

Effective communication for adults with an intellectual disability

Review of the literature prepared for the
National Advisory Committee on Health and
Disability to inform its project on services for
adults with an intellectual disability

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CONTENTS

	Page No.
Plain language summary	iii
Introduction	1
The communication difficulties experienced by people with an intellectual disability	3
Specific difficulties associated with particular conditions	5
Down syndrome	5
Fragile X syndrome	7
Autism	7
Summary	8
How do other people contribute to the communication difficulties experienced by adults with an intellectual disability?	9
Staff as communication partners	9
Families as communication partners	12
Summary and implications	13
Issues of assessment for communication intervention	14
Summary and implications	15
Communication intervention	16
Facilitated communication	19
The voices of people who have experienced (successful) communication intervention	21
Implications for support services for adults with an intellectual disability	22
References	25
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Table 1: Characteristics of interactions intended to meet various social purposes	2

PLAIN LANGUAGE SUMMARY

Communication with other people is a very important part of all our lives. Many people who have an intellectual disability have problems in communication. These problems can be in hearing, understanding, speaking, reading, or writing. All of these are ways we communicate with other people.

Other people also need to try to communicate clearly with people who have an intellectual disability. People who work in disability support services have a duty to listen to and communicate clearly with their clients.

Communication with other people is necessary to:

- tell them what we need and want
- give information
- express friendship and affection
- take part in ordinary conversations.

Communication is not just speech. It involves other behaviours too, like the expression on someone's face.

Sometimes people communicate through their behaviour because they are frustrated that people do not understand them.

There are lots of different reasons why people with an intellectual disability have problems with communication, and their problems are all different.

What sorts of difficulties are there?

When they were children, adults who have an intellectual disability are usually slower than other children in learning to talk.

As adults they might have:

- problems in seeing and hearing
- problems in speaking clearly
- difficulties in reading or writing.

Some adults may not be able to speak at all and need help to communicate in other ways, like signing or using a communication book.

Many adults in New Zealand will have missed out on the sort of help that young children with an intellectual disability get today with their communication. Some adults may not have had the chance to learn to read.

Very few adults with an intellectual disability have any help from speech-language therapists, because there are not enough therapists. Also, other people might not believe that this help would be useful.

People with Down syndrome, and people with some other conditions, show particular problems with speech and language. The research shows that they can be helped with these problems. It is not too late to learn to understand and communicate more clearly.

Other people's role in communication

Communication always involves two people. It is therefore not enough to focus only on the person with the communication difficulty.

Other people need to learn to:

- pay careful attention to how a person tries to communicate
- listen carefully
- spend more time interacting with the person
- use any special form of communication the person needs, like signing or pointing to pictures in a communication book.

Staff in services may not spend enough time interacting with people who have communication difficulties. They may also not notice when a person who cannot speak is trying to communicate. Staff training could help staff to be better communicators and supporters of their clients.

Family members are also important as communication partners. They may be better at understanding what a person is trying to communicate. There is very little research on communication in family settings.

Assessment

Good assessment looks carefully at the person's problems **and** the sort of communication opportunities for the person. This means that what other people do needs to be looked at too. All areas of a person's life and communication needs should be looked at.

Assessment needs to be on-going, as people change and learn more communication skills.

No one should be denied assessment because someone thinks they are too disabled.

Assessment should lead to intervention that helps people to communicate more effectively and participate in everyday life in the community.

Intervention

“Communication intervention” means providing special help for a person who has communication difficulties. Even people who cannot speak can be helped to communicate.

There are special ways of teaching that can help adults with an intellectual disability to understand language and communicate more effectively.

There are also lots of different communication aids for people who cannot talk. Some of these are very complicated, but sometimes a simple aid, like a communication board, is the best option.

People who cannot talk and do not seem to interact with other people can learn to be more interested in people. To increase their communication they need lots of experience in enjoyable interactions with other people.

A special technique called “Facilitated Communication” is sometimes used with people who cannot communicate very well. People disagree about whether this technique works. Research has shown that the person who is helping (the facilitator) can unconsciously influence the disabled person. This can mean that the disabled person is not really typing what they want to say. However, some people have learned to type or talk by themselves as a result of Facilitated Communication. It might help some people. We need more research on this technique.

People with disabilities themselves

People with an intellectual disability who also have problems with communication want better communication with other people. Better communication improves their lives and means that they have more control over what happens to them. They believe that they have a right to be given all the help they need with their communication.

What does this report say we need to do?

The importance of communication in the lives of adults with an intellectual disability must be recognised at government level.

We need more trained people who have special knowledge about communication.

Staff need to be more aware of the importance of communication and trained to be better communication partners.

Needs assessment services need training to recognise when a person has unmet communication needs.

We need research to show how many adults with an intellectual disability have unmet communication needs. This research could also give examples of good provision of services.

Staff who support people who have challenging behaviours need to be trained in ways to help people learn more effective ways of communicating.

EFFECTIVE COMMUNICATION FOR ADULTS WITH AN INTELLECTUAL DISABILITY

Introduction

Communication with other people is one of the most basic elements of human functioning. A significant proportion of people with an intellectual disability experience difficulties with communication, particularly with speech. It has been estimated that approximately 0.8 percent of the population is unable to speak (Beukelman and Mirenda 1992). Other estimates have been higher, with an Australian survey providing a rate of 0.12 percent (Bloomberg and Johnson 1990). Much larger proportions have a range of speech and language difficulties.

The importance of communication within service provision has been recognised in New Zealand law, with the right to effective communication provided in Right 5 of the Code of Health and Disability Services Consumers' Rights, enacted under the Health and Disability Commissioner Act 1994. This right emphasises the critical role of the communication partner in any social interchange. It also reflects the importance of the **content** of a message, not just the **process** of communicating. In other words, the actual form of language used affects the receiver's understanding. As outlined in a brochure from the Health and Disability Commissioner, this right means that:

- information should be given in a form, language and manner which you can understand
- you should be listened to
- a competent interpreter should be available if you need one and if it is reasonably practicable
- communication should take place in an environment that supports open, honest and effective discussion.

The issue of effective communication therefore requires an examination of the behaviour and skills of all those who seek to communicate with people with an intellectual disability, in addition to a review of the issues of specific impairments which can affect communication in people with an intellectual disability.

Communication itself is a very complex phenomenon which is used to achieve a variety of goals. Four broad purposes of communication have been identified by Beukelman and Mirenda (1992):

- communication of needs and wants
- information transfer
- social closeness
- social etiquette

Each of these purposes entails different goals and different requirements of the communication partners. The following table, reproduced from Beukelman and Mirenda (1992), outlines the many facets of communicative interactions for the four types of exchange.

Table 1: Characteristics of interactions intended to meet various social purposes

Social purpose of the interaction				
Characteristics	Expression of needs/wants	Information transfer	Social closeness	Social etiquette
Goal of the interaction	To regulate the behavior of another as a means to fulfil needs/wants	To share information	To establish, maintain, and/or develop personal relationships	To conform to social conventions of politeness
Focus of the interaction	Desired object or action	Information	Interpersonal relationship	Social convention
Duration of the interaction	Limited. Emphasis is on initiating interaction	May be lengthy. Emphasis is on developing interaction.	May be lengthy. Emphasis is on maintaining interaction	Limited. Emphasis is on fulfilling designated turns.
Content of communication	Important	Important	Not important	Not important
Predictability of communication	Highly predictable	Not predictable	May be somewhat predictable	Highly predictable
Scope of communication	Limited scope	Wide scope	Wide scope	Very limited scope
Rate of communication	Important	Important	May not be important	Important
Tolerance for communication breakdown	Little tolerance	Little tolerance	Some tolerance	Little tolerance
Number of participants	Usually dyadic	Dyadic, small or large group	Usually dyadic or small group	Dyadic, small or large group
Independence of the communicator	Important	Important	Not important	Important
Partner	Familiar or unfamiliar	Familiar or unfamiliar	Usually familiar	Familiar or unfamiliar
Source Light J. (1988). Interaction involving individuals using AAC systems: State of the art and future directions. <i>Augmentative and Alternative Communication</i> , 4, 66-82: reprinted by permission.				

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Communication also involves important non-verbal components, such as facial expression, “body language”, body posture, and personal space. These non-verbal aspects of communication involve both comprehension (of the non-verbal aspects of communication of others) and expression (the use of appropriate non-verbal communication oneself). An example of the importance of this component of communication is seen in the difficulties many people with Autism Spectrum disorder have in understanding and identifying different emotions from facial expressions.

This brief introduction shows the breadth and complexity of the field of communication. This literature review cannot possibly cover the huge scope of research in the areas of communication intervention and social interaction research involving adults with an intellectual disability.

Much of the literature on communication is highly technical and clinical. Difficulties in communication are so variable across individuals, even with the same clinical conditions, that intervention must be individually designed rather than delivered as a “programme”. Experimental designs are rare in research in this area, with more reliance on methodology more suited to individually designed interventions, such as single case designs. Also, the majority of the research literature in the area of communication and language development and intervention focuses on young children. This is understandable given its critical role in early development. However, direct generalisation to intervention with adults is questionable.

There is also an increasing recognition that all behaviour has communicative potential, (Donnellan, Miranda, Mesaros and Fassbinder 1984) and this fact has proved extremely useful in developing more humane and effective approaches to supporting people with a severe intellectual disability who also have challenging behaviours (eg, Bott, Farmer and Rohde 1997; Carr, Levin, McConnachie, Carlson, Kemp and Smith 1994). Reviewing this latter area of research is beyond the scope of this review, but it highlights the critical centrality of communication to the developmental opportunities and quality of life of people with a more severe intellectual disability.

The enormous variation in underlying neurological conditions and damage which can affect language development and communication also precludes any comprehensive review of the field.

The purpose of this review is therefore to provide an overview of critical areas which have implications for the promotion of effective communication for adults with an intellectual disability, particularly for planning, policy, and service provision in New Zealand.

The communication difficulties experienced by people with an intellectual disability

People with an intellectual disability experience a wide range of communication difficulties. As young children they are likely to have had delayed language development, and because of their high rate of associated impairments often have ongoing difficulties with communication, in its variety of forms, such as speech, reading, and writing.

Demographic studies have noted difficulties in speech or language in a majority of the population. Morrison, Beasley and Williamson (1976) found 74 percent of people with an intellectual disability had “speech impairments”. McLaren and Bryson (1987) simply noted that speech and language difficulties were “common”. Wen (1997) noted an estimate of 23 percent as having speech difficulties. These estimates vary due to definitional and methodological differences.

Impairments in other areas of functioning, particularly sensory and physical impairments, can also affect communication development and skills. Given the high rate of multiple disabilities among people with an intellectual disability (Morrison, Beasley and Williamson 1976), it is important that appropriate interventions and supports are provided in other areas of impairment. The traditional approach to support arbitrarily assigns one aspect of impairment as the “primary” disability, and fails to ensure adequate assessment and intervention for other co-existing disabling conditions. For example, Harbridge (1998), in the United Kingdom, notes that although one in three people with an intellectual disability have a sensory impairment, they are typically excluded from services for those with hearing or visual impairments, such as education in sign, or orientation training.

In a consideration of the communication difficulties of adults with an intellectual disability in New Zealand, it is important to describe the context in which many of them grew up. Few of the current adult population would have experienced appropriate early

assessment and intervention from a relevant professional such as a speech language therapist during their developmental years.

Within the education system they were part of, if they even went to school, children with an intellectual disability at that time rarely experienced any speech-language therapy input. As Seriere, Heeney and Rutledge (1987) wrote, although speech-language therapy had had a presence in New Zealand since the 1920s, even in the 1980s:

speech language therapists have not been encouraged to work with children with special needs and consequently this group has been seriously disadvantaged. In general, provisions have been superficial (p 299).

Children with special needs or disabilities had to compete for this scarce resource with children labelled “normal”, “for whom the service was established” (p 300). These authors conclude that “it could be claimed that the greater the need, the more difficult the access” (p 301).

A recent study provides evidence for effects of differences in educational experiences of different cohorts of adults with an intellectual disability. Bochner, Outhred and Pieterse (2001) examined the development of language and literacy skills in a group of 30 young adults with Down syndrome, aged 18 to 36 years. The adults varied in the general expectations and resulting education that had been provided to them as children. This group of adults with Down syndrome were born either just before, or during the period when significant changes to special educational provisions were occurring in Australia. In particular, early intervention and inclusion in regular classes and schools were introduced during the 1970s.

The researchers found expected relationships between age, integration experiences, and the achievement of more advanced reading and language skills, including speech intelligibility. These skills also continued to develop in the post-school years. (The importance of literacy will be expanded in a later review of adult education).

With increasing recognition of the importance of early intervention, young children with an intellectual disability should all now be provided with expert input in the areas of communication and language development. But school-aged children are still competing for an extremely scarce resource. The Speech-Language Initiative of Special Education 2000, for example, is focussed on the first three years of schooling (Mitchell 2000).

In their adult years, very few people with an intellectual disability are likely to have had communication intervention involving professionals with expertise in the field. Many of the more senior New Zealand-trained speech-language therapists would not have been trained to work with this group nor would they have had much experience in working with adults who have an intellectual disability. Moreover, as a continuing scarce resource, even if a need for such a service was established for an individual, the resources of expertise are insufficient. It is sad, but salutary, to note that among the many special resources to be provided for the residents of Kimberley Centre as they move into the community, there is no mention of speech-language therapy or communication intervention (September 3, 2001, Press release, Minister for Disability), but the Report on Future Service provision notes this area as one of scarcity in workforce (Ministry of Health 2001).

Specific difficulties associated with particular conditions

Intellectual disability is the result of a multiplicity of causal factors, many of them unknown and unidentified. As it is a disability whose essential characteristic is difficulty in learning, language and communication development are inevitably affected to some degree. However, language and communication are also very complex developmental areas, and the types and degrees of difficulties vary enormously across individuals with an intellectual disability.

There are some particular conditions, which usually result in some degree of intellectual disability, for which research has identified some common patterns of communication problems. In this limited review, some evidence will be described relating to Down syndrome, fragile X syndrome, and autistic spectrum disorder (ASD).

Down syndrome

Down syndrome is the commonest identifiable condition associated with some level of intellectual disability. Language and communication are key areas that significantly affect the personal and social development of people with Down syndrome. Research in the last decade challenges some of the previous assumptions about intervention and assistance for speech and language difficulties experienced by this group (Miller, Leddy and Leavitt 1999).

The specific difficulties can involve problems in:

- speech intelligibility (one study found problems in 95% of the group)
- expressive language that is limited in complexity
- comprehension levels which are difficult to assess
- higher levels of understanding than is seen in their language production
- more advanced vocabulary skills than syntax or grammar.

Miller et al (1999) explain how the problems in speech intelligibility experienced by individuals with Down syndrome lead to adaptations by them to help listeners to understand. These adaptations include reducing their messages to a minimum, selecting one- or two-syllable words, and using single-thought-unit utterances in their efforts to be understood (p 5). Partners also react to unintelligible speech by reducing their demands. These adaptations by people with Down syndrome **and** their communication partners result in an assumption that people with Down syndrome have limited language production skills, which can further lead to underestimation of their cognitive skills.

In a review of recent research on the language development of children and adolescents with Down syndrome, Miller et al (1999) conclude that:

- language therapy should be continued into late adolescence, because continued language development can be expected in comprehension, production, and intelligibility of speech (p 37)
- later interventions should target grammar and sentence structure
- interventions should use a wide variety of natural contexts to support communication learning

- the use of augmentative or alternative communication systems should be used where appropriate to support success in communication (eg, signing, reading, and writing)
- interventions should draw widely from teaching knowledge on how to enhance language acquisition and use (eg, sociodramatic play, song, poetry).

Speech intelligibility problems in individuals with Down syndrome can be contributed to by a number of factors, including:

- fluctuating hearing problems (probably experienced by more than 75% of children with Down syndrome)
- problems in speech fluency (smoothness or rhythmicity of speech production)
- speech sound articulation problems (a variety of factors can contribute to these difficulties); research suggests these problems are due to both linguistic influences and impairments in the system of speech motor control (Miller et al 1999: p 68)
- problems in voice production (ie, pitch, loudness, and quality).

Intervention around these difficulties experienced by individuals with Down syndrome requires the specific expertise of speech-language therapists, who have a thorough understanding of the biological problems and neuromuscular difficulties that the individual may experience. Research by Leddy and Gill (1996) (cited in Miller et al 1999) showed that interventions with adults with Down syndrome produced significant improvements in speech intelligibility and repairing communication breakdowns.

Leddy and Gill (1999) provide a recent overview of research on interventions to enhance the speech and language skills of adults with Down syndrome. Based on an extensive clinical research programme with adults with Down syndrome, they noted the following strengths in this group (p 206):

- visual memory
- vocabulary and semantics
- the use of reading and writing
- the use of hand signs and gestures to communicate
- the motivation to communicate.

Basing their interventions on these strengths, Leddy and Gill outline some examples of successful clinical intervention methods with adults who have Down syndrome. These methods include (p 207-8):

- incorporating reading material into intervention planning as a means of improving verbal communication skills
- teaching skills to prevent, recognise, and repair communication failure
- keeping family members and other communicative partners of adults involved in the intervention programme, so that the adults can practice communication skills daily in real-life situations
- teaching specific skills to improve problems in speech intelligibility, and cuing adults when and how to use these skills during speaking

- teaching useful sentence patterns to increase spoken message content, to encourage whole-sentence statements and questions instead of single-word utterances
- for adults who have extremely poor speech intelligibility or are completely non-verbal, using augmentative or alternative communication systems.

Leddy and Gill (1999) note significant differences between younger and older adults in their clinical research which they attribute to different educational experiences between the two age cohorts. In contrast to the younger adults, the older group did not have functional reading skills, they often deferred to others to communicate for them, and did not know how to play “the communication game”.

Leddy and Gill conclude that past assumptions about the communication development of people with Down syndrome are unwarranted. It had been generally accepted that by adolescence, people with Down syndrome reach a plateau in learning and that continued communication intervention was not justified. In fact, Leddy and Gill found a wide range of variability in adult communication skills learning, but each individual in their sample achieved a measure of success.

Fragile X syndrome

Fragile X syndrome is the most common inherited cause of intellectual disability in males, with an estimated prevalence rate of 1 in 4,000 (Roberts, Mirrett and Burchinal 2001). Roberts et al studied the developmental patterns of receptive and expressive communication skills over time in 39 males with fragile X syndrome, between two and seven years of age. Overall, they found marked delays in language development but substantial individual variability. Eight of the group also showed features of autism. Rates of the acquisition of expressive language skills were significantly slower than for receptive language. These discrepancies increased with age. Neither cognitive skills nor autism status predicted these differences in rates of acquisition.

If this finding is borne out by future research with larger samples over a longer time period, there are important implications for intervention, including:

- focusing on strengths in receptive language
- targeting expressive language skills in vocabulary, syntax, and language use
- maintaining intervention into at least the primary school years (Roberts et al 2001: p 225).

Studies of adolescents and adults with fragile X have also described a distinct speech pattern with frequent word and phrase preservation.

Autism

People with ASD (Autistic spectrum disorder) also experience a range of communication difficulties. In fact, difficulties in receptive and expressive communication are features of this syndrome. Some people with ASD are also diagnosed as having an intellectual

disability, in terms of the functional criteria of a contemporary definition of intellectual disability (eg, AAMR 1992).

In New Zealand, partly because of our small population, adults with ASD are often supported within services for people with an intellectual disability.

A review of communication intervention for adults with ASD is beyond the scope of this broader review. Autism is a very complex and puzzling disorder which, despite its relatively low incidence, is the focus of extensive research, a variety of theories, and disagreements regarding intervention.

There is broad agreement, however, that communication intervention is critically important, and should begin as early as possible. Many adults with autism continue to have difficulties in communication and social interaction, and some remain non-verbal. It is critical that access to some form of augmentative or alternative communication system is provided for these adults, and specific instructional strategies may often also be necessary. Systems which rely on visual pictures or symbols, including writing for some adults, may be more successful than relying on receptive and/or expressive communication through speech.

Developments in early intervention strategies with young autistic children are occurring continually, and today's adults will not have had the benefit of this new evidence (eg, Potter and Whittaker 2001). It is important, therefore, that we do not assume that it is too late for them to benefit from communication intervention. Much of the research with children has some implications for intervention with adults.

During the 1990's, a "new" communication intervention strategy called Facilitated Communication has been the continuing focus of controversy and research. Many of the people who, it was claimed, benefited from this intervention were adults with autism. The research in this area will be reviewed in the later section on "Communication Intervention".

Summary

There is a wide range of complex and specific communication difficulties among people with an intellectual disability. Some specific patterns are characteristic of certain conditions or syndromes. However, even within a particular condition, there is considerable variability.

Assessment practices and communication intervention should consider the known difficulties related to specific conditions. This knowledge requires professional training, expertise, and skills. Such expertise is insufficient, however, to lead to effective intervention without consideration of the critical role of communication partners.

How do other people contribute to the communication difficulties experienced by adults with an intellectual disability?

The traditional approach to communication assessment and intervention for people with an intellectual disability has been to focus on assessing and remediating the deficits of the individual within a clinical or 1:1 training situation. With the growth of behaviourally based training in the 1970s and 1980s, numerous studies were published showing how individuals could be taught isolated skills, such as naming objects, requesting, and simple social etiquette. However, the promise of these studies were not fulfilled, in that people with more significant communication difficulties showed limited or no generalisation of these skills to natural settings and to communication with other people. The conceptualisation of language and communication in these studies was overly simplistic and often failed to draw on the large body of research involving young children. As Shaddock explained in the foreword, (Butterfield, Arthur and Sigafos 1995) “It failed to acknowledge that communication is a dynamic, two-way process requiring genuine interest, sensitivity, adaptation, reciprocity and turn-taking” (p ix).

Research in the 1990s acknowledged the critical social context in which communication occurs and moved its focus from the disabled individual to the communication environment. For example, Kaiser and Goetz (1993) highlighted three important assumptions in more recent research into communication with people who have severe disabilities:

- communication is a fundamental characteristic of human interactions (p 137)
- communication is independent of the specific mode which is used as a channel for communication (p 138)
- communication occurs when shared meanings have been established between communication partners (p 138).

When individuals have impairments which affect their language comprehension and/or ability to express language in typical ways, then the role of the more able communication partner becomes critical. Because many adults with severe communication difficulties receive extensive staff support in their daily lives, recent research has focussed on the behaviour of staff as communication partners.

Staff as communication partners

Research on staff as communication partners has typically involved very small samples and detailed observational data. However, the findings are consistent and also mirror many similar studies of children with an intellectual disability and their communication partners, such as parents and teachers.

The importance of staff as communication partners and critical members of adults’ social networks has been confirmed in recent research. Robertson (2001), studied the social networks of 500 adults with an intellectual disability living in a variety of residential settings. The median size of individuals’ social networks was two (excluding staff). More social networks included a staff member (83%) than even those including a family member (72%).

In an earlier study (Rosen and Burchard 1990), over half of the adults with an intellectual disability named a staff person as their most frequent source of companionship and support.

Despite their importance, however, staff may not provide many opportunities for communication and social interaction. Hile and Walbran (1991), in a study of staff behaviour in a large, residential facility, found that direct-care staff engaged in very few interactive activities with individual residents. In fact, 20.7 percent of their time was spent in their own leisure or socialisation (with other staff) than in socialisation or training activities with residents. Residents only experienced about 10 minutes each per hour of any interaction and this was mostly in the form of supervisory staff activities. The researchers also identified environmental factors that affected the amount of interaction with residents. Contrary to expectation, a **higher** staff-to-residents ratio was associated with **lower** levels of staff-resident interaction.

A New Zealand doctoral study (McDonald 1997) provides both an extensive review of relevant research in this area and confirms the importance of the physical and social environment on communication in people with a severe intellectual disability. McDonald carried out extensive observations over five months of four adults with a severe intellectual disability who had no verbal communication. In addition to these adults' behaviours, he recorded the communicative behaviours of all staff (in both residential and vocational settings) who were involved in supporting the four adults.

The data collected involved detailed running records of behaviour from which quantitative and qualitative analyses were undertaken, and assessments of the environmental context, such as the type of activity.

This study showed that the non-verbal adults used a wide range of strategies to communicate, depending on the individuals' specific impairments and difficulties. The traditional perception of non-verbal adults as unable to communicate was challenged, as was the unwarranted assumption that adults with such severe disabilities seldom initiate communication.

An additional critical finding, however, related to the behaviour of staff in response to these communication attempts. The staff rate of response was extremely low in both settings, in contrast to the high rate of response by the disabled adults to staff communication.

Most of the communication opportunities created by the disabled participants went unnoticed, much of the communication that staff initiated was to give instructions, and there were few activities or events in which people participated that created occasions for communication (p 304).

McDonald also undertook in-depth interviews with staff to explore their perceptions of their roles and attitude towards their clients. These interviews highlighted the importance of perceiving individuals as communicators, and behaviour as having a communicative function. The importance of focussing on relationships, rather than an over-formalised, training role, in supporting communication development, was also noted.

This study also demonstrated the effectiveness of staff training, based in real practice and actual data, in increasing staff responsiveness and support of communication in their clients. McDonald suggests significant implications for communication assessment, intervention, and staff training, confirming the conclusion from other research, that “relationships are the fundamental basis on which communication development occurs” (p 34). He concludes:

... to develop communication, people need to be able to interact in natural settings that facilitate interaction... To ensure that this can happen, the communication partner must have an in-depth knowledge of all of those strategies used by an individual with a communication difficulty, they must be aware of the circumstances under which communication is facilitated and they must be aware of the effect of their own behaviour on the communication process. Therefore, where intervention occurs, it must be directed towards potential communication partners in the first instance, rather than being focussed on those experiencing communication difficulties (p 281-2).

The general findings of this New Zealand research have been confirmed in other studies.

McLeod, Houston and Seyfort (1995) examined the effect of staff training (a 2 1/2 hour workshop) on increasing five categories of staff behaviour to promote communication in non-verbal adults. Both naïve and experienced staff were randomly assigned to a training and control group. Staff showed a significant improvement following training, with no differences between naïve and experienced staff. Anecdotal evidence suggested that the training had changed the attitude of participants towards viewing communication as occurring even when individuals had no speech or alternative communication system.

McConkey, Morris and Purcell (1999) carried out an observational study of staff in residential and vocational services. Forty-three staff were videotaped interacting with a client in a familiar setting for 15 minutes. An analysis of this data showed that:

- staff were four times more likely to initiate interactions (but the subtle initiations of clients which were found by McDonald were unlikely to be noted in this short term observation)
- both staff and clients were equally likely to respond to initiations
- staff tended to use the same type and frequency of communication for all clients, with little individual adaptations to the clients’ level of understanding
- staff gave clients few opportunities to engage in communication as equal partners, with a reliance on verbal acts, and frequent use of directives and questions.

A further report by Purcell, Morris and McConkey (1999) found that staff underestimated hearing disabilities among clients, overestimated clients’ ability to understand spoken language, and had difficulties in identifying non-verbal behaviours as a means of communication.

Domingo, Barrow and Amato (1998) also found that staff show a high use of directives and questions in their interactions with clients. On the other hand, clients communicate more with staff than peers, and use very few directives and questions. They interpret this pattern of client use of communication as consistent with the phenomenon of “learned

helplessness”, and a reliance on the “regulation of others”, rather than developing “self-regulation” (p 294).

In an observational study of staff in three residential homes, Baker, Freeman and High (2000) found few differences among staff or between homes in the frequencies of client-directed communication. However, they did find that communication differed according to activity, with the highest rates during leisure activities. Unlike McConkey et al (1999), staff did show different amounts of communication to individual clients. Baker et al suggest the importance of increasing the frequency of preferred interactions within residential homes, to improve the social climate (presumably for residents), increase staff satisfaction, and decrease staff turnover.

Zilber, Rawlings and Shaddock (1994) observed staff behaviour in work and day programmes. They identified specific staff behaviours which encouraged or discouraged service users to make and communicate decisions. The broader context in which these behaviours occur was also addressed. They concluded:

... if staff wish to enhance choice making in consumers with severe intellectual disability they must ensure effective, two-way communication and exposure to real-life options, all in an atmosphere of positive expectation and mutual trust and respect (p 21).

Even when adults with an intellectual disability do have access to augmentative or alternative communication systems, staff may fail to use them. Bryen and McGinley (1991) studied the use of sign language with 17 adults with an intellectual disability in 10 community residential settings. The findings were not encouraging. Three staff knew no signs at all, and those staff who did rarely used sign in communication with the adults who used signs, and mostly failed to interact at all. The adults could spontaneously produce only an average of 20 signs. The use of sign was not based on a comprehensive assessment and appropriate rationale for the adults involved, and few used sign spontaneously. They conclude:

Intensive exposure to particular language forms is needed for language learning... and this exposure cannot occur if there is limited interaction, limited knowledge, and limited use by significant others of the targeted language forms (p 213).

These authors also note that, in contrast, in normal language learning, research provides estimates of three and a half million models per year of various categories of language components. In this study, learners who had learning difficulties and the need for even more exposure, were only exposed to about 1200 examples per month. It is no wonder that adults often fail to make progress in communication.

Families as communication partners

Although the majority of adults with an intellectual disability live with or under the supervision of their families, there appears to be a dearth of research into the role of family members in communication. Krauss, Seltzer and Goodman (1992) cited evidence that 80 percent or more of adults with an intellectual disability live in these family

environments. These researchers studied the social support networks of 418 adults with an intellectual disability who live with their families. They found an average social network size of 7.1, but there was considerable variability. The networks were comprised primarily of family members. These networks were characterised by their durability, high level of contact, and proximity, in contrast to the characteristics of networks found in some studies of adults living in non-family residential settings. The researchers concluded that “living with family appears to insulate adults with mental retardation from a reliance on paid professionals for social support, may result in less social contact with friends, and ensures a continuing relationship with family members (p 439).”

The role of family members as communication partners for adults with an intellectual disability was not specifically addressed in this research. Family members may be more responsive to attempts to initiate communication and better able to interpret communicative attempts, due to their familiarity and emotional bonds with these adults. This area appears to have received surprisingly little attention in the research literature, compared to the extensive research on the role of parents as communication partners for children with an intellectual disability.

Summary and implications

Effective communication for adults with an intellectual disability requires consideration of the role of communication partners. There is significant evidence that the communication environment experienced by many adults is not conducive to effective communication and to further development of language and communication skills.

There is an urgent need to develop the skills of communication partners in order to generate opportunities for interaction and build effective communication strategies for adults with an intellectual disability who have communication difficulties.

In terms of staff training, the following areas are likely to need attention:

- attitudes towards and expectations of adults with communication difficulties
- awareness about communication and its multiple modes (in addition to speech)
- knowledge about communication development
- skills in generating communication opportunities
- skills in responding to communication attempts
- skills in the use of specific strategies and use of augmentative or alternative communication with particular individuals.

As Butterfield et al (1995) point out, “there is little or no point in teaching communication skills unless others with whom the individual interacts are responsive and affirming (p 3).

This review will now consider broad issues in the important area of assessment – the basis for developing appropriate communication interventions for individual adults with an intellectual disability.

Issues of assessment for communication intervention

Any approach to assessment of the communication difficulties of adults with an intellectual disability will be based on a particular theory of communication or language development.

Traditional, standardised assessment instruments have been criticised for failing to adequately consider context as an important factor and often misrepresenting a person's communicative competence (Jackson 1993: p 155). Furthermore, such assessment tools were not designed with language intervention specifically in mind (Lucas, Weiss and Hall 1993). In contrast, "learner-centred" assessment is promoted, involving an assessment of the person's actual communicative behaviours across a variety of relevant pragmatic and environmental contexts. This type of assessment can then lead directly into intervention which is individually designed to support the person's communication in the actual settings in which the person functions.

An assessment model which is based on the person's communication "needs", rather than on a model of "language development" is not without criticism. Hill and Romich (1999) suggest that a "Needs Model" may result in limited vocabulary choices and a narrow view of what is possible. Their major concern appears to be that assessment should consider more than simply addressing communication of "needs and wants". Other purposes of communication development should also be considered, such as information exchange, social closeness, and social etiquette.

As shown in the research on the behaviour of people in the person's environment, assessment must be wider than only the person with the disability. It should also include the communication environment. The first requirement of any communication intervention must be to ensure that there are aware and motivated communication partners available. According to Beukelman and Mirenda (1992), this is "at least as important to the success of a communication intervention as is the availability of an appropriate access system" (p 258).

The first practical issue affecting adults with an intellectual disability is whether they are even considered as candidates for communication assessment. Traditionally, they have been seen as inappropriate recipients of assessment and intervention due to assumptions that their cognitive limitations preclude any further communication development (Beukelman and Mirenda 1992). Some of the earlier communication approaches with people with more severe disabilities were also based on unwarranted assumptions about the need to acquire "readiness skills (eg, eye contact) as a prerequisite to "real" communication.

Contemporary models of assessment are typically embedded in a wider context of community participation for people with an intellectual disability. This wider, inclusionary context of communication in everyday life reinforces the pragmatic, needs-based approach which is now more widely accepted in the literature as representing "best practice."

One example of this approach is seen in the principles set out by Beukelman and Mirenda (1992) for their "Community Participation Model" of assessment for communication intervention. These principles state:

- everyone **can** communicate. Everyone **does** communicate
- assessment is not a one-time process. Assess to meet today's needs, then tomorrow's, and tomorrow's...
- a primary purpose of assessment is to identify strengths and abilities, not weaknesses and deficits
- a collaborative team should be involved in the assessment process and must involve the person with an intellectual disability and his/her family, and other support people. "Consensus today keeps dissension away"
- the purpose of communication intervention is to facilitate meaningful participation in daily life activities
- assessment should include the identification of barriers to communication opportunities. These barriers may include: policy, practice, attitudes, knowledge, and skills
- assessment should also consider the constraints on possible intervention or augmentative or alternative systems eg, user and family preferences; attitudes and abilities of communication partners; funding (Beukelman and Mirenda 1992: p 101-30).

With the special expertise required, the multiple areas of functioning, and the requirements for environmental assessment, the time and resources required for "best practice" assessment may not always be available. Barker-Collo (1996), aware of these issues, developed an assessment screening tool (specifically for use with people who have an intellectual disability) that is less time-consuming.

This tool can also be completed by the key support worker involved with the person. The Communication Ability Screening Survey, (CASS), covers three broad aspects of communication: expressing needs and wants; participation in social interactions; and modes of communication. CASS takes an average time of 20 minutes to complete, and the published evaluation noted that no specialised training or clarifications were needed by the support workers of the 42 individuals in the study. Inter-rater and test-retest reliability were both high in two of the three areas, and professionals who used the tool provided generally positive comments on its usefulness and face validity. As one professional said, "It is helpful in assessing new clients as it is easy to fill out and gives a good base to start from when developing a plan of action" (p 25).

Summary and implications

Assessment approaches to communication intervention must be broad and consider the environmental context as well as the specific strengths and difficulties of the individual.

The variety of purposes for communication should also be considered, as they promote the person's inclusion and participation in a variety of settings.

No individual should be considered ineligible for communication intervention, and assessment should identify current behaviours which are used to communicate.

Assessment should identify barriers to communication and should be an on-going process, not a one-off event.

These conclusions pose significant challenges to the current lack of provisions and resources in the area of communication for adults with an intellectual disability in New Zealand, especially in the light of the typical lack of appropriate communication assessment and intervention in their childhood.

Communication intervention

The majority of recent empirical research on communication intervention for adults with an intellectual disability focuses on individuals with severe communication difficulties. The major influences on this recent focus have come from two sources: the development of a range of structured intervention strategies which are used in natural communication contexts, and the rapid growth of resources and expertise in the area of augmentative and alternative communication defined as:

... an area of clinical practice that attempts to compensate (either temporarily or permanently) for the impairment and disability patterns of individuals with severe expressive communication disorders (ASHA 1989: p 107).

As discussed when examining trends in assessment, these developments challenge a traditional psycholinguistic model of language development (the “Dictionary and Rules” model, Jackson 1993) and place a much stronger emphasis on functional communication and the influence of context. This latter model, it is claimed, provides a much more useful basis for communication intervention with people who have severe disabilities. Jackson (1993) describes these changing views as a major paradigm shift which “provides one way to redress the tyranny of linguistic competence as a measure of human worth” (p 157). He outlines the implications of this different theory or model:

It emphasizes that (a) communication is a collaborative process at the most fundamental level; (b) message productions that affect and inform others are the key to successful communication and not “grammaticality”; and (c) communication is something much broader than the traditional domains of speaking, reading, and writing (p 157).

This review will outline the major structured intervention approaches which have been successful, to varying degrees, in communication intervention with adults who have a severe or profound intellectual disability.

Beginning communication strategies require signals for three basic functions: gaining attention; acceptance; and rejection (Beukelman and Mirenda 1992). The critical functions of acceptance and rejection are much more basic than a “yes/no” response which requires greater cognitive understanding and sophistication. At this cornerstone level of communication, the focus must initially be on training the communication partners to “tune in” to these “signals” and respond consistently to them, to foster a relationship within which communication can develop. As shown by McDonald (1997) and other researchers, the communication attempts made by people with severe disabilities are often ignored or unnoticed by the people around them.

One system for promoting early communicative behaviours was developed by Van Dijk (1966, 1967, cited in Beukelman and Mirenda 1992), initially for use with people who have dual sensory impairments. It has since been adapted for people with a severe or profound intellectual disability. As outlined by Beukelman and Mirenda (1992) this approach involves six “levels” of intervention.

- Nurturance – to develop a warm, positive relationship.
- Resonance – to help the person shift attention from the self to the external world.
- Coactive movement – to develop an understanding of sequence, and anticipation.
- Non-representational reference – to teach the individual to identify body parts, in three-dimensional then two-dimensional models.
- Deferred imitation.
- Natural gestures (p 259-60).

A similar approach to establishing basic interaction is described by Lovell, Jones and Ephraim (1998). This single-case experimental study demonstrated the effect of intensive 1:1 interaction with a withdrawn, non-verbal man with a severe intellectual disability.

The interaction included imitation of the man’s behaviours, “joining-in” with him, “reflecting” his behaviour back to him – all similar activities observed in mothers of young infants at a pre-verbal level. Over a time period of only three days, the intensive interaction, compared to physical proximity only, led to an increase in: initiation of physical contact; looking at people; engaging in joint attention; vocalising, smiling and laughing. There was also a decrease in hiding his face. The increased sociability of this man also generalised to some degree. The authors conclude that this simple, non-time consuming approach can encourage interactions with other people, an essential basis for further communication development.

These types of “non-symbolic” techniques of communication intervention are directed by the individual and are responsive to her behaviour, based on the principle that all behaviour is **potentially** meaningful and communicative (Mirenda, Iacono and Williams 1990; Beukelman and Mirenda 1992).

Alternative modes of communication (to speech) are commonly used with people for whom speech is absent or minimal. The use of manual signs (such as the Makaton vocabulary) were once very popular with adults who have an intellectual disability. Many people can be taught to use at least a basic core of signs, if they have the necessary manual abilities. Communication partners must also learn to sign if it is to be an effective mode of communication.

Mirenda et al (1990) conclude that the limitations of manual sign systems are that spontaneous use often does not occur and use is limited because communication partners are usually untrained. Also, as shown by Bryen and McGinley (1991), even when staff do have some signs, they may use them very infrequently. There is some evidence on which signs are easiest to learn, and that generalisation is more likely to occur from expressive language to receptive language, rather than vice versa (Mirenda et al 1990).

Communication systems can also include a variety of objects, pictorial or static symbols, to which the person points in some fashion. These symbols can be visual or tactile, and most do not require reading, writing, or spelling. In terms of a hierarchy of difficulty, real

objects and colour photographs are the easiest to learn to use. Photographs are easier than line drawings. Blissymbols and writing are the most difficult symbol systems to learn. However, Miranda et al (1990) caution against assuming that literacy is not possible.

With the rapid development of technology over the last 15 years, many communication devices are now available. However, it is important to remember that such technology is a tool for communication, not an end in itself. “Low tech”, simple systems, such as communication booklets, or simple communication boards, may be more available and just as effective (eg, Barnes 1991; Storey and Provost 1996).

All these augmentative or alternative systems are only effective if users **and** partners know how to use them **and** actually use them in communicative exchanges.

For building communication development in adults with an intellectual disability, Miranda and Beukelman (1992) recommend:

- providing structured opportunities for practice within routines, in natural contexts (in contrast to traditional techniques eg, Duker and Jutten 1997)
- offering opportunities for making choices
- teaching skills which allow “beginning communicators” to introduce and establish topics of conversation (eg, using communication books with photos of people, objects, preferred activities)
- providing assistance for receptive language also (eg, pictorial schedules, scripted routines).

There is also extensive published research evidence to support the effectiveness of a variety of strategies to develop communication skills in children and adults who have an intellectual disability. All of these structured interventions, while developed from earlier behavioural research, emphasise teaching in natural contexts to promote functional learning and generalisation of skills. Effective use of structured teaching techniques does require expertise in assessment and the design of appropriate strategies. However, while they may appear technical, implementing the strategies can be successfully taught to communication partners within the person’s social environments. These structured intervention strategies include:

- contingent responding
- milieu teaching, including incidental teaching, mand-model techniques, and a time-delay procedure
- interrupted behaviour chains (see Carter and Grunsell 2001, for a recent review)
- teaching generalised and explicit requesting and use of an attention-getting signal
- verbal prompt-free and expectant delay procedures
- differential reinforcement of communication.

Butterfield et al (1995) have identified four broad, “best practice” characteristics of communication intervention for people with an intellectual disability on which there is a general consensus:

- communication intervention should take a functional or pragmatic approach
- it is important to build spontaneity into a person’s communicative repertoire

- intervention needs to specifically plan for the generalisation of communication skills to a range of partners and contexts
- the development of “partner” skills must be included in any communication intervention including “listener preparatory behaviours” (Kaczmarek 1990).

Facilitated communication

Communication intervention, as a field of practice and research, is not without its controversies. The most recent focus of attention in the media, the Courts, and the scientific literature has been the approach known as “Facilitated Communication”. Facilitated Communication (FC) involves “providing physical and emotional support to individuals with severe communication impairments as they type or point to letters or pictures” (Biklen 1993).

The strategy has been presented as an augmentative or alternative form of communication. The method has been used with individuals who have a variety of conditions, including cerebral palsy, autism, and (presumed) severe intellectual disability. Initial claims were made by some proponents that FC “unlocked” enormous hidden intellectual potential in many non-verbal people. FC has been used and continues to be used in New Zealand, but its use is not widespread or highly publicised.

The critical point of debate about FC centres on the issue of authorship of the communication. Opponents claim that the source of the message is the facilitator who, possibly unconsciously, influences the communicator to point to or type particular letters to spell out the message. There are published experimental evaluations of FC which support this claim (eg, Green and Shane 1994; Wheeler, Jacobson, Paglieri and Schwartz 1993). Green and Shane (1994) note that, by 1994, there were more than 24 controlled scientific or clinical evaluations of FC which show that FC is not an effective system of communication, but shows facilitator influence as the source of the message. On the other hand, there is also published evidence about some individuals, who were previously non-verbal or had very minimal expressive language, progressing to independent communication through typing or speech. Somehow the experience of FC has enabled these individuals to become independent communicators, at least some of the time. This evidence is largely presented through qualitative research and case studies. The personal descriptions and explanations from individuals using FC, or who are now independent, provide another insight on this controversial method (Biklen, Morton, Saha, Duncan, Gold, Hardardottir, Karna, O’Connor and Rao 1991; Olney 1995; Rubin, Biklen, Kasa-Hendrickson 2001; Schubert 1997).

The controversy has raised two much broader areas of debate. At one level it is a debate about what counts as knowledge, and how we establish “truth” – essentially an issue based in the history and philosophy of science, although not always recognised as such by those at the polar ends of the debate. Goode (1994) believes that “the problem for the scientific service community is basically an epistemological one (p 309)”.

At another level, the controversy raises very challenging questions about our definitions and assumptions about “intellectual disability” and “autism”. What do our diagnoses mean? What challenges does FC bring to our basic assumptions about people who cannot speak or communicate? (Rubin et al 2001).

There can be no doubt from **both** the published experimental **and** qualitative research that unknowing (ie, not purposeful) “facilitator influence” occurs in FC much of the time. FC users who have become independent communicators confirm this themselves, and acknowledge that it poses difficulties for them (Rubin et al 2001). The experimental literature has also found some instances in which there **was** evidence of authorship of the message by the person with the disability (eg, Simon, Whitehair and Toll 1995). These variable findings make it very difficult to establish authorship in individual instances of communication.

Levine, Shane and Wharton (1994), in a detailed identification and discussion of the potential risks and benefits of FC, concluded that the potential for harm (with the use of FC) was greater than the potential for gain. One particular area which has caused great controversy is the allegations of sexual abuse which have often been made through “facilitated” communication, and have led to a number of highly contested court cases, particularly in USA. (A similar case in New Zealand, in which physical evidence was also present, confirmed the veracity of a “facilitated” communication from a non-verbal, autistic girl, (Re S (Care and Protection), (1996) 14 FRNZ and Laumalili v S, (1994) NZFLR 413).

On the other hand, it has been pointed out that no other form of communication intervention (involving augmentative means) has had to undergo such rigorous evaluations or risk-benefit analyses (Halle 1994). Kaiser (1994) concludes that “it is not reasonable to apply standards to one communication intervention that are not applied to other communication interventions (p 189)”.

A further aspect which needs serious consideration is how “communication is conceptualized” and the issue of “authorship” evaluated. Ferguson and Horner (1994) point out that the complex and contradictory evidence about FC forces us “to recognise that communication always involves an influencing interaction between the communicator and the receiver of communication (p 306)”. Kaiser (1994) describes communication as an “active construction of shared meaning” (p 189).

What can be reasonably concluded from the evidence and debate to date?

- FC may be useful in helping some individuals to communicate (through typing or pointing to letters).
- FC may be useful to help some individuals develop their communicative competence and language capacity (eg, Olney 1995; Schubert 1997; Rubin et al 2001; Broderick and Kasa-Hendrickson 2001).
- FC may eventually lead to independent communication for a few individuals, at least some of the time.
- Facilitator influence does occur in the use of FC, and independent verification of authorship and other safeguards should be sought regularly, and particularly for “critical” messages (Simon, Whitehair and Toll 1995).

The original claims for the widespread “success” of FC cannot be substantiated by current evidence, Goode (1994) concluded:

In the end, it is likely that FC will be useful in helping some individuals and not others and that it will not be a magic bullet or panacea for all forms of intellectual limitation (p 311).

- The use of FC should not be promoted as the sole mode of communication for an individual, but other “more independent” modes of communication should also be encouraged or worked towards eg, speech (Schubert 1997) or independent typing (Rubin et al 2001).
- FC as a phenomenon, and the research it has led to, has challenged many assumptions about cognitive and language development and functioning, particularly linear and hierarchical models of development. We need more research (Broderick and Kasa-Hendrickson 2001; Ferguson and Horner 1994).

The vast literature on communication intervention, as in other areas of intellectual disability research, seldom provides any information from the people at the centre of the research, which is understandable but still regrettable.

The voices of people who have experienced (successful) communication intervention

Without communication intervention, people with severe communication difficulties have little or no voice. People who have been “diagnosed” as having a severe or profound intellectual disability (partly on the basis of their communication difficulties) are the group most likely to be left with no voice. Because of the often unquestioned assumption that “people who cannot speak do not think”, communication intervention may not even be considered, or may be seen as a waste of scarce resources.

There are not many voices in the published literature, but some of those are included here.

Bob Williams, a former USA Commissioner for the Administration on Developmental Disabilities, the first non-speaking person in the world to head a government department, called for a “communication imperative” (Crossley 1999: p 11).

Every person, regardless of the severity of his/her disabilities, has the right and the ability to communicate with others, express every day preferences and exercise at least some control over his or her daily life. Each individual, therefore, should be given the chance, training, technology, respect and encouragement to do so.

Broderick and Kasa-Hendrickson (2001), published a case study of “Jamie”, an autistic student, who developed reliable speech, that appears to have been assisted by FC and a conversational device called a Lightwriter™. Jamie recently wrote the following poem:

*I used to be a silent boy
Living in walls of mostly moving lips
My ears were senseless, but now,
I am living in the world of words and speech.
(Broderick and Kasa-Hendrickson 2001: p 23).*

Jamie also said, “To say words is to live life as others” (p 18).

Rubin, a young woman with autism, who progressed to independent typing through the use of FC (Rubin et al 2001) says:

When I wasn't able to communicate, I was not relating to the world. Was I retarded? Sadly I think I was because I wasn't able to assert myself in any way. Actually I was a non-person.

... When people see me they are forced to admit that their assumptions about mental retardation are wrong.

In 1996, a civil rights group of people with disabilities in Oldham, UK, at a conference focussing on communication, produced some conclusions, including:

- Makaton (a sign system) is restrictive because it is only taught in special places
- it is a person's right to have free and open access to a suitable form of communication. Under the present system this is not available
- the need to look at **total communication** and to have an awareness of multiple forms of communication
- the present system is oppressive as it keeps people with a learning difficulty dependent on support staff to enable society to understand them
- this dependency is an abuse of someone's civil rights... Everyone can communicate. Society must learn how to listen ... We need a multitude of different forms of communication and an awareness of them all. (Author unknown, Community Living 1996: p 17).

Implications for support services for adults with an intellectual disability

The vision contained for disabled people in the New Zealand Disability Strategy is:

A society that highly values our lives and continually enhances our full participation.

A core aspect of valued lives and participation is communication with others but a large number of adults with an intellectual disability experience difficulties in communication. In particular, difficulties in communication limit self-determination and the development of relationships. In fact, the frustrations experienced by people with an intellectual disability whose communications are ignored or misinterpreted can lead to challenging behaviours and further restrictions and controls over their lives.

In New Zealand, it appears that few adults with an intellectual disability who have communication difficulties have access to any appropriate communication assessment and intervention. In a discussion with the manager of one service, she identified 60 percent of her clients as having communication difficulties but none of them had any access to augmentative or alternative communication strategies. This service did try to be responsive to all communication attempts and look closely at their own interactions with clients, but there was no coordination with the clients' residential services. The manager

noted barriers to improving their services as: lack of expectations; lack of expertise; and lack of resources.

This overview of the literature has shown that there is a range of well established assessment and intervention strategies to support the communication of adults with an intellectual disability, including those with severe and profound communication difficulties.

The implications of this review for service policy, planning and practice in New Zealand are far-reaching.

There needs to be a commitment at the policy level to the crucial importance of effective communication for adults with an intellectual disability. Without commitment at this level, the critical planning and resource allocation cannot occur.

Workforce planning needs to be undertaken to meet the gaps and scarcity in expertise in communication intervention for adults with an intellectual disability.

The workforce problems are wider than the shortage of speech-language therapists. A collaborative, team approach is promoted within the literature.

The lives of adults with an intellectual disability and communication difficulties who use support services could be greatly enhanced by strategies to raise awareness of the crucial importance of staff as responsive communication partners.

The research has clearly shown how clients with little or no verbal communication typically receive very low levels of responsive interaction from staff.

Needs assessment services should be encouraged to prioritise communication needs in their assessment of needs of adults with an intellectual disability and should receive the necessary training in this area.

Research is urgently needed in New Zealand to identify the current level of unmet need in communication intervention for adults with an intellectual disability.

Research could also identify examples of “best practice” and strategies to raise staff awareness and increase staff responsiveness and interaction.

Services which are designed to provide support and intervention for adults with an intellectual disability who have challenging behaviours must have appropriate expertise in evidence-based practice in communication-based intervention.

As Carr et al (1994) conclude in the Epilogue to their book:

It is unfortunate that for too many people with disabilities exhibiting severe problem behavior is an important way, sometimes the only way, of influencing others. ... problem behaviors may serve important purposes for the individuals displaying them. Therefore, it is critical not to focus efforts simply on eliminating problem behaviors but rather to focus on replacing them with new, socially acceptable behaviors that serve the same purposes as the problem behaviors but

do so more efficiently. Education, not behavior reduction, is the real priority. Through education, people with disabilities are better able to achieve their goals without resorting to self-injury and aggression.

Through education, people with disabilities are better able to gain more influence over their lives thereby becoming more similar to people without disabilities. Last, and most important, through education, people with disabilities can enter into social relationships with parents, teachers, direct support staff, and other members of the community, relationships that are characterized not by control but by reciprocity, not by passivity but by participation, and not by being a category but by being a friend (p 219).

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