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Planning and Support for People with Intellectual Disabilities

Issues for Case Managers and Other Professionals

Edited by Christine Bigby, Chris Fyffe and Elizabeth Ozanne

Foreword by Jim Mansell
# Contents

**FOREWORD**  
*Jim Mansell, Professor, Tizard Centre, University of Kent, UK*  
9

**THE CONTRIBUTORS**  
13

**Introduction: contexts, structures and processes of case management**  
Christine Bigby, Reader and Associate Professor, School of Social Work and Social Policy, La Trobe University, Victoria, Australia; Chris Fyffe, Director, specialist disability consultancy firm (Grimwood Pty Ltd), Mandurang, Victoria, Australia; and Elizabeth Ozanne, Associate Professor and Head, School of Social Work, University of Melbourne, Victoria, Australia  
17

1  **Case management with people with intellectual disabilities: purpose, tensions and challenges**  
Christine Bigby  
29

2  **Understanding intellectual disabilities**  
Chris Fyffe  
48

3  **Balancing rights, risk and protection of adults**  
David Green, Social Work Teacher, La Trobe University, Melbourne, Australia; and David Sykes, Manager of Policy and Education, Victorian Office of the Public Advocate, Australia  
65

4  **Walk a day in my shoes: managing unmet need on a daily basis**  
Lesley Gough, Disability Case Manager, Melbourne Citymission, Victoria, Australia  
84

5  **Case management in a rights-based environment: structure, context and roles**  
Tim Stainton, Associate Professor of Disability Policy, Theory and Practice, University of British Columbia, Vancouver, Canada  
90

6  **Working with other organisations and other service sectors**  
Estelle Fyffe, Psychologist and Chief Executive Officer of annecto – the people network, Victoria, Australia  
108

7  **Working to empower families: perspectives of care managers**  
Gordon Grant, Research Professor, Centre for Health and Social Care Research, Sheffield Hallam University, UK; and Paul Ramcharan, Lecturer, Division of Disability Studies, RMIT University, Bundoora, Australia  
121
8 A life managed or a life lived? A parental view on case management 139
   Marie Knox, Senior Lecturer and Assistant Director (Teaching and Learning),
   Queensland University of Technology, Brisbane, Australia

9 Taking it personally: challenging poor and abusive care management practice 150
   Margaret Flynn, Principal Researcher, Sheffield Hallam University, UK; and
   Peter Flynn, Manchester, UK

10 Be there for me: case management in my life 162
    Colin Hiscoe, Melbourne, Australia; with Kelley Johnson, Senior Lecturer,
    RMIT University, Melbourne, Australia

11 Working things out together: a collaborative approach to supporting parents with intellectual disabilities 171
    Margaret Spencer, Registered Nurse, Sydney, Australia; and Gwynyth Llewellyn,
    Dean, Faculty of Health Sciences, University of Sydney, Australia

12 Intellectual disability and the complexity of challenging behaviour and mental illness: some case management suggestions 191
    Gary W. LaVigna, Clinical Director, Institute for Applied Behavior Analysis,
    Los Angeles, USA; and Thomas J. Willis, Associate Director, Institute for Applied
    Behavior Analysis, Los Angeles, USA

13 The importance of friendships for young people with intellectual disabilities 208
    Brenda Burgen, School of Social Policy and Social Work, La Trobe University,
    Melbourne, Australia; and Christine Bigby

14 Issues of middle age and beyond for people with intellectual disabilities and their families 215
    Christine Bigby

15 The role of the case manager in supporting communication 233
    Susan Balandin, Associate Professor, University of Sydney, Australia

16 Accessing quality healthcare 247
    Philip Graves, Developmental Paediatrician and Head of the Developmental
    Disabilities Clinic, Monash Medical Centre, Victoria, Australia

17 Supporting children and their families 264
    Susana Gavida-Payne, Senior Lecturer, Division of Psychology, RMIT University,
    Melbourne, Australia
Review of evaluative research on case management for people with intellectual disabilities

Janet Robertson, Lecturer in Health Research, Institute for Health Research, Lancaster University, UK; and Eric Emerson, Professor of Disability and Health Research, Institute for Health Research, Lancaster University, UK

NOTES
SUBJECT INDEX
AUTHOR INDEX
For people with severe or complex disabilities, such as intellectual disabilities, redistribution of resources, for example money, housing and employment, is usually not enough to obtain equality of opportunity. The nature of people’s impairments means that they need help from others in order to realise the opportunities that life presents. Thus, the relationship between helper and helped is the most important relationship in providing services to disabled people. It is the place where money and resources are turned into the kind of life the person wants to live.

The nature of this task includes helping to identify and prioritise appropriate goals; finding, organising and allocating resources; and then using those resources to achieve the person’s goals. This is often a long-term process, and so reviewing and revising arrangements is required. These are the tasks that have come to be called ‘case management’. They differ from social work in that the case manager, at least ideally, controls resources and can use his or her own judgement to arrange them in a way best suited to help the disabled person.

Case management has been a central component of the development of social services in many western countries since the growth of community-based services in the 1970s and 1980s. Writing in the 1980s, Applebaum and Austin (1990) pointed out that ‘case management has become omnipresent, even when there is limited consensus about just what it is’. They attributed its rise to the move away from institutional care, in which all of a person’s needs were intended to be addressed in one place, to community-based services. These were, they argued, fragmented and complicated. People with substantial needs required services from different agencies and, therefore, faced a difficult task of obtaining and coordinating their access and delivery – a task that may be beyond the personal resources of the individual. Adding a coordination role addresses this need.
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Wilson, C. (1998) 'Providing quality services for individuals who are aging in community based support settings: what are the issues for service providers?' Presented at the 34th Annual Conference of the Australian Society for the Study of Intellectual Disability, Adelaide University, Adelaide, SA, 28 September 1998.

The role of the case manager in supporting communication
Susan Balandin

The aim of this chapter is to explore the role of the case manager in supporting communication for people with intellectual disabilities. Definitions of terms such as 'augmentative or alternative communication' (AAC) and 'complex communication needs' are provided, and a number of issues pertinent to effective communication are discussed, including:

- successful communication
- assessment
- behaviour and communication
- communication systems.

Although responsibility for effective communicative interactions does not rest with case managers alone, case managers do need to understand the importance of communication and how they can facilitate optimal communication for their clients. Communication is a key to successful community participation and inclusion. Indeed, it can be argued that verbal communication is a distinguishing feature of humans and an essential component of adequate quality of life. According to Light and Binger (1998), verbal communication fulfils four purposes:

- communication of needs and wants
- information transfer
- social closeness
- social etiquette.
Effective communication can be deemed a basic right (National Joint Committee for the Communication Needs for Persons with Severe Disabilities 2002).

**Communication rights**

People with intellectual disabilities, including those with complex communication needs, have the same communication rights as people who can speak, including the right to make choices and decisions, the right to ask for information and to have their communicative acts acknowledged, and the right to be communicated with in an appropriate and respectful manner. Case managers are integral to ensuring that the communication rights of the clients they support are respected and upheld and that their clients are given every opportunity to communicate successfully. Many people with intellectual disabilities have complex communication needs and will always experience difficulty with communication. Consequently, they will always rely on having skilled communication partners to assist them to communicate. The case manager is well placed to ensure that communication partners have the necessary support and training in order to develop the skills to interact with people with complex communication needs.

**Complex communication needs**

People who have little or no functional speech and require alternative or augmentative communication have complex communication needs, which are defined as a person having ‘needs associated with a wide range of physical, sensory and environmental causes which restrict/limit their ability to participate independently in society. They and their communication partners may benefit from using alternative or augmentative communication methods either temporarily or permanently’ (Balandin 2002, p.2).

Complex communication needs are associated with long-standing conditions such as intellectual disabilities, and people with complex communication needs require support in order to communicate effectively.

**People who require support with communication**

It is estimated that there are 588,700 people in Australia with intellectual disabilities. Although the severity of the impairment may vary, the majority of people with intellectual disabilities experience some restriction in the core activity of communication. Such restrictions include difficulty in being understood by
familiar and/or unfamiliar communication partners and difficulty in understanding what familiar and/or unfamiliar communication partners say to them. Additionally, people with intellectual disabilities may have difficulty with literacy and access to printed information.

Case managers are likely to be required to support individuals with lifelong disabilities who experience communication difficulties, including people with complex communication needs, people with autism-spectrum disorder, people with cerebral palsy, and people with challenging behaviours. Case managers have a responsibility to ensure that they make every effort to include the person with disability in any communicative interaction. Proxies may be helpful in determining what a person wants and for assisting the person to participate optimally. A proxy is someone who knows the person well and can speak on his or her behalf. Proxies can be very helpful when planning for a person and ensuring that his or her needs and wishes are met and respected. For example, Stancliffe and Parmenter (1999) demonstrated that proxies are accurate when assisting people with intellectual disabilities with whom they are familiar to make choices.

Nevertheless, proxies are not always available or appropriate to use when communicating with a person with an intellectual disability, and therefore it may fall to the case manager to consider a variety of alternative communication methods to include the person with disability. Such methods may be as simple as allowing more time, communicating with the person in a familiar environment or providing pictures or photographs to support comprehension, for example when discussing changes in accommodation. If the case manager identifies the person's behaviours as communicative, a referral to a communication specialist will be appropriate.

Thus, it is important that case managers focus on the person and his or her needs and aspirations. This focus includes a responsibility for ensuring that the communication needs of the person with an intellectual disability are not neglected. Case managers may need to take responsibility for coordinating the selection and development of communication strategies that will foster interactions with a variety of communication partners across a range of community contexts.

**Successful communication**

Effective communication is essential for a good quality of life. Without effective communication, it is impossible for a person to interact with others successfully. Despite a strong focus on verbal communication within the community, it is
important to recognise that people, including those with intellectual disabilities and complex communication needs or little or no functional speech, are still able to communicate a variety of messages, particularly if they have access to appropriate support (Beukelman and Mirenda 2005). Communicable messages include the expression of wants, needs, choices, hopes and dreams; asking for information; and communication for social closeness, such as having a chat with a friend. People with complex communication needs may require a third party to speak for them or require an alternative or augmentative communication system (Beukelman and Mirenda 2005).

Successful or effective communication is an interaction in which both participants are satisfied that a message has been conveyed clearly. Failure to develop functional communication and the ensuing problems with message expression or understanding can have devastating effects on both the individual with disability and people who are close to or interact regularly with that person, such as family members, friends and service providers. Any difficulties with understanding or being understood by others act as significant barriers to effective communication. Sadly, many people with intellectual disabilities and complex communication needs have no alternative or augmentative communication system or, indeed, access to any functional communication system. In other words, they have no way of communicating effectively, including the use of systems such as letter boards, pictures, signs and gestures, and they must rely on others to recognise that they are trying to communicate and interpret what they are trying to say. Both service providers and others in the community may find this a difficult task, and one that most people are unable to do well without support and training.

Consequently, due to lack of training and resources, people with intellectual disabilities and complex communication needs may not be well catered for by services that are stretched to cope with large caseloads. It can take time to learn about the idiosyncratic communication of a person with intellectual disabilities and no functional communication system. It also takes time and resources to develop suitable communication systems and to train communication partners in how to use such systems effectively. Service providers may focus on the here and now of providing support and avoiding crises and rarely consider the future impact of limited communication or lack of a functional communication system on the person with intellectual disabilities. This is a cause for concern, as communication experiences, including early literacy experiences and developing a strong sense of self, are likely to influence both the future quality of life and the independence of people with intellectual disabilities.
Without an effective communication system, it is not possible for the person with intellectual disabilities to express his or her choices, needs and aspirations or to participate in a variety of contexts. Equally, it is difficult for case managers to ensure that their clients are involved in determining their own lives to the maximum of their ability. Indeed, it can be argued that case managers will be unable to adequately support people with intellectual disabilities unless they understand the importance of communication and have knowledge of a variety of ways to facilitate communication. Thus, the case manager may have to coordinate the development of communication strategies for the person with intellectual disabilities, commencing with ensuring that the person has an appropriate assessment of his or her current communication skills and future needs.

**Assessment**

In the past, many people with intellectual disabilities were assessed with standardised tests, and their results compared with those of a ‘normal population’. Often, a mental age or language age was determined based on the person’s score on the test. Thus, it was common to hear a person with a chronological age of, for example, 18 years being described as having a ‘mental age’ of a three-year-old. This practice led to confusion and the oppression of people with disabilities and acted as a barrier to maximising people’s opportunities to participate in their community and develop skills. It also led to further marginalisation of people with disabilities, who were viewed and treated as childlike despite their obvious maturity.

An adult with a disability is quite unlike a child; rather, the adult is similar to any other adult with or without a disability. Physical and sexual maturity, life experience and ongoing learning opportunities mean that no adult is like a young child, and yet families may have some difficulty in recognising this. The case manager has a role in ensuring that a person’s chronological age is respected. This recognition and respect must be communicated appropriately. Thus, it is important not to infantilise the person with disability during communicative interactions, when selecting activities and when developing communication systems. Communication systems and materials should be appropriate for an adult, and the person should be treated like an adult. This means that language can be simplified but the person should never be spoken to as if he or she were a child. Many materials are now available to support people with intellectual disabilities to acquire new skills across the lifespan. Communication materials may include photographs and symbol systems that are designed to be age-neutral and
are, therefore, appropriate for a range of ages. In using these, case managers and others involved with the person must also ensure that activities and choices are age-appropriate and not those that could further marginalise the person if he or she selected to do them.

The Participation Model described by Beukelman and Mirenda (2005) provides a useful framework for the assessment and development of interventions that facilitate the participation of individuals with disabilities in activities in which their peers without disabilities participate. The Participation Model is based on the functional participation requirements of peers without disability of the same chronological age as the person with disability who is being assessed. The model is a multiphase assessment that incorporates consensus-building across a variety of people involved with the person with disability in order to assess current and future participation patterns and communication needs. At the same time, the Participation Model can be used to identify opportunity and access barriers to participation and to assist with planning appropriate intervention goals and evaluating the outcomes. Although the model is focused on people who use augmentative and alternative communication, it is appropriate for use with anyone who is experiencing difficulty in being an integrated member of the community, including people whose main barrier to participation within the community is due to problem behaviours.

**Behaviour and communication**

Many people with intellectual disabilities or autism-spectrum disorders have problem behaviours that can be attributed to communication difficulties. Indeed, Mirenda (1997), in a review of the research on communication and challenging behaviour, suggested that all behaviours are communicative. Consequently, it is important to consider functionally equivalent communication options when supporting people with challenging behaviours. A functionally equivalent communication option is a communication behaviour that serves the same function as the challenging behaviour. An example of functional equivalence is teaching a child to sign *more* to replace screaming or biting until more of the desired object or activity is provided. Case managers are unlikely to have to manage the intervention for problem behaviours, but they may be involved in organising comprehensive assessments of the behaviours and coordinating the intervention approach so that the person is presented with a variety of interesting opportunities that will promote engagement in the community (Beukelman and Mirenda 2005).
It is not surprising, then, that case managers who support people with intellectual disabilities may be the key service personnel to ensure that every effort is made to facilitate and support their clients' communication, including the initial assessment. It is important to remember that a person with communication difficulties will be disadvantaged in both learning and social activities unless every effort is made to ensure that he or she has an effective and functional means of communication (Beukelman and Mirenda 2005).

Therefore, case managers may need not only to consider the impact of communication on their client's ability to express choices, needs and aspirations but also to ensure that every effort is made to make certain that the client's communicative attempts are considered. Case managers may need to refer clients to a communication specialist (e.g. speech pathologist, AAC specialist) in order to seek advice on the implementation of appropriate communication systems. In addition, case managers must be prepared to use a variety of communication modes to assist their clients to participate as fully as possible in any interaction.

Supporting communication

Readers who have travelled to places where they were unable to speak the local language or who have experienced communicating with people for whom speech is a not primary or functional communication mode may understand that communicating using modes other than speech can be time-consuming and frustrating for both partners in the communicative interaction. Both partners may need to alter their usual communication pattern in order to achieve a satisfactory communication outcome. Indeed, fear of difficulty with communication is a major inhibitor of communicative interactions between people with and without disabilities.

Speech is the primary communication mode for most members of the community. Although they may supplement their speech in a variety of ways, including using gesture, facial expression and body movements, the majority of the community, including service providers experienced in working with people with intellectual disabilities, may have limited experience of communicating using modes other than speech. Indeed, researchers have demonstrated that many people, including service providers, experience difficulty in moderating their language to accommodate the communication needs of the person with intellectual disability. People with intellectual disabilities may rely on non-verbal sources of information during interactions. Non-verbal sources include the time of day when routine activities occur, the context within which a request occurs, and
gestures and facial expressions. The use of non-verbal sources aids comprehension but may mask a person’s communication difficulties.

Bartlett and Bunning (1997) and Bradshaw (2001) studied the interactions between individuals with intellectual disabilities and the staff members who supported them. Bartlett and Bunning (1997) assessed the verbal comprehension of each client and compared the assessed level of verbal comprehension with the staff members’ expressive language output during structured and unstructured tasks. Both Bartlett and Bunning (1997) and Bradshaw (2001) identified that staff often overestimated what the adults with disabilities could understand—that is, they overestimated the communication skills of the residents with whom they worked. This overestimation resulted in many of the staff members’ utterances being too complex. It is hardly surprising that people with intellectual disabilities do not respond or may respond inappropriately if they do not understand what is being said to them. Staff may deem the person to be non-responsive or non-compliant or to have challenging behaviour.

Case managers need to be aware of their own communication and the communication of others. For example, at a planning meeting, if the person with a disability sits quietly throughout the meeting, this does not always mean that he or she is understanding and participating fully in what is happening. Similarly, if a person paces the room and is disruptive, it may mean that he or she is frustrated because of not knowing what is going on. Case managers may be able to prevent these scenarios by ensuring that the person with a disability is prepared for the meeting and that every effort has been made to provide communication materials and support or at the very least that there is someone present who knows the person with a disability well and can attribute communicative intent to his or her actions. As noted already, case managers do not have to take on all these roles themselves, but they are the key personnel for advocating for the person with a disability and coordinating the various experts and service providers who can facilitate communication and ensure that the voice of the person is heard.

Useful communication systems
People with intellectual disabilities may benefit from the use of additional communication systems or multimodal communication, not only to aid them in expressing what they want to say but also to support their understanding of what is said. If people with intellectual disabilities and little or no functional speech do not have a functional communication system, they will be unable to express themselves. An inability to talk does not mean that the person has nothing to say.
Similarly, people who are acquiescent either may be anxious to please a person (e.g. service provider) who they perceive as an authority figure or may not understand what is being said and therefore may choose to agree or say nothing in order to 'save face'. Importantly, case managers need to be aware of, and prepared to use, a variety of communication modes in order to increase opportunities for people with intellectual disabilities to participate in their own decision-making and in accessing the broader community. There are a number of different communication modes and systems that can be used with people with intellectual disabilities to aid them in expressing what they want to say and in understanding (see Table 15.1).

**Augmentative and alternative communication systems**

AAC systems include 'low- or light-tech devices' (e.g. word- and letter-boards, pictures, photos and objects), 'high-tech devices' (e.g. speech-generating devices, computers) and unaided systems (e.g. signs) (Sigafoos and Iacono 1993). Importantly, having speech does not preclude the use of AAC. People with disabilities who have speech can still benefit from AAC systems. Indeed, we all use these from time to time, for example writing a shopping list or using a picture or product logo as a memory aid. An overview of AAC systems used by people with intellectual disabilities is provided in Table 15.1.

Some systems, such as schedules and keyword signing, can be used to support both comprehension and language expression. Case managers may be asked whether the use of an AAC system will inhibit the development and use of speech. They can be confident that the use of an AAC system not only promotes communication and understanding but also may assist in the development of speech. It is not yet clear to what extent the use of AAC influences the development of speech, but there are reports (e.g. Romski and Sevcik 1996) that some people have started to use some speech after learning to use AAC systems, such as voice-output communication aids and signs.

**Augmentative and alternative communication and language**

Researchers have conducted longitudinal research on the use of AAC to promote language and communication with children and young adults with intellectual disabilities. These researchers have successfully increased language production in primary-school students, adolescents in secondary school and young adults (Romski and Sevcik 1996) and very young children with intellectual
**Table 15.1 Overview of high- and light-technology augmentative and alternative communication (AAC) systems**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
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| High technology        | Utilises microcomputers and specialised software  
Synthesised or digitised speech  
May interface with a computer, environmental control system or telephone  
Accessed directly (e.g. using fingers or head pointer) or indirectly (e.g. scanning using a switch)  
Requires a power source (e.g. battery)  
Requires specialised repair  
Expensive to purchase and maintain |
| Light technology, aided| No electronic parts, but can include electromechanical switches  
Accessed directly (e.g. finger-pointing, eye gaze) or indirectly using another person to ask which symbol is required  
Examples: letter-boards, chat-books, object communication systems, schedules, symbol boards  
Talking Mats™ (Murphy and Cameron 2002, 2005)  
Easy to maintain, but setup and maintenance can be costly in time  
Useful across a variety of contexts and can be tailored to different needs (e.g. community request cards to enable the person to order a meal independently or participate actively in activities such as going to the hairdresser or choosing a gift) |
| Light technology, unaided| Manual signing  
Examples: Auslan, British Sign Language  
May use signed keywords to support comprehension expression  
Sign interpreters are useful with deaf people who are fluent sign-language users but may not be useful with people with intellectual disabilities who use a few keyword signs |
impairments (Romski, Sevcik and Forrest 2000). Romski and colleagues suggested that in order to use AAC and develop language, it is important to understand not only the relationship between a spoken word and its referent but also the relationship between a visual symbol and the spoken word. People with limited comprehension must first learn the relationship between a visual symbol or manual sign and its referent before they can use AAC expressively. Some may never understand this relationship and will communicate using idiosyncratic gesture, vocalisations, movements and physical manipulation of others in the environment. Consequently, case managers endorsing the use of AAC to support and enhance communication must be cautious when discussing the likelihood of speech developing. AAC has been shown to assist in the development of speech for some people, but more importantly, the use of AAC ensures that people with little or no functional speech have a way to communicate and additional resources to aid their understanding.

Case managers may find simple systems that incorporate photographs or pictographs such as Picture Communication Symbols™ (PCS) useful when communicating with people with intellectual disability. It is beyond the scope of this chapter to describe the many systems available, but a discussion with a speech pathologist or searching a website such as www.isaac-online.org will provide useful information about ways to improve communication interactions. Case managers may also find techniques such as Talking Mats™ (Murphy and Cameron 2002) invaluable when assisting people with intellectual disabilities to make choices and express their hopes and dreams.

**Talking Mats**

Talking Mats is ‘a visual framework that uses picture symbols to help people with a communication difficulty communicate more effectively’ (Murphy and Cameron 2005, p.3). Using pictures to represent topics and options and a visual scale with people with little or no speech and people who have difficulty in understanding speech can assist them to express their wishes about what will occur in their own life. Service providers, including case managers, can use this tool to help the person with disability consider and discuss a variety of options. The pictures are placed on a mat so that the person with disability can look at the options and choices available and then move them using the visual scale to indicate how they feel about each option. The visual scale might include symbols for liking something, for being unsure and for definitely not liking or wanting something. More
complex visual scales can be created, depending on the person's needs and abilities.

The use of a visual system such as Talking Mats gives people an opportunity not only to see their options but also to easily indicate a change of opinion. It is easy for the case manager to make a record of the decisions by photocopying or photographing the mat, and this can be used as the basis for ongoing discussion and decision-making. In order for this system to be effective, it is important that as many people as possible who are involved with the person with disability are consulted to ensure that a range of possible options are presented pictorially.

Many people with a variety of disabilities use Talking Mats successfully. Nevertheless, there are some people for whom this system is not suitable. Murphy and Cameron (2005) suggested that to use Talking Mats successfully, the person using the mat must be able to recognise picture symbols and must be able to understand at least two keywords at a time. The person must also have a reliable way of confirming his or her views so that the case manager or service provider can be sure that the placement of pictures on the mat does in fact reflect the person's views.

Case managers may also find useful tools such as the Social Networks Communication Inventory (Blackstone and Hunt Berg 2003). This inventory aids functional goal-setting and personal planning. The inventory can be used to identify a person's current and potential communication partners and the communication modes that are used with each person. This provides a means of mapping the social networks of the person with a disability and ensuring that comprehensive information about his or her communication abilities, needs and outcomes of communication interventions are tracked. This information will assist case managers to use and advocate for a variety of communication options that will facilitate the inclusion of the person with a disability in a range of activities with a range of different communication partners.

**Conclusion**

Communication encompasses more than the expression of wants and needs. It also includes understanding, asking for information, getting along with other people, making choices and expressing hopes and dreams. Communication is a key not only to a good quality of life but also to effective planning support for a person with intellectual disabilities. Case managers do not have sole responsibility for a person's communication or for the barriers and solutions to successful community
participation. Nevertheless, the case manager, by virtue of his or her position, may be responsible for advocating for communication resources and supports for clients with intellectual disabilities. Case managers may also be the appropriate people to ensure that their clients have the opportunities and services that are needed in order to reach maximum community inclusion and participation. Communication underpins community participation. Without an understanding of the importance of communication and an idea of the resources and services available, case managers will struggle to meet their clients’ needs. In addition, their own communication with their clients will be impoverished. Communication is a key to a good quality of life. Case managers who understand this will take the time to develop successful communication with their clients with intellectual disabilities and their families.

References
