classroom interaction patterns (see chapter appendix);
- up-front preparation list;
- handout on the process of teaching;
- smaller communication boards for use by children with LNFS.

All the basic training materials for the in-situ training were provided to the teachers. These included four facilitator boards or communication boards for use by the teacher. Four activities were trained, namely arts and crafts (Figure 13.1), food preparation (Figure 13.3), song board for 'Mr Crocodile' (Figure 13.4) and the 'gingerbread man' storyboard (Figure 13.5).
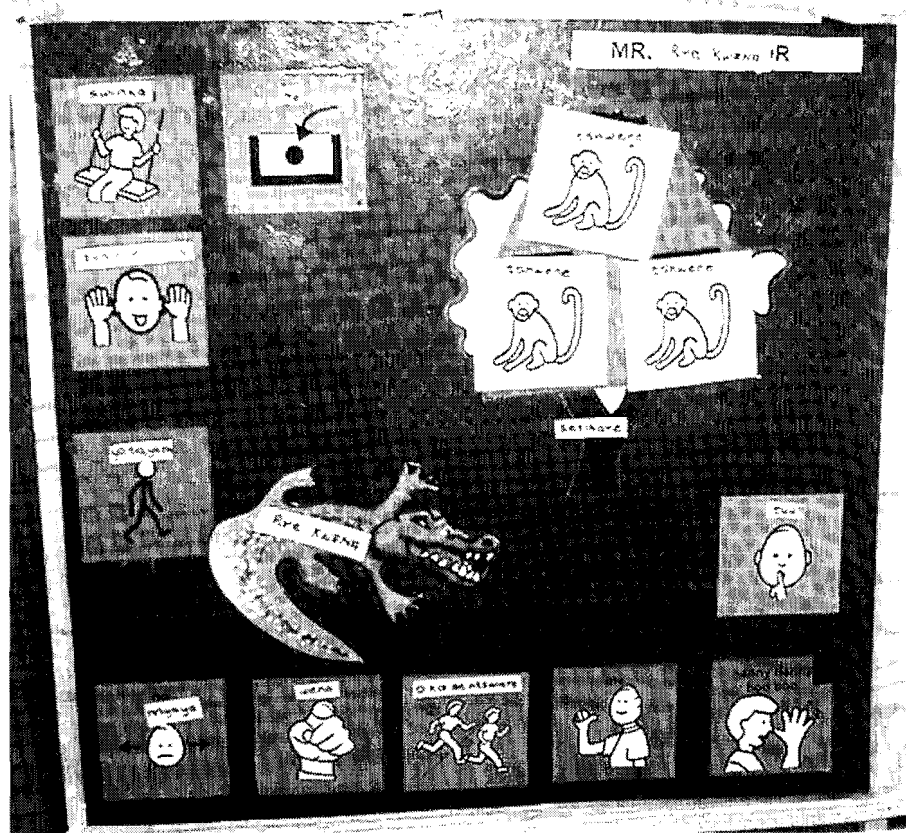
Figure 13.4 The translated 'Mr Crocodile' board.
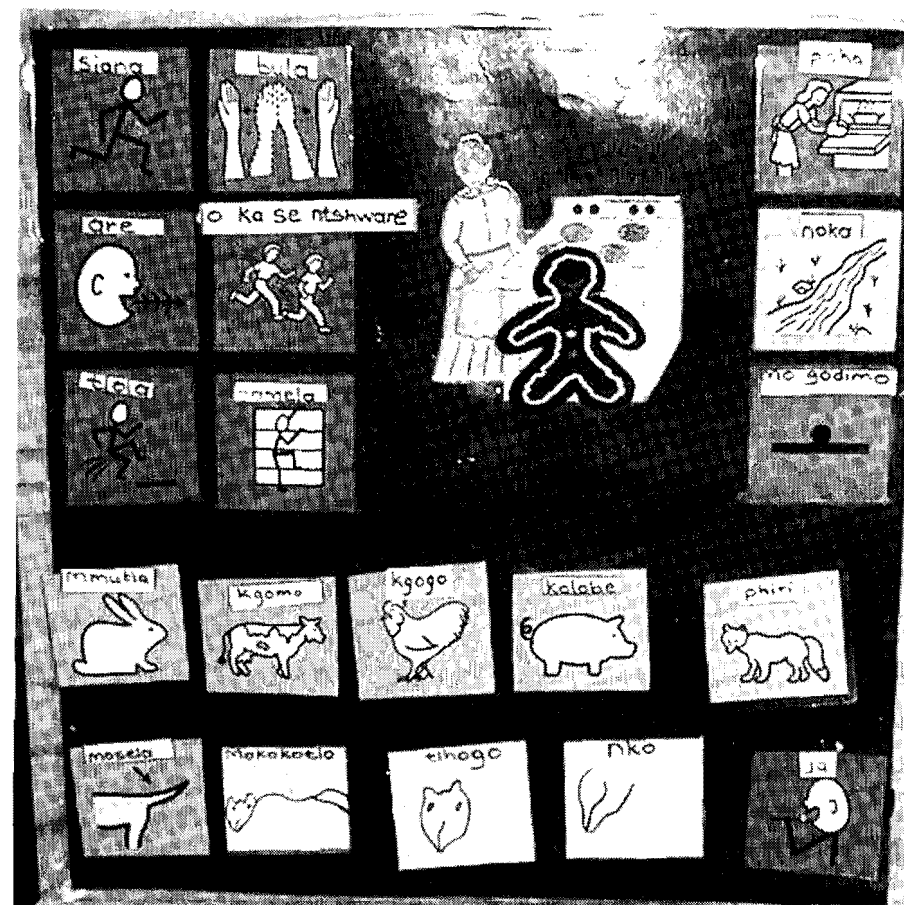
Figure 13.5 The translated 'gingerbread man' storyboard.

There were three in-situ visits during the training. The aims for each visit are shown in Table 13.1.

Outcomes for phase 2

Teachers improved their skill in aided language stimulation as they were able to use pointing and talking simultaneously. In addition they were successful in adapting and aligning the aided language stimulation concept with the current teaching curriculum including assisting with focusing on activities of literacy development and placing literacy activities high on the teaching agenda. Additional resources were also developed in accordance with the curriculum. The teachers developed storyboards based on stories that were told in the class, and Setswana

Table 13.1 Aims for each of the in-situ training sessions

In-situ training session 1	In-situ training session 2	In-situ training session 3
• To obtain an idea of teachers' current practice	• To observe and video-record the teachers using aided language stimulation with a song and story-board activity	• To observe the teachers' skills in using aided language stimulation for the food preparation and an arts and crafts activity
• To introduce teachers to the resources and skills required to do aided language stimulation		
• To assist with the implementation of aided language stimulation in the classroom through physical organization of the class for optimal learning, identifying the unique challenges in each classroom	• To facilitate the implementation of strategies learnt at the two-day training course including the use of the communication boards in the class, using the principles of aided language stimulation	• To discuss implementation of aided language stimulation with the teachers
	• To slow down the rate of input	• To problem-solve some of the difficulties experienced
• To expand and generate ideas of how to achieve greater student participation in the classroom	• To use symbols with dual representation (i.e. PCS and gloss)	
• To help teachers to develop better understanding of the level of representation of each student	• To make recommendations based on the video recordings for the next visit	
• To demonstrate the use of the communication boards in the classroom by the trainers	• To facilitate the students' participation in the activities	
• For teachers to practise doing aided language stimulation with a song board	• To translate the concepts on the communication boards into Setswana for easier aided language stimulation	
	• To assist teachers with keeping records of progress made by both teachers and children	

song boards were also developed. The existing boards were used repeatedly in a creative manner to teach curriculum themes. For example, the gingerbread man was used to teach body parts. Another activity was to teach clothing items and this was done by dressing the gingerbread man. The 'Mr Crocodile' song was adapted using different predators and their

prey. Numeric skills were included here on a basic level. For the older students, the teacher used the board as a memory cue to assist the student in telling the story to the class using the communication board. The students with LNFS were also able to participate in the activities through the use of their own communication boards. Other students who participated and directed activities in the class also used the facilitator boards. The teacher-directed adaptations facilitated greater participation of students and the group, which is in line with the current outcome-based education philosophy used in schools in South Africa. The participation of all the students increased and there was more consistent and interactive participation from the students. The implementation of the aided language stimulation principles facilitated 'calmer' classrooms with children seated and concentrating. Teachers were also encouraged to keep records of their own progress as well as of the students to facilitate an increased awareness for the need of monitoring and reflection on the teaching process.

Evaluation of the training programme by trainees and trainers

After teachers implemented aided language stimulation using an activity, they completed an evaluation of their performance on a four-point scale using a checklist of 'Classroom Interaction Patterns for Teachers' (see chapter appendix). The checklist was developed specifically for the training, and considered five areas:

1. The teacher's awareness of her interaction – this section asked questions relating to the teacher's familiarity with the students' prior experiences and learning.
2. Language use of the teacher – refers to the use of communication boards by the teacher during the activity.
3. Comprehension of training – this section deals with the teacher's skill in determining students' comprehension of instruction and the activity.
4. Knowledge of teacher – refers to the teacher's skill in planning lessons that are appropriate for the students.
5. Progress – this section deals with the teacher keeping records of her own as well as students' progress.

The trainers also completed the same checklist for the teachers and identified skills that could be further developed for the next session. After the evaluation, the trainers and teachers would discuss the strengths of the session and would suggest strategies for the next session. These

suggestions were then jointly agreed upon and provided to the teacher in written form for reference.

The results of one school (two teachers) are discussed below to highlight common issues. The results are discussed by presenting the teacher–trainer discussions for each session. In addition, the teachers' self-evaluation as well as the trainer's evaluation on the pre-training and post- in-situ training are presented and discussed. Table 13.2 illustrates the discussions and suggestions between the teachers and trainer after each in-situ training session. Figures 13.6 and 13.7 illustrate the teacher's self-evaluation as well as the trainer's evaluation.

Table 13.2 In-situ training discussions between teachers and trainer

In-situ training	Aim/objective	Strategies	Results	Recommendations
1	Teachers to demonstrate the use of the 'Mr Crocodile' and 'gingerbread man' facilitator boards	Aided language stimulation, i.e. point and speak Incorporate all the children in the class	Teachers were inconsistent with pointing and speaking simultaneously The teachers demonstrated that they were able to engage the entire class	Teachers to practise using the activity boards by writing the sentences that can be said using the words available on the board Increase student participation by organizing the seating of the children to be more conducive to participation Ideas for storing symbols were introduced as well as ideas to facilitate children's participation through the use of boxes for picking symbols
2	To demonstrate the use of the activity boards To demonstrate how to block out symbols to facilitate the use of	Use aided language stimulation, i.e. point and speak as well as using more statements than questions	The teachers were able to incorporate the strategies into the session. The use of aided language stimulation improved; however, teachers found	Teachers were asked to block out some of the symbols on the 36 matrix activity boards (Goossens' et al., 2000). Only 20 symbols were then exposed. This would facilitate their skill with aided language stimulation greatly. It was further recommended

Table 13.2 contd.

In-situ training	Aim/ objective	Strategies	Results	Recommendations
2 contd	augmented language stimulation for students with LNFS	The written gloss was translated into Setswana	the activity boards more difficult to use than the song and storyboard The translation of the boards reportedly made instructions easier	that this could be removed as their skills increased To expand the use of the boards in creative ways to meet other academic agendas by developing work-sheets around the activities and including literacy agendas Facilitate the participation of children with LNFS through encouraging the use of the individual communication boards
3	To demonstrate the use of all the facilitator boards To engage the group equally in the activities To extend the activity by incorporating literacy and academic agendas	Demonstrate aided language stimulation in terms of pointing and speaking simultaneously and using more statements than questions	Teachers found the method of blocking of symbols facilitated aided language stimulation in the early stages of implementation for the activity boards Group participation was facilitated and the children using communication boards successfully incorporated Finally, teachers used worksheets to include a literacy agenda for the older children and fine motor activity and matching skills for the younger children. They also extended the themes in accordance with the curriculum by including body parts and animals of prey etc. into the activity	Teachers were encouraged to continue with the aided language stimulation and to develop more boards for their activities They were encouraged to gradually increase the matrix size of the activity boards as their skills developed (Goossens' et al., 2000) Increasing strategies like prompting, time delay and pausing to facilitate participation were also encouraged

Teacher 1

Sections

▨ Teacher pre-in-situ training   ▦ Teacher pre-in-situ training
☐ Teacher post-in-situ training   ▧ Teacher post-in-situ training
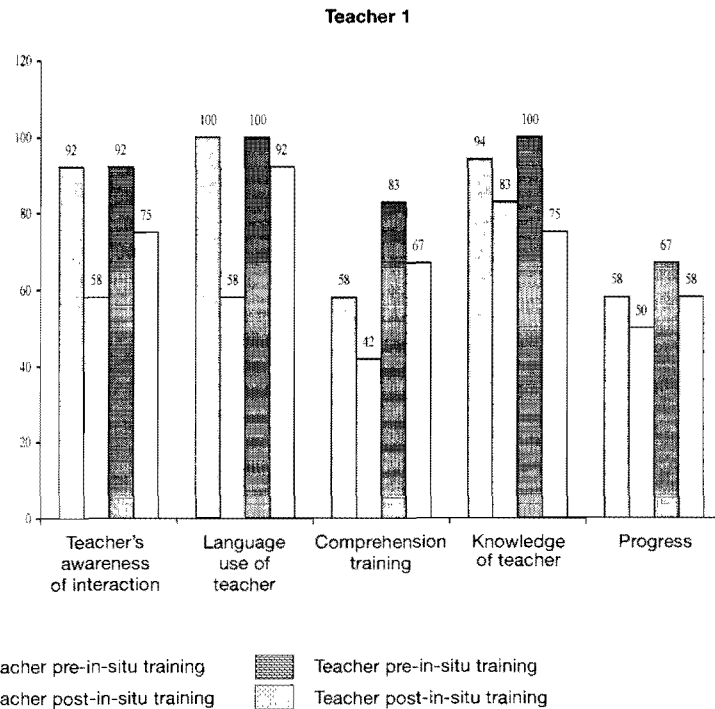
Figure 13.6 Comparison of evaluation: self-rating of Teacher 1 and trainer evaluations pre- and post-training.

Results and discussion of Teacher 1

It is evident from Figure 13.6 that Teacher 1 rated herself as having skills in all the five sections, i.e. between 58 and 100 per cent. Her ratings were consistently higher when compared with the trainer's ratings on the pre-in-situ training which were generally between 50 and 83 per cent. The teacher's ratings on the post-in-situ training indicated an improvement in skills in all sections except the section on teacher's awareness of interaction and language use of teachers. The trainer, on the other hand, noted differences in all but the section on knowledge of the teacher. Also, minimal progress was made on the section of monitoring progress (50–58 per cent). Table 13.2 shows that this was not a matter strongly focused on by the trainers, which may be a reason for the lack of progress in this regard. The teacher's perceived lack of improvement in comprehension training may be attributed to the teacher becoming more critical of her skills, particularly in relation to facilitating comprehension of all the children in her class and not only those with verbal skills. It is evident from Table 13.2 that the recommendations for in-situ training session 2 were specifically

related to facilitating participation of children with LNFS. It would appear that the recommendation was carried out, as is evident in the trainer's higher rating on the teacher's awareness of interactions. The nature of the language used by teachers was another area on which the trainer rated the teacher higher (58–92 per cent). It is evident that the recommendations made in the in-situ training sessions 1 and 2 had a positive impact on Teacher 1's use of language with the children.

In the post-in-situ training, it is evident that the teacher's and trainer's ratings were more congruent. The implications of this congruence are twofold. The first is that the teacher's skills had improved and therefore the trainer rated Teacher 1 higher on the scale. The second postulation is that Teacher 1 developed critical and reflective skills about her own teaching and was therefore able to evaluate herself more stringently.

Results and discussion of Teacher 2

Figure 13.7 illustrates that Teacher 2's rating of her skills on the pre-in-situ training was high, with Teacher 2 rating herself 100 per cent and 94 per cent on the sections on language use and knowledge. The ratings for the other sections were between 75 and 92 per cent. The trainer, however, rated Teacher 2 consistently low on all five sections with scores

Teacher 2

Sections

▨ Teacher pre-in-situ training   ▦ Teacher pre-in-situ training
☐ Teacher post-in-situ training   ▧ Teacher post-in-situ training
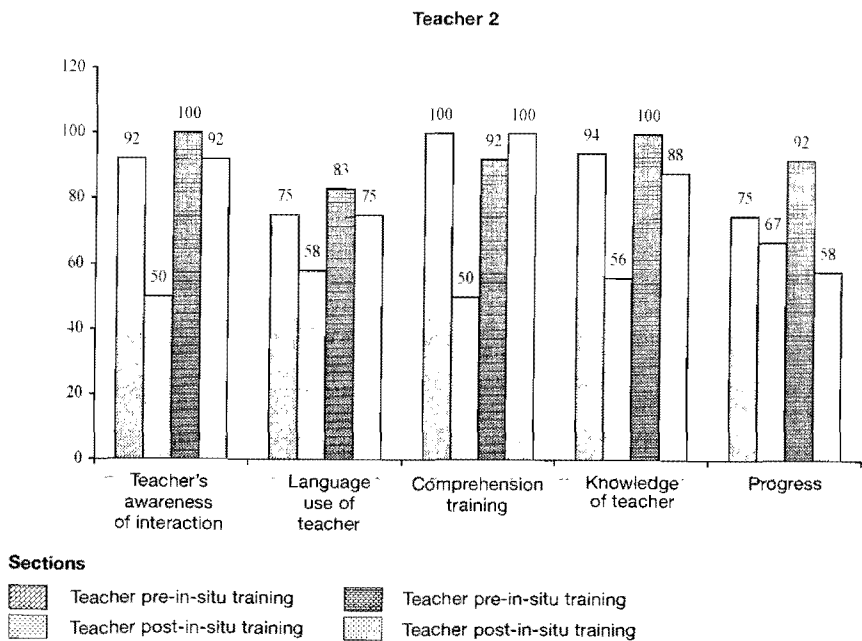
Figure 13.7 Comparison of evaluation: self-rating of Teacher 2 and trainer evaluations pre- and post-training.

between 50 and 67 per cent. The discrepancy between Teacher 2's and the trainer's ratings for the pre-in-situ training is evident. The discrepancy may be attributed to Teacher 2 having difficulty with critical reflection. A similar trend is seen in the post-in-situ training ratings. Teacher 2 rated her skills between 83 and 100 per cent with the trainer's ratings being between 58 and 100 per cent. From the trainer's ratings it is indicated that Teacher 2 had improved in all five sections of the scale; however, the gap between the two ratings remained quite big. It is interesting to note that the raters noted substantial improvements in the sections relating to all the areas except monitoring progress. The areas that showed progress are those that were focused on the in-situ training. Table 13.2 illustrates that the emphasis of the in-situ training was on developing the teachers' skills in providing aided language stimulation and facilitating participation of all children.

Figures 13.6 and 13.7 indicate that the training improved teachers' skills in all of the areas on the checklist, particularly the areas pertaining to the teachers' awareness of interaction, the language used by the teacher, comprehension training and teachers' knowledge. These were the areas directly focused on during the initial formal two-day training. It is, however, clear from the above ratings that teachers still experienced difficulties with the monitoring of progress in the classroom and that additional assistance in this area was needed.

Critical discussion and recommendations for future consideration

The results of the training programme indicated that the aided language stimulation programme is a programme that is easily accepted and utilized as a group strategy in a classroom. The teachers were positive about the impact it had on the students in terms of controlling disruptive behaviour and the manner in which it facilitated group work. It also provided teachers with the skill to cope with students with diverse needs and skills. This was evident in the graphic symbols serving various functions for the students. For some students it served as a means of expression and for others it served as a memory cue and facilitated their independence. The teachers' responses to the strategy were positive and they were keen to see its application more widely.

There were some concerns, however, about the adaptation of the strategy to fit more closely with the curriculum. Advice and support for ensuring that the strategy used in a manner congruent with the curriculum was needed. In addition, the cultural appropriateness of the stories and activities needed to be increased to ensure that communication

boards enhance the dynamic process typical of classroom interaction. For example, the activities needed to be based on those used within the settings. Information on stories or information exchanged in the classroom need to be visually represented to ensure that communication remains relevant and stimulating to children. In addition, the food preparation and arts and crafts activities needed to be based on the resources available as well as types of activities typically done in such a setting. These are pivotal in enhancing sustainable interaction between teachers and students. From the above it is indicated that although teachers used these facilitator boards to interact with the students, concerns were raised in relation to long-term use of these boards as a dynamic force in classroom interactions. More support will be needed to assist teachers in expanding on the present interactions using aided language stimulation strategies.

An additional concern was the difficulties that teachers experienced in monitoring the progress of individual children in the classroom while using aided language stimulation. This aspect needed to be addressed, because the documentation of what learners gained from class activities forms an important part of the outcomes-based education philosophy in the schools.

Another important aspect was that the boards were made and developed based on the English language. However, they were used in two schools in the vernacular languages of Afrikaans and Sepedi. The gloss above the graphic symbols were therefore translated into the languages and used on the boards. Hence, attention needs to be placed to the development of the boards when used in different languages. The vocabulary used on the boards should then also lend itself to translation and also facilitate grammatically correct aided language stimulation. Figure 13.4, for example, clearly indicated the different types of pictures introduced to facilitate first-exposure familiarity to the children. These aspects are indeed important as discussed in Chapter 6. Sensitivity thus relates not only to the vocabulary introduced in different languages, but also to the visual representation of these concepts to facilitate identification with the process. Clearly, as children become more familiar with the process these issues might become less important as students relate better to more abstract symbols (see Chapter 3).

The advantage of aided language stimulation is that it is a group strategy that lends itself to use with multiple and diverse students simultaneously. However, this strategy requires that the teacher or facilitator engage with all students equally and not be distracted by a particular student. Hence, the facilitator needs the support of a secondary facilitator. Given the scarcity of resources in most schools in low-income countries or contexts, schools require new methods of incorporating secondary facilitators. These options may be to get volunteers to assist on a

rotational basis or to get teacher aids to assist where necessary. This issue needs further exploration to ensure sufficient support for the implementation of this strategy in the classroom context.

Another observation relates to the discrepancy between the trainees' self-evaluations and the trainers' evaluation, particularly in the beginning of the process. This observation is not new, as trainers have often reported on trainees' rather uncritical appraisal of their own skill before training (Wium, 1994; Bornman, 2001; Reed et al., 2002). There are various possible explanations for this phenomenon, including lack of proficiency in the English language, lack of knowledge or insight in being able to rate their own behaviour and attitudes and lack of trust in the context as to how the information will be used (Reed et al., 2002). The tendency to become more self-critical after training is, however, a positive indication, as the trainees' and trainers' evaluation clearly tended to converge in their perceptions. Perhaps the meaningfulness of this process is centred more on the convergence of opinions and discussion of the participants than on the individual ratings between trainees and trainers.

Aided language stimulation is a strategy that works particularly well with preschool and beginning primary school children. However, its role in stimulation with older children needs to be further explored. Typically the classes were diverse in the ages of the students in the class: some children were seven years of age while others were older. Hence, the strategy needs to be flexible to facilitate and meet the needs of diverse students and needs. The use of this strategy to facilitate multilingual interactions also needs to be further expanded on.

In conclusion, the introduction of aided language stimulation as a strategy in schools for children with varied disabilities proved a most exciting and meaningful venture. The refinement of this approach in assisting teachers both to monitor progress of individual students and to make adjustments necessary to maintain and enhance the dynamic interaction in the classroom (see Chapter 2) pose substantial demands on the teachers. Clearly this is a strategy that can best be implemented within a strongly teacher-supported context where teachers can work together to make material, but also can focus on the system as an open system to enhance learning not only between teacher and class but also between students.

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Appendix

A CHECKLIST OF CLASSROOM INTERACTION PATTERNS: TEACHERS

Teacher: _____ Date: _____

Period/Lesson rated: _____

This rating is aimed at providing the teacher with a basic understanding of the interaction patterns in the class. It is intended for use as a guideline to improve classroom interaction within a specific lesson context.

	1	2	3	4
Section 1: Teacher's awareness of interaction				
1. Does the teacher ensure that the children are familiar with the classroom routine, i.e. interactional rules?				
2. Is the teacher able to introduce a topic and share her teaching agenda to ensure that students understand the purpose of the teaching session?				
3. Does the teacher show an awareness of prior experiences and knowledge of the children?				

		1	2	3	4
Section 2: Language use of teacher					
4.	Does the teacher use the communication board when speaking?				
5.	Does the teacher co-ordinate her pointing and speaking simultaneously?				
6.	Does the teacher use more questions than statements in the interactions?				
Section 3: Comprehension training					
7.	Does the teacher probe to determine the comprehension of the pupils?				
8.	Is the teacher able to assist the students who demonstrate a breakdown in comprehension?				
9.	Is the teacher able to make all the children participate?				
Section 4: Knowledge of teacher					
10.	Is the teacher knowledgeable about the social environment of the children?				
11.	Is the teacher aware of the personal needs of the children?				
12.	Is the teacher focused in what she wants to teach the children, i.e. are the lesson goals specific?				
13.	Does the teacher help to organize new information into existing frameworks for the children?				
Section 5: Progress					
14.	Does the teacher use a system for describing the progress of each student?				
15.	Does the teacher record progress consistently?				
16.	Does the teacher record her own progress?				
TOTAL					

Promoting leadership and advocacy

ROY McCONKEY AND ERNA ALANT

This chapter focuses on the formation of service-user groups, either of parents who have children with disabilities or people with disabilities themselves. The role they can play in lobbying for and providing better services to children and adults with communication disabilities is examined. Ways are described in which rehabilitation professionals can nurture and support these associations. However, there are particular challenges that these associations face, especially in low-income countries, that cannot be easily overcome given the many socio-economic problems these countries face. Even so there are some examples of self-help among parents and people with disabilities in many low-income countries that can provide hope and inspiration to others seeking to promote associations of augmentative and alternative communication (AAC) users or their families and friends.

Changing times

Internationally there has been a shift from organizations that speak *for* people with disabilities towards those made up of persons *with* disabilities who speak for themselves. The perspectives of AAC-users in the book entitled *Speaking Up and Spelling It Out* by Fried-Oken and Bersani (2000) also reflect this important paradigm shift. In fact the slogan that originated in South Africa, 'Nothing about us without us', coined by Disabled People South Africa (DPSA) is a clear reflection of the movement towards self-determination and self-representation of people with disabilities. This group also includes associations of parents who have children with disabilities, as they are the persons best suited to advocate for their sons and daughters. With some disabling conditions this may have to

	1	2	3	4
Section 2: Language use of teacher				
4. Does the teacher use the communication board when speaking?				
5. Does the teacher co-ordinate her pointing and speaking simultaneously?				
6. Does the teacher use more questions than statements in the interactions?				
Section 3: Comprehension training				
7. Does the teacher probe to determine the comprehension of the pupils?				
8. Is the teacher able to assist the students who demonstrate a breakdown in comprehension?				
9. Is the teacher able to make all the children participate?				
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extend also into the adult years although this at times may generate tensions between parents' views and those of the people who have the disability.

This development has followed in the path of wider societal trends such as the promotion of human rights for women and ethnic minorities, the outlawing of discrimination on the basis of sexual orientation and religion, for example, and the promotion of democratic principles of justice and freedom of speech. There has also been an increasing awareness of issues surrounding women and children with disabilities as well as the association between poverty, disabilities and social exclusion (see Chapter 4: Disability and poverty). Arguably these trends have opened up the possibility for the voice of people with disabilities to be heard.

Yet this comes after generations when disability was seen as a stigma and a curse on the person and the family; when people with disabilities were seen as worthless and a drain on the family and the tribe; when people with disabilities were denied the opportunities offered to others to grow and develop, such as attending schools. The centuries of oppression in nearly all societies around the world have left a legacy of insecurity and inadequacy among persons who are labelled disabled preventing them from advocating for their rights and to assume the responsibilities that flow from them.

Leadership

Nevertheless in the past 20 years there has been a growth in disability rights movements internationally. A variety of documents facilitating these movements in both industrialized and low-income countries include the United Nations' (UN) Declaration of the Rights of Mentally Retarded Persons in 1971 and the UN Declaration on the Rights of Disabled Persons in 1975, the adoption by the UN General Assembly in 1981 of the World Programme of Action Concerning Disabled Persons (WPA), which was followed in 1993 by the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

The success of these actions is due in no small measure to the leadership of certain individuals, be they parents or people with disabilities, who brought a unique combination of talents to the task.

First, they were personally credible in that they had various disabilities or were parents of people with disabilities. They knew at first hand what it means to have a disability and to have experienced the stigma and discrimination that flowed from it. No longer were able-bodied people promoting the cause of the disabled. No matter how good their intentions, it maintained the myth that people with disabilities were not able

to speak for themselves. The rallying cry became 'disability is not inabilty'. Self-determination and one's ability to make independent decisions are highly valued, as the leadership in disability movements becomes more focused on how to promote more appropriate role models for young people with disabilities.

Good communication skills and a good understanding of issues facing people with disabilities across many different groups in society are but two of the most important leadership attributes (Fried-Oken and Bersani, 2000). Networks of contacts who could help to further the cause, first among other people with disabilities but also among the non-disabled, and seeking out the sympathizers and turning them into activists too are relevant in working for change within a broader community context. Among the latter, community leaders, politicians and journalists were especially helpful. This interaction between people with disabilities and those without is increasingly important due to the focus on social inclusion.

Invariably within associations there are disagreements on priorities and strategies, so effective leaders are required to be diplomats and negotiators yet keeping to the fore a vision of how the future could be different, and bringing others along in pursuit of their goals.

Perhaps the pre-eminent qualities though are those of energy and enthusiasm. The many tasks undertaken by leaders are draining, physically and emotionally, yet they need to maintain their enthusiasm if they are to win over the hearts and minds of others to their cause. The self-sacrifices that so many leaders of disability associations have been prepared to make for the greater good of their constituents are indeed humbling. It is truly remarkable to note the talented people who have led disability associations around the world, many without high educational attainments and from poor backgrounds and little or no previous experience save that of disability. Hence there is hope that around the world there are many more potential leaders waiting to be nurtured.

Challenges for AAC-users

Nonetheless people with disabilities who also have communication difficulties are doubly disadvantaged from taking up leadership positions within society. It is so much harder for them to speak up for themselves. The importance of good communication skills on different levels is, however, widely acknowledged by AAC-users themselves, as Johnson (2000) stated: 'Honest and effective communication is crucial for any healthy relationship and even more so when one of the partners is an augmented communicator' (p. 47). Like various other AAC-users, she describes life as a series of challenges and sees her ability to develop a streak of

stubbornness early on as essential in coping with these. Bersani and Fried-Oken (2000) summarize the essays of all the AAC-users in their book as defining five main areas of support: access to devices and equipment, direct support staff, training, funding and supportive peers to facilitate integrated and active lives for those with little or no functional speech. These supports focus on the importance of not only access to technology and training, but also facilitating the supportive network of friends to increase the opportunities for communication.

Herein lies a major challenge facing AAC intervention: people with severe communication disabilities need assistance to not only supplement their existing communication but simultaneously to expand opportunities for communication, within the personal network of the individual, but also within communities (Beukelman and Mirenda, 1998). Blackstone and Hunt-Berg (2004) developed the social network system that describes the personal interaction opportunities of AAC-users in an effort to broaden the analytical as well as intervention framework of AAC-users. The challenge, however, remains one of ensuring that the AAC system becomes integrated within the lifeworld of the individual – to facilitate interaction in an authentic way. Too often are AAC systems prescribed and purchased without sufficient collaboration between the individuals with severe communication disorders and the environment they live in. Integration of assistive technology within the lifeworld of the individual therefore remains one of the major challenges facing self-representation for people with severe communication difficulties (see Chapter 9). The Augmentative Communication and Empowerment Supports (ACES) (2004) programme (run by the Institute on Disabilities, Pennsylvania's University Center for Excellence in Developmental Disabilities based at Temple University) is one prime example of a training programme focused on broader self-representation issues for people with severe speech difficulties. Not only does this programme include issues surrounding access to communication, but also much attention is focused on the vision of the individual in planning and gaining control over their own life.

Another consideration is for different organizations for people with disabilities to work together on common goals. This offers another way whereby the needs of people with communication impairments can be articulated but this time it is by persons with other disabilities rather than able-bodied interpreters. Even so, people with communication difficulties will often need someone to effect these introductions and to assist with their integration in the wider disabled grouping.

It is not surprising then that all over the world it has fallen to parents to speak up for their children with communication difficulties. Many parent associations have achieved great things for their members, and

their formation in countries or regions where previously there were none can only be commended. Yet it is important to see them as complementary and not alternatives to organizations for people with disabilities. Sadly there are many examples of conflicts between these two types of associations, which are perhaps not surprising as they may have different aspirations and needs to promote and defend. But these differences weaken the message which the wider society needs to hear, and much energy gets expended in 'internal battles'. Partnership working between associations of parents and those of disabled people is the ideal goal.

The role of associations

In this section we examine the role of associations and how they help families and people with communication difficulties. We identify three main functions: providing members with solidarity, information and advocacy that are common across all associations for people with disabilities or of parents irrespective of their size and sophistication.

Solidarity

Parents who live in poverty often are demoralized and not able to represent their own children adequately. This is particularly evident as generational or chronic poverty (see Chapter 4) is often associated with social isolation. In recent interventions with a group of parents in a rural area outside Pretoria in South Africa, for example, parents were asked to identify their social structure by filling in a modified version of the Inventory for Social Support developed by Trivette and Dunst (cited in Dunst et al., 1988). Figure 14.1 describes whom they see as their major sources of support.

Parents had to rate the frequency of support they receive from different social sources on a scale of 1 (not at all) to 5 (almost every day). Ratings 1 and 2 were combined and categorized as 'not helpful', while ratings 4 and 5 were categorized as 'very helpful'. From this figure it is evident what number of these parents (total n = 25) experience support from people in the community. Parents found their contact with professional helpers most helpful whereas friends, neighbours and other community-oriented contacts were rated as less helpful. This could reflect the lack of social capital and distrust, which are often associated with families who live in poverty contexts. Parents also admit their hesitancy to engage in each other's lives. It is also important to point out that the professional assistance, which is rated so highly, is a social worker from a church group who visits the area twice a week. Clearly, within this
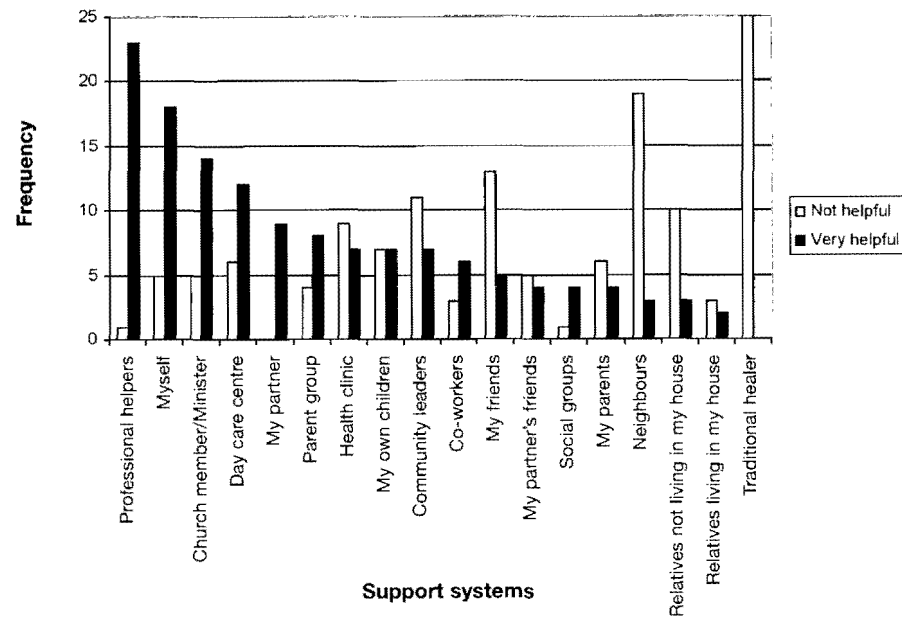
Figure 14.1 Support structures of parents in parent group (n = 25).

context, the development of associations for parents as a means to empower themselves to act more effectively as advocates for their children becomes most important.

Meeting others who have been through or who are going through similar experiences can assuage the heartache that comes from feeling alone with a problem. This emotional support can be crucial in helping families adjust to the birth of a child with severe disabilities or when a mother is shunned by the family because they blame her for the child's disability (Balasundaram, 1995). For people living in poverty this solidarity is often difficult to achieve due to suspicion and lack of trust.

Equally it is easier to join others to challenge prevailing attitudes and practices in society rather than to take action single-handedly. Membership can also boost self-confidence and help to create a sense of pride in having a child with disability. This appears to be best fostered at a local level; hence national associations need to develop a network of branches. Alternatively, groups of parents and/or people with disabilities can come together to form their own association that may later affiliate with regional or national bodies.

Solidarity can also be nurtured internationally through regional groupings of national associations or by linking organizations in the industrialized world with those in low-income countries. These linkages enable stronger

and longer-established associations to share their expertise and resources with those who are struggling to make their voice heard at a national level. Exchange visits can assist greatly in cementing these relationships.

Information

Parents bemoan the lack of information that is available to them even when they have access to a range of professionals (Chen and Simeonsson, 1994). 'Today parents expect straight talk, not evasion. They want as much information as possible about their child's condition, and they expect truthful answers to their questions and in terms they can understand' (Batshaw, 1991, p. 3). Often the need is for information tailored to their present needs and concerns and presented to parents in readily accessible ways. In Lesotho, Southern Africa, the leaders of nine branches linked to the national parent association identified the following needs for their parents, who had children mostly with intellectual disabilities (McConkey and Mphole, in press):

* knowing how to assess, teach, train and handle their child;
* ways of raising parental awareness and of mobilizing parents;
* rights of people with disability;
* disability issues generally;
* working alongside professionals and report-writing for committee members;
* making teaching aids and equipment.

Disability associations often produce newsletters for their members; most organize meetings, conferences and training events with invited speakers; some have telephone helplines and others employ 'parent advisers' or development workers to provide information and training for their members. Russell et al. (1999) demonstrated the gains to families in Southern India of participating in ten weekly group-based sessions that provided information on a range of topics.

Advocacy

National associations have a vital role to play in speaking up for the rights of people with disabilities. The first declaration of rights adopted by the United Nations for people with disabilities was that for People with Mental Disabilities in December 1971, followed in 1978 by a statement of the Rights of Persons with Disabilities. Many of these statements remain inspirational in many countries of the world.

Disability associations often organize events to profile issues of concern and gain the interest of media such as radio and newspapers.

Delegations from the association may also meet government officials to press their case. Likewise, the national association may support individual members as they confront local issues. In Lesotho the parent association lobbied on the school enrolment of children with communication difficulties, and the police refusing to prosecute the rapist of a lady with intellectual disabilities.

The advocacy role is likely to be more effective if alliances are made with other disability organizations that share a common interest. In many countries there is now some form of national disability council that brings together all the disability organizations.

Common challenges facing disabled people's organizations

All over the world, disabled people's organizations face various challenges that reduce their effectiveness and indeed may even threaten their continuing existence. Among the most common are the following.

Fragmentation

The needs of people with different impairments and talents are hard to reconcile within the one association. Indeed the practical difficulties of finding a common means of communication and an accessible venue for meetings can prove impossible to overcome, not to mention the different priorities and aspirations held by various constituents.

Maintaining enthusiasm

Life is a struggle for many people with disabilities. They may have problems with travelling from home and insufficient disposal income to cover travel and entertainment expenses, and are more likely to feel ill-equipped to undertake the tasks involved in the smooth running of an association. Nor are they immune to the inter-personal conflicts and petty jealousies that afflict many community associations.

Conflicting aspirations

Associations also have to contend with different views among their members as to their main aims. Some will want to adopt a rights perspective and will be prepared to advocate protest and political actions in pursuit of justice. Others are more comfortable with building coalitions and networks of support in the hope of providing a better quality of life for

themselves and their fellow members. Still others may support the continuation of special and segregated systems which, they feel, advantage disabled people. It requires skilled leadership and strong powers of negotiation to mould these diverse aspirations into one set of common aims. Not surprisingly, in absence of this, associations can split into factions that expend energy in arguing among themselves rather than promoting the cause of disabled people.

Fostering associations for parents of children with disabilities

Much of the foregoing is just as applicable to associations of parents of children with disabilities. However, it should be noted that these groupings are rarely confined solely to parents, as they usually welcome other family members or people who are 'friends'. The latter can include professional or community personnel involved with the client group. The mix is valuable, especially as it brings a wider range of experience and expertise to the group, but care must be taken to avoid a takeover by professionals with an agenda that can be different to those of the parents for whom the association was created. One safeguard is for parents to be in the majority on the management committee of the associations.

The form and functions of parent associations can vary. Three main models can be distinguished, although they may co-exist to some degree in all parent associations.

Empowerment model

The three functions of building solidarity, supplying information and promoting advocacy noted earlier are all summarized in the concept of *empowerment*, which some would see as the pre-eminent function of parent associations or organizations for persons with disability (Skogmo, 1995). This model of association has certain implications. The management and control of the association rests solely with parents and people with disabilities; professionals can only have a supportive role to them. Associations must grow indigenously; they cannot be imposed by governments or by professionals or from outside the country, no matter how well-meaning the donor agency is to develop these sorts of associations.

The empowerment model has many achievements to its credit, not least through raising the profile of disability and making sure these issues are given attention in the media and by politicians. However, it is not without its critics, notably from disability specialists who feel that only minority views are represented and the needs of more vulnerable and weaker

persons are not voiced. Moreover the fragmentation among the disability movement into groups that focus on different disabling conditions has produced unwitting competition for attention.

Service model

In many countries, associations have gone on to organize services for their members and for other families who have a child with disabilities. Most often these have been day centres and schools for children, and sheltered workshops for adult persons. However, other associations have launched preschool home-visiting services, supported employment schemes and residential facilities. In Zanzibar, the community-based rehabilitation programme is run under the auspices of the Zanzibar Society for People with Disabilities. Often these new services were developed as 'model schemes' with the hope that they would be taken over or emulated by government, which has indeed happened in many instances.

These endeavours, however, produce a very different model of association. Greater priority has to be given to fundraising with a consequent danger of perpetuating the charitable image of people with disabilities rather than promoting them as members of society with equal rights (Bersani, 1998). As more paid professional staff join the association, power and influence can slip away from the members as they defer to those with training and expertise in disability such as doctors and therapists or those with backgrounds in financial and personnel management. The organization can shift away from addressing the needs and concerns of people with disabilities and their families, towards an agenda set by staff and the funding agency.

Two broader risks are also present. First, the services are more likely to be available to the more affluent, better educated, urban-based families and people with disabilities, especially if charges are levied for using the service. Second, government agencies are given the perfect excuse for not developing services or making mainstream services available to those with disabilities, as the special services set up by the associations are already doing the job!

In reality, most associations invariably end up providing some services to their members, and it can hardly be otherwise when the needs in some countries are so great. Often this takes the form of food distribution and clothing, the provision of medicines or aids such as wheelchairs, or the development of income-generation schemes for members or family carers such as mothers. In more industrialized countries, leisure schemes and holiday breaks for people with disabilities are common, as these forms of services are unlikely to receive government funding or require professional involvement. However, knowing what *not* to do is as crucial for the future well-being of an organization as knowing what to do.

Partnership model

The advent of community-based rehabilitation (CBR) schemes has given rise to another model of association (Helander, 1993). Although CBR programmes were initially conceived as being led by professionals who instigated the training and support of the support workers, more recently the emphasis has shifted onto building community ownership of local schemes (O'Toole, 1995). Local management committees are established, consisting of persons with disabilities, family members, community leaders, and interested community staff such as teachers and health workers. This group takes responsibility for different aspects of the CBR programme, such as the support and training of families, provision of resource centres, community education initiatives and the development of community facilities that promote the well-being of everyone in the community. Likewise, in parts of China, neighbourhood resident committees undertake some of these functions as part of the welfare system (Tse, 1995).

This model brings together families and people with various disabilities, unlike the previous ones that tend to concentrate on a specific disability. Moreover relationships are forged among the various stakeholders; membership is not confined to parents or people with disabilities. These schemes are, however, invariably localized – often based in rural areas – as it is difficult to replicate this model at a national level. Instead a national federation of local CBR schemes that retain their autonomy holds promise as a means of attaining a national voice and profile.

In sum the tensions among these three main models of parent associations are likely to persist for some time within low-income countries, although in the industrialized world two trends are becoming clear. First, parent organizations are including persons with disability as full members and consequently shifting more towards an empowerment rather than service model. Second, a partnership model is becoming more remote as associations for more specific disabling conditions proliferate, each intent on ensuring that its particular demands are met. The consequences of both these trends will become apparent in the years ahead.

Common challenges facing parent associations

There are challenges that parent associations in low-income countries share with their sister organizations in more affluent countries.

Involving fathers

Invariably women have been to the fore in instigating and managing parent associations. A common complaint is the lack of support received

from fathers. In part this may be because professional services have tended to relate more directly with mothers, although it is likely also to be reflective of a wider cultural ethos in which child-care is predominantly women's work (Herbert and Carpenter, 1994). This has undoubtedly weakened the impact of parent associations, especially in their dealing with male-dominated politics and governmental systems. Few solutions have been found, although there are notable exceptions from around the world – so it is perhaps too soon to give up on the male of the species!

Redefining families

As the incidence of divorce rises, so too does the number of single-parent families (Kwok, 1995). Likewise the number of children living in reformed families is increasing as parents remarry and children are adopted by foster parents or live in child-headed households due to the devastation of the HIV/AIDS epidemic, particularly in southern Africa. Moreover, with the breakdown of the extended family, parents come to depend on support from their friends, who may become more part of the nuclear family than the child's blood relatives (Carpenter, 1997). The impact of these worldwide social changes on parent associations has not been studied but a pragmatic response would be to ensure that membership of such groups is welcomed from all those who are playing a 'parenting' role.

Ageing associations

Many associations are started by parents who have young children. As their sons and daughters grow older the needs and interests of the membership change. In time, it can mean that the association is no longer seen as relevant to younger parents and so the association or branch 'dies out'. Equally, ageing parents may no longer be able to play an active part in associations. This may mean that pertinent issues for this group are not addressed. One solution is to try to enlist the adult siblings of the people cared for by ageing families, although to date this does not appear to be happening to any great extent (Krauss et al., 1996).

The role of rehabilitation professionals

Werner (1995), a disabled activist, asks: 'What kind of rehabilitation efforts would be most appropriate from the perspective of people with disabilities?' He answers his own question thus: 'Clearly they are ones which will help us to empower ourselves, so that we can join with other disadvantaged and socially concerned groups, both locally and globally, to work towards changing the power structures that deny us our basic rights'

(p. 17). This is indeed an important call, as it not only focuses on the internal interests of the specific organization for people with disabilities, but also makes a plea for the broader identification with other equally important social causes. Disability specialists can support associations in a number of interrelated ways, such as the following.

Recommendations

If associations exist, then specialists need to get to know the leaders and the work they are doing so that they can personally recommend the association to the parents and disabled people they meet in their work. If there are no associations, the role is then commending the idea of forming one to the parents and people with disabilities they know who have leadership potential.

Networking

Disability specialists should be able to put local people in touch with similar associations in other parts of the country or in neighbouring countries. If finance permits, exchange visits could be arranged. Alternatively, literature could be sent, telephone calls made or emails despatched. A key step is helping local groups affiliate to regional or national groupings, as this will not only build links with people who have come through similar experiences but also strengthen feelings of solidarity and progress being made.

Resources

Specialists can also assist associations in accessing resources. These can include making available a room for meetings, covering postal and telephone charges, providing administrative support for typing letters or sending emails, the provision of refreshments at meetings and identifying possible donors.

Training

Disability specialists can provide advice on identifying training needs, devise awareness-raising and training inputs, acting as a trainer/facilitator for the committee and for the association members on pertinent topics, and locating colleagues who could do this also. The provision of training resources such as video equipment and the photocopying of leaflets can also be of great assistance. The example from Guyana demonstrates the impact which disability specialists can have when they work with local groupings of disabled people, parents and interested community supporters (see box on p. 336).

Training initiatives in Guyana

The Community Based Rehabilitation (CBR) Programme in Guyana, South America, produced a number of training packages based around specially made video programmes recorded in family and community settings. These programmes were shown in villages with a locally recruited person to act as course leader (O'Toole and McConkey, 1998).

Experienced community volunteers (including parents of people with disabilities) organized local courses for various groups, using specific training packages. For example, a training package on integrating children into mainstream schools has been used by a cadre of experienced CBR workers to provide a 20-hour training course for teachers from nursery and primary schools in their areas. Nearly 300 teachers participated in local courses in one year.

Likewise a training package giving basic health messages – Facts for Life – was presented by local CBR teams to over 4000 persons in the interior region of Guyana, and two recently produced packages aimed at promoting the well-being and development of all children and hence preventing developmental disabilities have been used with approximately 2000 persons.

When we free our mind from the traditional image of 'trainers in disability' services, then we can begin to appreciate that the number of potential tutors could be very much greater if they were provided with suitable resource materials. Community staff, parents of people with disabilities and people with disabilities themselves are but three groups who would be well motivated to undertake the task. Their skills and confidence for this task can be developed through training workshops (McConkey et al., 2000).

Counselling

Association leaders and committee members often benefit from having a trusted counsellor with whom they can discuss in confidence some of the difficulties they are encountering, and talk through with them the various options open to them and the likely consequences of following each. Throughout, the role must be one of empowering the leaders to make their own decisions rather than trying to solve the problems for them.

Resource centres

Many associations have started a resource centre in their locality which acts as a focal point for a range of activities such as preschool crèches, income-generation activities, book and equipment library, advice centres, training location or simply a meeting place. Disability specialists can often assist with the setting up and funding of such locations. Many of

these centres start in borrowed accommodation such as nursery school classrooms, halls linked to churches or temples, clinics or community centres. Some make progress to having their own rented accommodation in an ordinary house or office-block, usually at favourable rates from a local supporter.

In all these roles, the disability specialist has to 'lead from behind' and preferably work in partnership with members of the association, thereby building their capacity to undertake these roles for themselves.

Priorities for promoting AAC by associations

In this section the focus is on three priorities for which associations in low-income countries need to advocate and support through local action. These hold the promise of giving people with disabilities and their families a fuller and productive life.

Early intervention from the first months of life

The growth and development of infants with disability needs to be stimulated through regular interaction with other people and involvement in family routines. The impact of early intervention programmes is well documented in affluent countries (Farran, 1990) and there is every reason to believe that similar interventions will be equally effective in poorer countries despite the extra economic and social stresses these families face (Zinkin and McConachie, 1995).

Associations can provide parent-counsellors who will visit families after the child has been diagnosed, and share with them their experiences and how they set about helping their child. These parent-to-parent schemes operate in various low-income countries with mothers sometimes volunteering, although others are paid an honorarium to undertake this work in their local community.

Likewise training can be offered in AAC to families at an earlier stage, and opportunities offered for the child's enrolment in preschool facilities, possibly provided directly by the association on certain days of the week or by mainstream facilities whose staff have been trained by members of the association and which they continue to support.

The support of parents with young children clearly needs to be focused on the identification of strengths and resources (Dunst et al., 1988), in an active attempt at building capacity and networks within the context to support early childhood development. Dealing with the child in fostering communication and other developmental processes needs to be an integral part of increasing parent self-efficacy and feelings of self-worth.

Education

Although the world's nations aspire to making education available for all children, a recent review paper prepared for the World Education Forum, held in Senegal in April 2000, estimated that 113 million children have no access to primary education; particularly disadvantaged were girls, working children and those with special needs.

Within affluent countries, children with disabilities have traditionally attended special schools – where they were available – but increasingly parents are opting for regular schooling with extra supports. In the developing world, few special schools exist and for most countries this is an unaffordable option even if it was thought desirable. Hence the only opportunity for many children with disabilities is to be educated by attending their local school (Hegarty, 1993). For these families, inclusive education is not an option but a necessity.

Yet given class sizes and the lack of expertise among teachers, it is vital that families continue to support the child's use of AAC and learning at school. This may mean associations maintaining close contact with teachers, finding people who can assist in classes – such as retired teachers or older siblings – as well as families assisting with homework. Integrating AAC systems as an integral part of the individual and family's life becomes the pivotal issue in strengthening educational opportunities for AAC-users and their families. Sound understanding and support of the values associated with participation of all individuals in society, regardless of their disability, language or race, is needed. Clearly, this becoming a reality requires exposure and involvement in activities and processes that can facilitate the development of positive attitudes as part of the education process. Apart from school-going individuals, teenagers and adults should also avail themselves of further education opportunities, such as vocational training courses provided locally.

Associations have a vital role to play in lobbying for these opportunities, in identifying allies among educationalists in their locality and encouraging parents to play an active role in supporting schools.

Productive employment

Disability and poverty are often first cousins throughout the world but more especially in poorer countries where there are no social security benefits (see Chapter 4: Disability and poverty). Any member of the family who is not productive is then a drain on family resources. Hence, as far as possible, children with disabilities need to become self-reliant in their personal care and be able to undertake jobs around the house, such as water-fetching, so that the family workload is shared.

It is better still if the young people can play a part in income generation, perhaps by assisting on the family farm or business or by holding down a job with local employers (Neufeldt, 1995). The latter option is becoming more of a reality in industrialized countries with the advent of supported employment schemes in which a support worker trains the person with a disability on the job, and remains available to offer support and guidance to employers and co-workers should problems arise. It is possible that similar schemes could operate in low-income countries – especially in urban areas and as industrialization advances. If people have a source of income the options for their care outside of the family are also increased.

Associations thus have a vital role to play in advocating for increased training and employment opportunities for AAC-users and in developing networks with potential employers to make them aware of people's talents. Some organizations for people with disabilities arrange capacity-building training for their members as well as organizing self-employment and co-operative work schemes.

Challenges facing low-income countries

Finally, associations in the world's poorer nations face some particular challenges that modern technological society struggles to understand and which can easily be overlooked. These are listed here with some possible solutions. We end this chapter with them because it is in future years that we will discover how these apparently insurmountable obstacles can be overcome.

Reliance on international donors

The amount of money that organizations or parent associations can raise locally is often inadequate for them to develop the infrastructures to meet their members' needs, and neither will their governments contribute to these costs. For many groups, the solution has been to seek donations from abroad, although this has often compromised their autonomy and means of working. International funding agencies need to develop more equal, trusted relationships with the groups whom they fund (Brohier, 1995).

Government prohibition

In some countries, the formation of associations is deemed unlawful and perceived as a threat to government. Official sanction may be obtained for associations to be formed, although this may be at the price of being a tool for the 'party' or government. Another alternative is for groups to meet under the name of 'social club' and ostensibly to eschew any form of action

that could be construed as political. Finally, in some cultures, men may not allow their wives to become involved with associations and they can also prevent visitors coming to the family home. Progress in these domains will only come about through wider cultural changes and democratization.

Communications

Telephone, fax and electronic communications are still sparse in many countries, certainly outside of the major cities. Likewise road transportation can be poor and even non-existent. O'Toole (1995) recounts how a husband and wife travelled ten days by canoe and on foot to attend training workshops in the Amazonian forests.

Satellite communications and modern information technology offer some hope but dependable electrical supply is often the greater problem. Again, as the national economic prosperity increases, these issues will fade.

Leadership

The initiative to form and maintain parent associations often comes from a few exceptional parents. The danger is that these same persons are likely to be the ones who will move on to fresh challenges. Hence the continuity and expansion of associations depends on developing the leadership skills of the membership. In Lesotho, for example, the national association organized training for committee members of branches in skills such as training, chairing meetings and raising community awareness (McConkey et al., 2000). Likewise, in USA, Canada and Britain, there is increased interest in training parents in policy-making and how they can influence service systems and practices (Barenok and Wieck, 1998).

HIV/AIDS

In many low-income countries, but especially in Africa, HIV/AIDS is taking a heavy toll on families, leaving many children orphaned and in the care of ageing grandparents and relatives. Among these are teenagers and adults with disabilities who will require lifelong care – yet who will provide it? The full impact of this tragedy has yet to be felt and may never be fully known. The hardships and misery for these families and their dependants will only be alleviated through planned and sustained programmes.

Conclusion

Disability affects every nation and many millions of families around the world. Despite the best efforts of medical science and disability specialists,

the incidence of disability is set to rise internationally over the coming decades (Helander, 1993). Hence the need for effective supports for families will continue to be present despite the demographic and societal shifts in affluent countries which are already impacting on low-income countries, such as the drift to the cities, retraction of the extended family and breakdown of localized communities, to name but three.

Yet the past decades have brought greater hope to families who give birth to a child with communication disabilities than in any previous generation. The vision of an ordinary lifestyle is coming closer to reality as these young people attend schools, obtain paid work and gain their own homes. Moreover there is greater acceptance internationally of human rights and equality of opportunity.

These gains did not come by chance or as the side-effect of other efforts. Rather they were hard-won through the efforts of parents, professionals and people with disabilities. Their legacy is not just the tangible services they have helped to create but also the systems and processes that produced these outcomes, most notably the family associations and organizations for people with disabilities that now exist in nearly all countries. To let these initiatives wither through apathy or ignorance is to put at risk a better life for those world citizens as yet unborn who will bear the label 'disabled'.

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Chapter 15
Epilogue

Erna Alant and Lyle L. Lloyd

This concluding chapter briefly summarizes the main issues raised, and discusses some of the implications for future research and training.

The main impetus for this book grew from the need to raise more explicitly some of the issues and ideas that many professionals, AAC-users and communities have to deal with on a daily basis when planning and implementing the use of AAC strategies for people who have little or no functional speech (LNFS) within low-income contexts. Even though many of the intervention issues remain the same as in industrialized countries, the intensity of the challenges tend to be much greater due to poverty, i.e. adverse socio-economic, health and educational conditions. It is this intensity of human suffering on individual, family and community levels that necessitates a commitment towards collaborative partnerships in moving towards long-term impact. Clearly, the call is for critical reflection on approaches towards AAC intervention to ensure that professional efforts in working with AAC-users and their families can have more lasting impact – not only for individual families, but also for communities. While various challenges are identified, certain suggestions are described as potential solutions. The operative word clearly is *potential* – as many of these ideas need to be applied in systematic ways to assist us in furthering the field with a view to evidence-based practice (Schlosser, 2003). As we move towards this process, it is pertinent to recognize that while the aim is to enhance understanding of processes underlying AAC intervention in low-income contexts, one of the biggest challenges remains the diversity and heterogeneity typical of low-income or poverty contexts. Whereas lack of trust and limited social capital can be a typical characteristic of many poverty contexts, trainers and researchers need to remain cognizant of the diversity represented in low-income communities. As stressed in Chapter 4, the complexity of the associations between disability and poverty

necessitate caution in the search for intervention strategies. Over-generalizations and stereotyping have never positively impacted on the development of meaningful solutions in any intervention context.

Synopsis of main issues

It is against this background that the following major, underlying ideas can be identified as basic themes that run through this book.

* *Sustainability in intervention*: Perhaps one of the strongest underlying threads of the book lies in the focus on intervention impact. Issues of effectiveness, sustainability and versatility of intervention are discussed in an attempt to highlight different components of the process. What is emphasized is the responsibility of interventionists to move beyond the confines of the therapy or intervention context, to facilitate the development of better support structures for the family or immediate support network of the individual, i.e. support-based AAC intervention.
* *Collaborative team intervention*: Teams that include professionals, immediate support networks and representatives from the community need to form the basis for intervention. To work for 'the good of all' and to extend intervention beyond the limits of the individual context need to become priorities if intervention in low-income contexts is to become sustainable. A joint vision needs to be developed to build capacity beyond the 'here and now' individual intervention context. This in no way involves minimizing the importance of a focus on the individual in AAC interventions, but requires a new approach in using the individual intervention context for broader impact.
* *Cultural and socio-economic influences on AAC intervention strategies*: There is a need to understand more clearly the different ways in which individuals and communities perceive and interpret visual symbols in communication. The field of sociolinguistics has largely focused on the study of verbal language variations, but these principles need to be extended into the field of AAC symbols to facilitate more systematic investigation. While it can be argued that the main issue for AAC-users is 'learnability' of symbols rather than iconicity, the association between iconicity or familiarity of symbols and ease of learning has been well explored (for reviews see Lloyd and Fuller, 1990; Lloyd et al., 1997). These issues, together with a better understanding of the impact of different AAC systems on interactional patterns within socio-cultural contexts, are pivotal in furthering the field of AAC intervention within diverse sociocultural contexts.

• *Accessibility and appropriateness of AAC technology*: Rather than deal-ing with AAC technology with the focus only on individual needs, implementation of assistive technology needs to be seen within a broader development perspective. The development approach has been well formulated internationally (Chambers, 1983; Riedijk, 1987), but there has been limited reflection on this process in the field of AAC technology.

The notion is clearly that technology is not good, bad or neutral: it depends on how it is used, to either facilitate socio-economic and polit-ical autonomy or dependence. The use of technology is a value-driven process, and communities and individuals might vary greatly in relation to their perceptions and evaluation of the outcomes of using technol-ogy. Reflecting on the basic tenets for the use of assistive technology (AT) within specific contexts is thus most relevant. It is not good enough for manufacturers and distributors to 'wait and see' if infra-structures for the use of technology can be developed in low-income countries. They also need to actively problem-solve with intervention-ists, communities and policy-developers towards facilitating access to state-of-the-art AAC technology for people with little or no functional speech in low-income countries.

• *Resource-based approach in dealing with challenges*: Although it is a major underlying issue within poverty contexts, the book includes rel-atively little discussion on funding issues. Clearly, financial issues are important, but only as an outflow of a resource-based approach towards intervention. For many years, the approach has been to high-light upfront the economic difficulties and lack of resources (needs-based approach – see Chapter 2. While these remain important, the context within which they need to be raised has to be based on an approach that focuses on empowering communities. Challenges need to be addressed from a position of relative strength rather than from a position of economic need.

Future needs for research and training

1. *Changing the training paradigm of professionals*: Focusing on profes-sionals' roles in facilitating the development of support systems for intervention clearly implies a changing paradigm in professional train-ing. Although the issue of transdisciplinary intervention has received some attention in the field of AAC (Lloyd et al., 1997; Beukelman and Mirenda, 1998) and the field of early childhood intervention (e.g. Winton et al., 1997), more specific guidelines for the training of professionals

need to be developed. Issues revolving around multiskilling of all involved in the intervention team need to be considered as a basis for developing support-based approaches to AAC intervention. This might well indicate a need for web-based training programmes focused on addressing issues relating to implementation of AAC within a diversity of poverty contexts to enhance multiprofessional and international collab-oration in moving towards solutions.

2. *The development of a methodology for the use of individual case stud-ies in intervention as a basis for extending capacity into the com-munities*: Conscious effort needs to be exerted to involve more than just the individual and close family members in the intervention process, by including relevant members from community associations that can facilitate the integration of the individual into the community. These community members are then in a position to use the informa-tion gained through the intervention process to the benefit of the broader community. Clearly, this approach to intervention necessitates careful planning to ensure that the process of capacity-building into the community is well-structured and accountable. Strategies of how to involve community associations in intervention with a view on extend-ing the benefits of exposure beyond the individual level need to be understood and refined to ensure more extensive impact of interven-tion efforts.

3. *Exploration of models for the effective transfer and development of AAC technology for sustainable use in low-income contexts*: While manufacturers and distributors need to make a living, it is important to realize that infrastructures take time and effort to develop. Only by investing long-term effort into conceptualizing and assisting in the building of support structures in low-income countries will AAC tech-nology become integrated into these contexts.

4. *A more fundamental understanding of factors impacting on long-term effectiveness of AAC strategies in culturally and socio-economically diverse contexts*: There is a critical need for data in relation to the effectiveness of AAC strategies in varied cultural con-texts, including both industrialized and low-income countries. This implies systematic research into perceptions and processes that both facilitate and inhibit the implementation of AAC strategies. For this to happen requires more basic research on how symbols are used and interpreted within different cultural contexts.

5. *Research studies on dual or multiple disadvantage*: From discussions in various chapters, but particularly in Chapter 4, it is clear that more attention should be paid to projects focusing on dual or multiple dis-advantage, for example disability and poverty as well as gender concerns. Priority funding needs to be considered to ensure that at

least some specified percentage of funding is allocated for research on dual or multiple disadvantages, particularly in relation to disabilities. Only by developing a more in-depth understanding of the interplay between these different variables can we make progress to facilitate socio-economic and policy development oriented towards facilitating vocational placement and integrated community living for those involved.

6. *Further exploration of the theoretical paradigms of communication to emphasize the symbolic interaction process and the development of meaning between people*: A closer association between theoretical models used and the impact of AAC strategies in facilitating these communication processes is important in the further development of AAC strategies. Interaction is much more than a routine exchange of messages (participation); it implies involvement in a rich, creative process of developing meaning between people. This process needs to be better understood to further enhance and refine AAC intervention strategies.

7. *The need for the development of collaborative partnerships in training and research between industrialized and low-income contexts*: It is evident from the discussions that there are indeed many similarities and differences between the AAC intervention challenges experienced in both low-income and industrialized contexts. The solutions to these difficulties do not lie in isolated struggles of professionals within countries, but rather in the building of international support, training and research networks. The complexity of moving towards sustainable solutions in intervention requires professional preparation programmes that are sensitive to the facilitation of international dialogue on cultural and socio-economic issues represented by a broad range of countries and contexts. This could take the form of informal interactions, for example through the ISAAC Emerging Countries Committee www.isaac-online.org and the list serv isaacem@kendy.up.ac.za, where people from both low-income and industrialized countries can share ideas, or it can be more formalized in the way of training and research collaborations.

The collaborative efforts between the AAC Programme at Purdue University and the CAAC at the University of Pretoria identified a variety of ways in which more formal collaborations can be initiated, which might stimulate further thinking in this regard. These include:

* Pregraduate study-abroad programmes that sensitize students to the different cultural and socio-economic contexts, to learn more about the diversity of conditions, activities and needs that varied contexts

impose on AAC-users and their families. These exchanges could be formal – between training institutions – or through community organizations such as Rotary International.

* Joint postgraduate training at Master's and PhD levels through web-based interactions as well as on-site visits to the different locations. Exchanging research agendas and the development of cross-cultural studies need to be high priorities for facilitating quality data on cultural influence in AAC interventions.
* Faculty exchanges between training institutions to allow staff to gain first-hand experience of training and research in different locations.

Perhaps the most fundamental point of departure in all these ventures is sharing and mutual gain. Gone are the days where industrialized-country solutions can be 'transferred' to low-income countries. The challenge is a joint responsibility – to develop long-term, sustainable AAC-intervention solutions while accepting the heterogeneity and richness of the contexts and countries that AAC-users and their families live in.

To communicate is human; to *keep* communicating – is what living is about.

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