NSW GOVERNMENT Family & Community Services

Complex Communication Needs

Practice Guide for Speech Pathologists who Support People with Disability

Summary: This document is designed to be read with and to be complementary to the Augmentative and Alternative Communication Practice Guide.

Document approval

Complex Communication Needs Practice Guide for Speech Pathologists who Support People with Disability has been endorsed and approved by

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Approved: 10 November 2015

Document version control

Distribution:	Internal and External Stakeholders
Document name:	Complex Communication Needs (CCN) Practice Guide for Speech Pathologists who Support People with Disability
Trim Reference:	AT15/90040
Version:	Version 1.0
This document replaces	NA
Policy link to	NA
Document status:	Final
File name:	Complex Communication Needs (CCN) Practice Guide for Speech Pathologists who Support People with Disability
Authoring unit:	Clinical Innovation and Governance
Date:	October 2015
Next Review Date:	October 2017

Contents

1 Introduction

1.1 Introduction and Purpose

Welcome to the Complex Communication Needs (CCN) Practice Guide for Speech Pathologists who Support People with Disability.

This practice guide is designed to be complementary to, and read in conjunction with, the Augmentative and Alternative Communication (AAC) Practice Guide. The Complex Communication Needs Practice Guide provides additional detail about some topics introduced in the Augmentative and Alternative Communication Practice Guide and some new information in this area.

It has been developed to support speech pathologists who are:

- new to working with people with a disability in the area of complex communication needs and augmentative or alternative communication
- entry level clinicians
- returning to work.

This practice guide is a practical resource to provide basic or core level information on complex communication needs for speech pathologists who work with people with disability, their families, caregivers and other professionals. The Complex Communication Needs Practice Guide outlines current principles, good practice, evidence and resources in:

- communication as a basic human right
- person centred practice and collaborative practice
- impacts of having complex communication needs – for instance, how this influences an individual's social skills, willingness to attempt to communicate, confidence and resilience in relation to having a disability.
- understanding that behaviour and communication are closely related
- assessment and intervention including considerations with non-symbolic and symbolic communicators
- the need to plan for changes in communication across a person's life, and
- future directions for people with complex communication needs.

There are many aspects that need to be considered when working with people with complex communication needs. The Complex Communication Needs Practice Guide complements the AAC Practice Guide as many people with complex communication needs may use or require AAC. The reason there are

two documents is to help practitioners to find practical information and specific references in each practice guide.

Readers are referred to the Appendices for additional resources.

Appendix 1: Glossary provides definitions of terms used within this practice guide.

Appendix 2: Table of assessment tools.

Appendix 3: A-Z of Intervention Methods and Resources provides additional information on specific interventions. This is a quick reference to help consider potential intervention options and provides a starting point for further learning. Please note that FACS does not endorse or recommend any particular intervention method or resource.

There is an appraisal accompanying this practice guide that is designed to support speech pathologists to translate their knowledge regarding complex communication needs into their everyday practice.

This guideline forms part of the supporting resource material for the core standards program developed by the Clinical Innovation and Governance Directorate, Ageing Disability and Home Care, Family and Community Services, NSW, Australia.

Please note that the information contained in this package is designed specifically for speech pathologists working with people with a disability in Australian settings.

Your feedback on this Complex Communication Needs (CCN) Practice Guide is welcome and should be sent by email to CIGcorestandards@facs.nsw.gov.au with the words *CCN Practice Guide* as the subject of the email.

1.2 Core Standards Program

ADHC has developed an overarching program of core standards. Four common core standards with practice guides, appraisals and other resources are available for practitioners[1] who provide support to people with a disability. These are located on the ADHC website. Definitions of disability and other key areas for speech pathologists are covered in the common core standards.

The common core standards cover the following areas for practitioners who support people with disability:

- Professional Supervision
- The Working Alliance

[1] The term practitioner as used here includes dieticians, speech pathologists, occupational therapists, physiotherapists, psychologists, behaviour support practitioners and nurses.

- Philosophies, Values and Beliefs
- Service Delivery Approaches.

In addition to the Speech Pathology specific AAC and CCN Practice Guides, an e- learning resource on mealtime management will be available in the future.

1.3 Copyright

The content of this practice guide has been developed by drawing from a range of resources and people. The developers have endeavored to acknowledge the source of the information provided. The practice guide also has a number of hyperlinks to documents and internet sites. Please be mindful of copyright laws when accessing and using the information through hyperlinks. Some content on external websites is provided for your information only, and may not be reproduced without the author's written consent.

1.4 Disclaimer

This resource was developed by the Clinical Innovation and Governance Directorate of Ageing, Disability and Home Care in the Department of Family and Community Services, New South Wales, Australia (FACS).

This practice guide has been developed to support practitioners who are working with people with disability. It has been designed to promote consistent and efficient good practice. It forms part of the supporting resource material for the Core Standards Program developed by FACS.

This resource has references to FACS guidelines, procedures and links, which may not be appropriate for practitioners working in other settings. Practitioners in other workplaces should be guided by the terms and conditions of their employment and current workplace.

Access to this document to practitioners working outside of FACS has been provided in the interests of sharing resources. The Information is made available on the understanding that FACS and its employees and agents shall have no liability (including liability by reason of negligence) to the users for any loss, damage, cost or expense incurred or arising by reason of any person using or relying on the information and whether caused by reason of any error, negligent act, omission or misrepresentation in the Information or otherwise.

The guide is not considered to be the sole source of information on this topic and as such practitioners should read this document in the context of one of many possible resources to assist them in their work.

Practitioners should always refer to relevant professional practice standards. The information is not intended to replace the application of clinical judgment to each individual person with disability. Each recommendation should be considered within the context of each individual person's circumstances. When using this information, it is strongly recommended practitioners seek input from appropriate senior practitioners and experts before any adaption or use.

The information contained in this practice guide is current as at 22nd October 2015 and may be subject to change. Whilst the information contained in this practice guide has been compiled and presented with all due care, FACS gives no assurance or warranty nor makes any representation as to the accuracy or completeness or legitimacy of its content.

FACS takes no responsibility for the accuracy, currency, reliability and correctness of any information included in the information provided by third parties nor for the accuracy, currency, reliability and correctness of references to information sources (including Internet content) outside of FACS.

2 What are Complex Communication Needs?

2.1 Definitions

> *Communication is the exchange of information and meaning between two or more people. It involves vocalising, speaking, hearing, listening, expressing, understanding, social skills, reading, writing, and using gesture, facial expression, symbols and signs.*
>
> *International Communication Project (2014a)*

This description of communication captures the breadth of communication and the importance of having shared meaning, whatever method is used.

"Complex communication needs" is a term used in the literature to describe people who have little or no speech, where there are many possible causes.

> *People with complex communication needs may have communication problems associated with a wide range of physical, sensory, cognitive and environmental causes which restrict/limit their ability to participate*

independently in society. They and their communication partners may benefit from using AAC methods either temporarily or permanently.

Balandin, 2002, cited in (Speech Pathology Australia 2012), p 9.

Within the context of the International Classification of Functioning and Disability — ICF (World Health Organization 2001), "complex communication needs" relates to people who have a severe limitation in communication functioning, related to their health condition, body structures and functions, activities and participation, environmental factors and personal factors.

In the future it may be more helpful to talk about people who have a "communication disability", (Blackstone 2013; Scopes Communication Resource Centre 2013) so communication is recognised as a primary disability in its own right and terminology is clearer. Disability exists as an interaction of various factors and does not only reside with the individual (Speech Pathology Australia 2012, p 8).

Additional reading and resources:

- Iacono, T. (2014). What it means to have complex communication needs. *Research and Practice in Intellectual and Developmental Disabilities*

2.2 Who has Complex Communication Needs?

People with complex communication needs are a very diverse group. They vary in their skills and abilities. In addition to a speech impairment they may also have a combination of physical, vision, hearing, sensory processing or cognitive impairment/s. Understanding a person's strengths and abilities as well as their impairments is essential. People with complex communication needs use many methods of communication. In addition to "non-verbal" aspects of communication we all use such as facial expression and body language, people with complex communication needs may use a range of augmentative and alternative communication strategies and systems.

Augmentative and Alternative Communication (AAC) *refers to an area of research, clinical and educational practice. AAC attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication.*

(ASHA Position Statement, 2005, cited in (Beukelman & Mirenda 2013), p 4.

A person with complex communication needs uses a multi-modal approach (Speech Pathology Australia 2012) and may communicate using:

- vocalisations and speech that is hard to understand
- atypical behaviours known only to familiar communication partners
- gestures, signs, pictures, words or spelling
- a non-electronic communication book, board or resource
- a computer, a dedicated speech generating communication device and /or a smart phone or tablet.

Given the multi-modal quality of people's communication, people with complex communication needs can also be called augmented speakers or augmented communicators (Fried-Oken & Bersani Jr, 2000).

> *"They use more techniques to communicate than the average student or reader uses, and they challenge all of us to expand the expressive repertoires of our own natural expression"*
>
> *Fried-Oken & Bersani Jr (2000),p14 .*

When people have multiple disabilities, it can be difficult to know if the person has impaired cognitive / intellectual abilities. Sometimes a person may have physical and/or sensory disabilities which make it difficult to gauge or measure cognitive capabilities.

Some primary diagnoses of people who may have complex communication needs are listed in the table on the following page.

Developmental	Acquired
Developmental delay Intellectual disability Cerebral palsy Autism Genetic / congenital syndromes Epilepsy Mental Health / psychiatric conditions, such as elective mutism and psychosis	Progressive neurological conditions, such as muscular dystrophy, motor neurone disease (also known as amyotrophic lateral sclerosis), multiple sclerosis, Parkinson's disease, Huntingdon's disease and Alzheimer's disease / Dementia. Cerebrovascular accidents (CVA) / strokes, resulting in dysarthria, dyspraxia and / or aphasia. Traumatic brain injury Surgical conditions, such as laryngectomy, brain tumor
	Adapted from Perry et al. (2004b), p267 - 268.

People with complex communication needs are a diverse group. This practice guide will primarily focus on people with developmental or intellectual disability who are unable to communicative effectively using speech.

2.3 Prevalence

It is estimated that 1.1 million Australians have a communication disability (Speech Pathology Australia 2014). Examination of available data indicates a possible 0.2–1.0% prevalence of complex communication needs in Australia. However, there is no consistent data or statistics for people in Australia who have complex communication needs (Clinical Innovation and Governance 2014a).

Data from the Australian Institute of Health and Welfare (2011) confirms that in Australia there are thousands of individuals with complex communication needs (CCN) who have a severe/profound core activity limitation affecting their communication. An estimated 6.1% (~1.4M) of the Australian population have severe or profound limitations in the core activities of communication, mobility and/or self-care (Australian Bureau of Statistics 2013, 2015).

A comprehensive report on cerebral palsy found that 40% of people with cerebral palsy in Australia had a severe–profound communication impairment, including 25% who were non-verbal (Access Economics 2008).

Indigenous Australians of the age 19–24 years require assistance with a core activity at around twice the rate of non-Indigenous Australians and this gap increases as the population ages. Around 26,000 Indigenous Australians have a severe to profound core activity limitation (Commission 2011). There is a significant area of unmet need in relation to complex communication needs within the Aboriginal and Torres Strait Islander (ATSI) communities.

In the United Kingdom, the Augmentative and Alternative Communication (AAC) Evidence Base Research Project (Communication Matters 2013), recently reported the prevalence of people with complex communication needs is just over 0.5% of the total population, around 318,500 people (Communication Matters 2013). Extrapolating this percentage to Australia, (population 22 million) suggests there would be around 110,000 people with complex communication needs. It is likely that these are conservative estimates.

Australian prevalence figures outlined in a recent submission to the Senate Inquiry into Communication Disorders and Speech Pathology Services (Speech Pathology Australia 2014 p73) are summarised below.

Australian Bureau of Statistics Survey of Disability, Ageing and Carers in 2012:

- 40% of people with a severe or profound core activity limitation, or approximately 215,000 Australians under the age of 65, require assistance with communication.

Commonwealth and State/ Territory Agreements indicate:

- 42% of people using disability support services require support for communication
- a further 2% need communication aids and devices (AIHW 2013a)
- 12% of disability service users had little or no effective communication. *Data did not include children under 5 years of age.*
- 27% of people had an intellectual impairment
- 23% of people with autism were reported as having no or little effective communication
- in Australia, around 6,900 people use electronic speaking aids to communicate
- over 15,000 Australians use non-electronic communication aids to communicate (ABS 2013).

Additional reading and resources

- Senate Inquiry Report for the ‘Inquiry into the Prevalence of different types of speech, language and communication disorders and speech pathology in Australia’.

3 Communication as a Human Right

> *Communication is the most fundamental of human capacities. People need to be able to communicate to fulfill their social, educational, emotional and vocational potential. Everybody has the potential to communicate.*
>
> *International Communication Project website (2014).*

3.1 United Nations Convention on the Rights of Persons with Disabilities

Australia ratified the UN Convention on the Rights of Persons with Disabilities (UNCPRD 2006) in 2008. This is essential reading for anyone working with people with disability. It discusses requirements for active participation and inclusion in all aspects of life, education and accessibility, including communication accessibility.

Communication:

> *"Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.*
>
> *"Language" includes spoken and signed languages and other forms of non spoken languages.*
>
> *(UNCPRD 2006), Article 2, p4)*

Freedom of expression and opinion, and access to information:

> *The importance of taking appropriate steps to ensure that people with a disability have the right to say what they think and share their ideas like other people do, through all forms of communication of their choice*.
>
> *(UNCPRD 2006 Article 21, p14-15)*

Article 24, outlines the responsibility to ensure an inclusive education for all, including the need to provide communication supports for individuals with complex communication needs *(UNCPRD 2006).*

3.2 Disability Inclusion Act 2014

Practitioners working in NSW, Australia need to be aware of current disability legislation.

The Disability Inclusion Act 2014 commenced on 3 December 2014 and replaced the Disability Services Act of 1993. The Disability Inclusion Regulation 2014 (the Regulation) supports the Act and provides the details needed for the Act to work properly.

> *This Act contains general principles which align with the UN Convention and acknowledge the human rights of all people with disability. It also includes principles recognising the needs of particular groups, such as Aboriginal and Torres Strait Islander people with disability, people with disability from culturally and linguistically diverse backgrounds, women with disability and children with disability.*
>
> *The Act uses a similar definition of disability as used in the UN Convention. The definition recognises that disability results from barriers in society that prevent or limit inclusion.*
>
> *NSW Department of Family and Community Services (2014)*
>
> *Disability Inclusion Act 2014 – Overview of the Act Factsheet, p1.*

The act:

- *makes it clear that people with disability have the same human rights as other people*
- *promotes the inclusion of people with disability by requiring government departments and local councils to engage in disability inclusion action planning*
- *supports people with disability to exercise choice and control through individualised funding wherever possible*
- *provides safeguards for people accessing NSW funded disability supports and services, including new employment screening requirements and the need for disability accommodation providers to report abuse or neglect of people with disability to the Ombudsman.*

(NSW Department of Family and Community Services 2015a)

3.3 Communication Bill of Rights

Speech pathologists have an important role in advocacy to help people to understand that communication is a human right. We all have responsibility to support a person's communication. One useful tool for doing this is The Communication Bill of Rights Poster, (Scope's Communication Resource Centre, 1999).

This poster is available for download and has been created around 12 basic rights, using COMPIC™ pictographs to convey the message for each concept. These concepts have been adapted from a USA initiative which involved

writing a Communication Bill of Rights specifically aimed at people with complex communication needs.

The poster says that everyone has a right to:

- express feelings
- understand communications
- reject
- request information
- have access to information
- be communicated with in a dignified manner
- aids, services and resources
- be listened to
- be included in social interaction
- learn about yourself
- learn about life
- be offered choices.

The Communication Bill of Rights Poster is a useful resource, to encourage increased awareness of ways to support communication in an environment.

3.4 Communication Access for All

Just as physical barriers make it difficult for people with disabilities to access buildings, travel and participate in community life, social and communication barriers exclude people with disabilities from full participation and inclusion in society.

> *Social barriers include negative attitudes to people with disability. Within social barriers we now include interpersonal barriers which exist in the way people communicate and interact. It is these barriers that exclude people and create social divide. By addressing these barriers, access is created to places, goods, services and people where previously it was absent.*
>
> *All types of access, including communication access needs to be considered across the full spectrum of settings which contribute to life experience. Whereas the literature reports on access to healthcare, rehabilitation services and information technology (Aday and Anderson, 1981, Heineman 2007, McKenzie 2007 cited in Owens 2009), a full list with specific examples of communication access includes access to:*
>
> - *Government services, e.g. negotiating with Centrelink*

- *Disability related services e.g. negotiating attendant care, communicating with a wheelchair vendor*
- *Emergency services, e.g. calling CFA or Ambulance and communicating with staff*
- *Professional services e.g. stating request in a bank requesting legal services*
- *Health services, e.g. family doctor, hospital, clinic, rehabilitation*
- *Leisure / Recreation, e.g. buying a ticket, asking for information, using a library, participating in sport*
- *Transportation, booking or cancelling a taxi, giving a pick up or drop off*
- *Retailers e.g. communicating with cashier, asking for an item.*

Solarsh (2012), pp 8-9.

Additional reading and resources

- A project by Scope Victoria based on communication as a human right is the Communication Access Symbol. Scope Victoria, Communication Access information.

4 International Classification of Functioning, Disability and Health (ICF)

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) is based on a bio-psycho-social model. There is an emphasis on human rights for all and measurement of outcomes related to everyday functioning. This model is at the heart of the approach taken in this document.

These guidelines suggest speech pathologists use the ICF in their assessment and intervention practices when working with people with complex communication needs. Please also refer to the section on the ICF in the Augmentative and Alternative Communication Practice Guide (2014, p14).

Speech pathologists providing services within early intervention, school and community / employment settings may help organisations develop their communication policies to promote support for autonomous communication for individuals, including those with the most complex needs. The ICF is a tool that helps to address questions such as:

- Who has complex communication needs?
- What are the barriers?
- What will facilitate communication?
- How can we implement communication supports?

The ICF can be used to quantify and rate a person's level of disability (World Health Organization 2001) so it can help us to gain a more accurate picture of prevalence within our current service systems to help address the needs for communication support.

By using the ICF framework, practitioners create a more holistic view, making intervention goals functional and relevant. Communication disability impacts the individual and the people they communicate with – their communication partners. Communication partners have additional importance when communicating with people who have complex communication needs. This includes learning to read a person's body language, learning sign language and fingerspelling, learning what specific behaviours mean and learning to use communication boards, books and devices.

> *"A communication disability does not just belong to the individual. It belongs to the entire environment of which the individual is the focal point."*
>
> *Sandwell – Communication Aids Centre, UK*

Looking at a person's communication within the context of environment and communication partners provides a coherent way to improve functional outcomes.

The framework consists of five domains:

- Body structures and functions
- Participation
- Activity
- Environment
- Personal factors.

All of these domains will be affected by complex communication needs, in some way.

People with complex communication needs come from all walks of life, from all cultures, and all ages.

Using the ICF, some examples of how a person with complex communication needs might present are provided below and in the following pages.

Using the ICF with a Child with Global Developmental Delay

Two Years Old

Health Condition	Global developmental delay
Body Structures and Functions	Low muscle tone, comprehending one step instructions, vocalising using mostly vowel sounds, with a few words 'mum' 'dad' and 'no'. Uses 20 signs. Eating puree.
Participation and Activity	Dislikes being challenged with gross motor activities (angry cry) Tantrums appear to be a way to avoid physically difficult things. Sits quietly when watching TV. Signs are only understood by family and her aide at daycare. Enjoys company of other children, tending to parallel play.
Environment	Home, attends day care, kindygym and numerous therapy appointments, with multiple communication partners.
Personal	Young girl, reluctant to participate in tasks she finds difficult; may need to develop confidence through task adaptation.
Complex Communication Needs	She is developing communication strategies, but communication partners are not trained across her environments. Beginning to develop behaviours of concern.

Using the ICF with a Child who has Cerebral Palsy

5 Years Old

Health Condition	Cerebral palsy spastic quadriplegia
Body Structures and Functions	Comprehension functioning close to age level. No speech – occasional vowel sounds only. Mild hearing loss (aided). Unable to walk. Pointing is not always clear, due to fine motor difficulties with hands / fingers.
Participation and Activity	Loves to attend the football with his dad and collect football cards. Spends a lot of time watching siblings' activities. At school spends most playtime with aide, who has been trained to use low tech communication system. A small amount of the curriculum is modified for him.
Environment	Home, school, swimming / hydro, therapy appointments. Member of a large, busy family of 5 children. Has a power wheelchair for mobility. Physical barriers are an issue.
Personal	Happy when following interests, e.g. football.
Complex Communication Needs	Comprehension is much better than expressive language which leads to frustration or shut down. Has a comprehensive low tech communication system to express a few needs and wants. Communication partners do not all know how to use system.

Using the ICF with an Adolescent who has Autism Spectrum Disorder

Health Condition	Autism spectrum disorder, mild intellectual disability
Body Structures and Functions	Comprehension 5th centile for age. Expression 0.1 centile. Verbal attempts which can be accurate and intelligible within context of very familiar activities. Behaviours of concern with anxiety. Sensory processing issues – soft textures and auditory sensitivity.
Participation and Activity	Enjoys time on the trampoline and similar activities, avoids and dislikes noisy environments - can cause behaviours of concern with little warning. Is rarely taken outside of the school and home.
Environment	Home. School (School for Specific Purposes) can maintain verbal communication with a small number of staff at school and his family when calm. Manages changes to routine when social stories and visual supports are used to prepare him.
Personal	15 years old. Finds any changes to his routine challenging.
Complex Communication Needs	Communication successful with a small number of partners, to express needs and wants and some feelings; very concrete in understanding. Has unpredictable violent behaviours.

Using the ICF with an Adult who has Multiple Disabilities including Severe-Profound Intellectual Disability

Health Condition	Cerebral palsy, spastic quadriplegia, epilepsy, severe-profound intellectual disability
Body Structures and Functions	Unable to assess comprehension – no consistent responses. Vocalisations, fleeting eye contact. Not sure how much he sees and hears. Some responses to sound and visual stimuli. Severe physical disability, curvature of the spine, stiffness and contractures in limbs, flexed hands and fingers.
Participation and Activity	Requires full assistance with all activities. Goes to day program three days per week where he attends weekly music therapy, shopping and swimming activities. Body relaxes when swimming in heated pool with full support from carer. At home spends time sitting in living room; sometimes he is taken outside for walk. Uses manual wheelchair for mobility, with head and side supports. Very slow in eating and drinking, requires moderately thickened fluids. Avoid bright and flashing lights, as these seem to "bring on" an epileptic fit. Has frequent colds. Personal information, mealtime and health plan must be with him at all times. All staff working with him require training regarding his needs.
Environment	Lives in supported accommodation. Family visit on weekend.
Personal	Body language indicates he enjoys most activities at day program. Likes it when his carer speaks to him and shows him things. Does not complain when left sitting on his own.
Complex Communication Needs	Orients towards person, and face brightens when person speaks to him, looks more alert; some smiling. Has a personal communication dictionary that goes with him to his day program. This describes ways he informally communicates using vocalisations (e.g., different sounds that indicate he is happy or upset), body language, brief eye contact when interested in an object / activity, and idiosyncratic gestures – one for toilet, paired with a vocalisation; one when he's had enough of an activity. No consistent yes/no signal – he smiles when he likes something and cries if he doesn't like something. Joins in more with music – takes turns making sounds with others in the group. No formal communication system.

5 Person Centred Practice

Person Centredness is about recognising and appreciating the value of each person and therefore giving each individual respect and dignity. Person Centredness involves developing relationships with others through deep listening and empathy. Person Centredness is a way of life that endeavours to enable all people to have a good life.

Definition workshopped with the Person Centred Champions from ADHC Southern Region, April, 2013, (Centre for Disability Studies 2014), p 2.

Person centred planning puts the person with disability at the centre of the planning, listens deeply to them and their family and friends, learns over time what it is they want for their life now and in the future, and then acts on this. It means a shift of power.

(NSW Department of Ageing 2008), p 7.

Person centred practice puts the person (with complex communication needs) *at the centre of decision-making rather than professionals.*

(Clinical Innovation and Governance 2014c),p 20.

People have different life experiences and knowledge about the goals they want to work on and the supports that may be available to help them achieve these goals. Some people with disability and their families/ carers will know exactly what they want, while others require support to be active decision makers. Many people will require training about the process of decision making. Decision making requires access to information, to enable people to make informed decisions about their own lives.

Speech pathologists can have an important role in:

- making information accessible to individuals, their families, carers and others who support them to enable the person to know about possible options related to decisions they are making, where it falls within their area of expertise
- problem solving ways to support the individual related to their communication abilities, for instance, to ensure the person understands the information provided and to enable the person to express their ideas, priorities and preferences.

5.1 Self Determination

Self-determination is the ability to make decisions for oneself without the influence from others. It enables people with disability to take control of their own lives.

Self-determination means a person with disability has:

- the ability and opportunity to make choices and decisions
- the ability and opportunity to exercise control over services, supports and other assistance
- the authority to control resources and obtain needed services
- the opportunity to participate in and contribute to their communities
- the support, including financial, to advocate, develop leadership skills, become trained as a self-advocate and to participate in coalitions and policy-making.

Information adapted from National Gateway to Self-Determination website.

Individualised planning encourages people to think broadly, is consistent with the ICF and is the approach being used by the National Disability Insurance Agency (NDIA) when developing plans with people.

A person who qualifies for individual planning in Australia is encouraged to think about:

- What support do you need to do everyday activities?
- How would you like your life to be in a few years?
- How can the NDIS help you?

NDIA planners assist people to identify and pursue their goals and aspirations, increase their independence and to take part in employment or community activities.

People are encouraged to consider informal, community and mainstream supports available. These include family, friends and community services, or more formal supports, such as health and education services.

The NDIS funds reasonable and necessary supports to enable people to live the life they choose.

Information adapted from (National Disability Insurance Scheme 2014)

For people with complex communication needs, there is a need to think carefully about how their individualised planning is organised. The individual, their families, carers, guardian and advocates will require different levels of support, depending on their needs. The rights of the person should always be put first (ACT Disability 2013).

It is important to ensure that there is sufficient support for individuals to be able to express themselves to actively participate in their own planning and decision-making. They need accessible information and support to consider options and to help work out priorities. Speech pathologists may take on professional roles such as a case manager or trainer to enable people to learn skills to enhance their capacity to be goal oriented and self-directed in planning for their future.

Additional reading and resources

- Talking mats are a useful tool that can help people to be involved with their own decision-making (Murphy & Boa 2012; Murphy & Cameron 2008; Murphy, Gray & Cox 2007).
- NSW Department of Family & Community Services (2012) Lifestyle Planning Guidelines.
- NSW Department of Family and Community Services (2012a) Lifestyle Planning – What tool to use?
- Ellis, Sherwin & van Dam (2011) Working in Person Centred Ways: A Resource Book for NSW Advocacy and Information Centres.
- NSW Council for Intellectual Disability website

5.2 Consent

People with complex communication needs must be involved in decision making when providing informed consent during planning, assessment and intervention. This includes consent for such things as:

- accessing their personal information and/or reports
- sharing their information with others
- any kind of behavioural intervention
- giving permission to use their images
- publishing their comments
- participating in a research study
- presentations concerning case studies
- student observations or interventions
- mentoring or being mentored.

There is a need to judge the capacity of the person to understand and to ask questions to be able to make an informed decision. A person is deemed to have the capacity to make decisions unless there has been a finding to the contrary. The NSW Government Attorney General's Department (2008) has developed a Capacity Toolkit which outlines what 'capacity' means and how to decide if a person has the capacity to make their own decisions.

Seeking informed consent involves using method/s of communication that best suit the individual, with assistance from those who know the person well to ensure that this is a thorough and ethical process (Iacono & Murray 2003). Where informed consent is not possible, a person may have the capacity to assent (Iacono & Murray 2003). For instance, it is possible to observe a person who has a severe-profound intellectual disability to look for signs that the person is happy to continue in a situation. If the person protests about something, such as having a stranger present, then the distress can be taken as an indicator that the person does not want the activity to continue.

Consent where children are concerned is generally obtained from their parents and guardians/carers. Speech pathologists should still take care to include the child as much as possible within the decision making process and to be responsive to their preferences. Some negotiation between children and parents/carers is sometimes required.

Additional reading and resources

- NSW Council for Intellectual Disability (CID) (2011) Rights and Complaints
- NSW Ombudsman
- CDDH Victoria website page Health and Disability: Partnerships in Action
- Queensland Health (2012). Guide to Informed Decision-making in Healthcare, Queensland Health.
- Browning, Bigby & Douglas (2014) Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice.
- Easy Health provide information and resources on developing accessible consent forms

5.3 Guardianship

People who have limited capacity to make decisions may be appointed a Public Guardian.

> *The Public Guardian promotes the rights and interests of people with disabilities through the practice of guardianship, advocacy and education.*
>
> *NSW Department of Justice website, Public Guardian information*

Processes for supported decision making by the public guardian are currently being reformed, as part of changes occurring across Australia (Public Guardian 2014). It is crucial the person understands what is happening to the greatest extent possible. When decisions are made by someone else, such as a parent/guardian or carer, it is important to ensure that the person is involved and agrees with the decisions.

A speech pathologist may play a role when the need for guardianship is considered. For instance, a speech pathologist may be asked to explain and demonstrate how a person communicates, so the guardianship tribunal can determine if a person is capable of making decisions. A speech pathologist may act as a communication support worker, enabling a person to communicate using their AAC system or provide information to the tribunal about an individual's receptive language skills.

Guardianship

The Guardianship Tribunal aims to protect people with disability and people who have age related disabilities that impact upon their ability to make lifestyle and/or financial decisions. The Tribunal sees people with a range of disabilities, including those with complex communication needs. It is comprised of three members: a legal member (who presides at the hearing), a health professional member and a community member, who is someone from the disability community.

Fiona Given is a community representative on the Guardianship Tribunal in NSW and is a lawyer with complex communication needs. She writes about her role:

> *"I bring my personal experience of using AAC to my role in the Tribunal. If we get clients who have complex communication needs I always make sure they have an AAC system in place before making any determinations as to their capacity to make decisions for themselves. I also raise awareness of AAC because I come into contact with so many different people (Tribunal colleagues, Tribunal staff, professionals and relatives associated with the clients).*
>
> *Clients who come to the Tribunal are often stressed. Sometimes they think they are in trouble. I think clients are put at ease when they see me because I am a peer. I endeavor to calm them by telling them that they are the most important person in the room and that we are there to help them. My role becomes even more crucial when the client is not there. I have to try to get the other Tribunal members to see the proposed orders through the eyes of the client. In 2014, I plan to train the staff in AAC. In particular, I hope to introduce a visual cues system in order to help them to better understand the process and therefore improve the clients' access to justice."*
>
> *Fiona Given, ISAAC Conference abstract, 2014*

5.4 Supported Decision Making

Some people may need only a little support to access information or weigh up a decision. Others, however, will need access to more comprehensive support, including support to understand decision-making, build expectations that they will be involved in the decisions that

are important to them, or consider the possibilities for decision support, even before they identify a decision and work towards its fulfillment.

(ACT Disability 2013), p 5.

Supported decision making is important for all people. For people with severe/ profound intellectual disabilities it is essential to tailor how support is provided.

'The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices'

(Beamer & Brookes, 2001 p.4, cited in Watson, Bink & Joseph, 2011, p 8.)

The Supported Decision Making Framework (Watson 2010) is one model that has been developed in Australia to address this issue. A training package called *"Listening to those rarely heard", A Guide for Supporters* (Watson 2011), is available to assist people working with individuals with severe–profound intellectual disabilities. The guide provides information about how to assist those with a disability to make a decision they face now or in the future.

The Supported Decision Making Framework involves:

- identifying a decision together
- listening together
- exploring together
- documenting together
- making a decision and acting on it together.

Practical options to enhance the way that people communicate with the individual in their everyday environments are also included in this process.

Sometimes decision making can take a long time. It is important that the person is not rushed or forced into a hasty decision. Give them time to consider the options and to make a decision.

Additional reading and resources

- Grove (2000). See What I Mean: Guidelines to aid understanding of communication by people with severe and profound learning disabilities.
- ACT Disability (2013). Spectrums of Support.

- Scope's Communication and Inclusion Resource Centre (2015) Inclusion of People with Disabilities in Counselling and Decision Making Using a Graduated Multi-Level Communication System.

5.5 Service Delivery Models

Speech pathologists who work with people with complex communication needs may work within different service delivery models. Team work can be multidisciplinary, interdisciplinary or transdisciplinary. These terms reflect differences in emphasis in how team members share information and work together.

Speech pathologists need to work collaboratively, with a range of professionals, as no one team member will have all the required skills. The person with complex communication needs / the person's family caregiver or guardian may organise their own team (with their individualised funding) to meet their needs.

Therapy services, including speech pathology, occupational therapy and physiotherapy, will often involve sharing skills with other team members. A mix of some direct "hands on" therapy with indirect therapy that involves training, consultation and advice will often best suit the service delivery for a person who has complex communication needs (Bundy et al. 2008).

Collaborative teamwork is strongly recommended for speech pathologists supporting people with complex communication needs (Clinical Innovation and Governance 2014a; Hunt et al. 2002).

Teams may include:

- the person with complex communication needs
- parents / guardians, who depending on the age and capacity of the person with complex communication needs, may take an active role in coordinating services
- key communication partners, such as family members, carers, teachers, learning support teachers and disability support workers, who interact with the person the most
- a speech pathologist, with expertise in communication and swallowing /mealtime management
- professionals with expertise in seating, positioning and movement, such as an occupational therapist and/or physiotherapist
- professionals with specialised skills in behaviours of concern, such as a teacher or behaviour specialist
- general practitioners, nurses, dietitians and medical specialists as needed

- vision and/or hearing specialists
- other allied health professionals and allied health assistants.

Good practices for service delivery include:

- using the ICF model to guide service delivery (World Health Organisation 2013); The Life Needs Model (King et al. 2002) is a recommended approach consistent with the ICF
- person-centred practice for all people with disabilities, with decision making under the choice and control of the person with a disability((AIHW) 2006; Clinical Innovation and Governance 2014c; World Health Organisation 2013)
- a family centred approach when working with children ; control moves to the individual with the disability more as they grow and become an adult (AIHW) 2006; Clinical Innovation and Governance 2014c; World Health Organisation 2013)
- a collaborative team approach to service delivery that enables team members to work closely together, share expertise and support each others learning (Bundy et al. 2008; Carter et al. 1995; Dule et al. 1999; Hunt et al. 2002)
- working in ways that are culturally sensitive (Verdon 2015)
- using accessible information, to assist with clear communication between team members (Clinical Innovation and Governance 2013; Turnbull et al. 2013)
- long term planning to meet needs across the lifespan ((AIHW) 2006; Blackstone & Hunt Berg 2003, updated 2012)
- assessment and intervention that monitors changes to quality of life(King et al. 2002)
- ongoing learning and high professional standards for all people who work with people with disabilities (Bundy et al. 2008; Speech Pathology Australia 2012, 2014).

Please also refer to the Core Standards program on Service Delivery Approaches (Clinical Innovation and Governance 2014e) and the Working Alliance (Clinical Innovation and Governance 2014f).

6 Complex Communication Needs and its Impacts

Communicating with a person who has complex communication needs has impacts for the individual and their communication partner/s. For people in the wider community, they may be unsure what to do when talking with a person who has complex communication needs. They may think that if a person can't speak, they also can't hear or have limited cognition. This can be very frustrating for the person with complex communication needs.

Within any environment, communication partners will need to adjust their communication when talking with a person who uses other methods of communication, to provide a more equal share of the conversation. (Shire & Jones 2014) Communication partners can learn skills to enhance communication exchanges between themselves and people with complex communication needs (Midtlin et al. 2014).

People with complex communication needs may experience barriers to many aspects of their lives. Having complex communication needs impacts on day to day life, health and well-being.(Fried-Oken & Bersani Jr 2000; Given 2014; Given & Cranko 2013; Light & McNaughton 2015; Solarsh 2012). An enormous amount of effort can be required to overcome the barriers to communicate successfully.

For people with complex communication needs, this can lead to a tendency to:

- speak or communicate sparingly
- not use "small talk"
- become isolated
- become emotionally overwhelmed, without being able to talk in depth about feelings and situations
- feel dependent on support from family and friends.

The life experiences of people with complex communication needs are different (Fried-Oken & Bersani Jr 2000). Sometimes the effort needed to communicate basic needs and wants means that some people have not had opportunities to develop more subtle aspects of communication competence that relate to social, strategic and cultural competence, particularly in less familiar situations (Light & McNaughton 2014). These are skills we need when socialising, at school, at work, when pursuing interests and leisure activities and when interacting with unfamiliar people in the community.

Differences in the quality of communication due to the modalities and timing of communication significantly impact even the most skilled communicators who have complex communication needs (Given & Cranko 2013).

6.1 Social

The impact of having complex communication needs on people's social skills and their ability to socialise with family, friends, peers and colleagues can be profound and often very isolating.

Research has shown that people with complex communication needs often have high levels of loneliness, isolation and limited friendship circles (Ballin & Balandin 2007; Cooper, Balandin & Trembath 2009). Interactions are mostly with immediate family and paid carers. This can intensify once a person has left school.

However, the type of impact varies depending on the individual, their overall level of communication competence and the ability of the people around them to modify their own communication accordingly.

Some examples of this may be as follows:

- A person who experiences barriers with comprehending the communication attempts of others might find it difficult to establish relationships with others.
- A person who has difficulties understanding and using appropriate social skills might be excluded from activities.

When working with people who have complex communication needs, it may be important to consider ways to enhance social skills and to build social networks to enable people to participate in their day to day life effectively, to have friendships and a wider circle of acquaintances to expand their community (Raghavendra et al. 2012). Light, 1998, cited by Farrall (2011a) found that the reasons for communication between adults, in ranked order, were:

- social closeness
- social etiquette
- information transfer
- wants and needs.

This highlights the need to consider social competencies as a priority area for assessment and intervention. Small talk (Farrall 2009; King et al. 1995), sequenced social scripts (Farrall 2011a; Musselwhite & Burkhart 2001), and use of social media to connect with others (Hynan 2013) are examples of strategies that may assist.

Additional reading and resources

- Farrall (2011b). Small talk, gossip and tall stories: Using AAC socially - workshop notes.

- Hynan, Murray & Goldbart (2014) 'Happy and excited': Perceptions of using digital technology and social media by young people who use augmentative and alternative communication, *Child Language Teaching and Therapy, 30 (2),* 175-186.
- Media Access (2012) Sociability: Social Media For People With A Disability.
- Thirumanickam, Raghavendra & Olsson (2011) Participation and Social Networks of School-Age Children with Complex Communication Needs: A Descriptive Study.

6.2 Psychosocial

Psychosocial factors must be considered in order to develop communication competence. Psychosocial factors include motivation, attitude, confidence, and resilience (Light & McNaughton 2014). These factors have a huge impact on the communication competence of individuals with complex communication needs (Light, Beukelman & Reichle 2003). This is becoming better recognised over the past decade and is supported by the ICF with its emphasis on personal factors within the framework.

How a person perceives her or himself impacts on how they interact with those around them. Constant difficulties in communicating can be highly frustrating and may result in behaviours of concern. Alternatively, some people respond by becoming increasingly passive and stop making active attempts to communicate (Light & McNaughton 2014; White 2011).

People with complex communication needs will actively engage and participate when their right to communicate by whatever means possible is recognised, respected and supported by people in their immediate environment. (Porter 2012).

An individual's confidence, resilience and attitude to their own disability, including their communication disability, will also influence how other's perceive them. For example, people who are confident may remember to take and use their communication system with them when they go to a birthday party. Alternatively, people who associate their system with limited communication success may well decide not to bother taking their system with them (Porter 2012).

6.3 Education

Some people with complex communication needs receive the educational and therapy services needed to develop their communication. However, it has been identified that there is a high level of unmet needs for students with complex communication needs communicating effectively at school so that they can

access their education (Northcott Disability Services 2010; NSW Legislative Council 2010b).

Article 24 in the United Nations Convention on the Rights of People with Disabilities (UNCPRD 2006) outlines the rights for all people with disabilities to education. It strongly supports the right for all people with disabilities to:

- a fully inclusive education
- equal opportunity
- human rights to develop to their fullest potential
- participate in a free society
- have the accommodation and support required to facilitate effective education
- environments that maximise academic and social potential.

Article 24 of the Convention is specific about the rights for children to communicate and the responsibility of educators to provide communication in whatever augmentative and alternative forms that are required e.g. Braille, sign language. The Convention also states that:

- education facilities should employ teachers that are trained in "disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities"
- people with disabilities also have the right to have reasonable accommodations in order to have access to life long learning opportunities such as "general tertiary education, vocational training, [and] adult education"

(UNCPRD 2006, pp16-18).

In NSW many students with high support needs attend Schools for Specific Purposes (SSPs), (NSW Legislative Council 2010b). These schools place students with the most severe disabilities, including autism, physical, intellectual, multiple disabilities, and emotional/ behavioural disturbances into classrooms together.

Some students with complex communication needs have significant challenges in learning to communicate and may develop behaviours of concern. Other students may have difficulties learning to read and write. Without acquiring these communication and literacy skills at school, many adults with complex communication needs become dependent on their families and social services for ongoing support. They may also be at high risk of developing mental health difficulties (White 2011).

Students with disabilities may face other issues at school that make it difficult for them to access their education, including bullying. Students with behaviours of concern may create unsafe situations, where they may be excluded or expelled from school (Disability Advocacy Association NSW 2013). There are many areas where there is a need for improved systems to enable people with complex communication needs to successfully access education.

On the other hand, there are positive examples of success when people with complex communication needs have experienced inclusive education. Inclusive education enables students with complex communication needs to listen and learn from peers who are able to speak, provide peer support and provide the frequent communication opportunities needed to learn to communicate. Inclusive education gives people the best chance to become competent communicators who can participate in society. For examples, see the AAC Voice members' International Communication Project video.

Education requires a robust support system for people with complex communication needs, including special educators and therapists with specialised skills in addressing the physical, health, communication and educational needs for students with high support needs (Giangreco 1996; Giangreco, Cloninger & Iverson 2011).

The *Every Student, Every School* initiative by NSW Department of Education and Communities (2012) has enabled public schools to determine the individual learning and support needs of students with a disability, learning difficulties or behaviour support needs. This initiative enables public schools to make reasonable adjustments to the learning program and access specialised support from a "range of professional areas, such as education, allied health services and assistive technologies" (DEC 2012, p17) to support student learning. This initiative, together with the implementation of the National Disability Insurance Scheme, may provide an opportunity for a more integrated system of therapy services and specialised supports to enable students with high support needs and complex communication needs to access their education.

Within the context of the current movement for equal opportunity for people with disabilities (UNCPRD 2006) and with the current work to establish a national curriculum, it would be timely for the Australian Government to consider how to improve access to education for people with complex communication needs on a national basis.

When people with complex communication needs are successful in education, they can go on to achieve employment, study at a tertiary level and become productive citizens in our society.

Additional reading and resources

- NSW Legislative Council (2010a) Media release on *Inquiry into the provision of education to students with a disability or special needs, 2010*.

- Disability Advocacy Association NSW (2013). A Parent's Toolkit - School issues for students with disabilities.
- NSW Department of Education and Communities (2012) Every Student, Every School: Learning and Support (Retrieved June 30, 2015) from https://www.det.nsw.edu.au/media/downloads/about-us/how-we-operate/national-partnerships-program/every-student-every-school/learning-and-support.pdf

6.4 Employment

What happens when people with complex communication needs leave school?

People with complex communication needs can apply for support to access:

- tertiary education
- a program to assist with transition to work or study
- a program to help them to pursue their interests
- voluntary work experience
- paid employment.

However, for many people with complex communication needs, participating in the paid workforce requires a lot of motivation, skill and determination, as there are attitudes, communication and physical barriers that make this difficult.

> *As human beings we are meant to communicate at a very high level both orally and written. For some crazy reason, I chose a career in law and policy, which requires an even higher level of communication than most other careers! I am the Policy Officer at the Australian Centre for Disability Law.*
>
> *While communication devices have indeed helped me to participate in the workforce and community I feel I need to be constantly on the lookout for the latest technology because the communication devices are inevitably going to be slower than natural speech. I find I really need to upgrade my communication technology as often as I upgrade my power chair. I'm currently looking at my communication technology again at the moment. In order to save time and effort, I tend to keep my communication brief, often to the point where I am misunderstood. This causes frustration to myself and the reader/listener.*
>
> *Given (2012), Communication – High Tech Equipment at Work, pp 6-7.*

Research into experiences of employment for people with complex communication needs found:

> *Participants identified a wide variety of barriers to obtaining and maintaining employment: skill limitations, lack of education and job*

preparation, attitudinal barriers, architectural barriers, transportation barriers, technology limitations, and communication breakdowns. Factors associated with successful employment included access to assistive technology, effective communication skills and a supportive work environment.

Light, Stolz & McNaughton,1996, cited in McNaughton, Light & Arnold (2002), pp 59-60.

From a purely fiscal perspective, supporting the communication needs of Australians with CCN from an early age facilitates their participation as financially contributing members of society. This is evidenced by the engagement in volunteer and paid employment that is achieved by many adults who use AAC technology, leading to long term financial independence.

PWUAAC have identified communication technology as an important factor in their successful ongoing employment (McNaughton, Light & Arnold 2002).

ISAAC Australia (2014), Submission to the Senate Inquiry, p 10.

Speech pathologists can play an important role in assisting people with complex communication needs to develop the skills they need to achieve successful employment. Communication at work and/ or when engaged in further study involves communication skills at a high level. There are many areas where we all need to learn “good communication skills” to work with colleagues and communicate successfully with customers. Using email, social media, making phone calls and getting your voice heard in meetings all involve quite specialised communication skills. For people with complex communication needs these requirements are all additional to specific issues related to their use of other communication methods.

Meredith Allan provides insights into her experience of the workplace:

Case in Point: Life and Work in the Verbal Culture

I live and work in the verbal culture. Sometimes I think it would be a whole lot easier to curl up in and live in the AAC culture, only letting family and a few friends enter my comfort zone. I like living in my world of gestures and saying a few words and expecting people to understand the unraveling book inside my head. However, gestures don't always work. I could end up with 3 kg of stir-fry instead of 300 grams. There are no shortcuts in the workplace. With a multicultural workforce I cannot say "arvo", I have to say "afternoon".

In my work a two cent error could mean hours of reverse work flow.

I have to be clearly understood. My words must be clear and concise in the information I provide to internal and external clients.

It has taken years to build up the respect and credibility I now hold. I have built a safe environment where my "voice" can be heard.

It is important to communicate with colleagues both in a business sense and socially. It is becoming increasingly noticeable with a mobile workforce that work friends are now social networks as well.

It is imperative to enable People with CCN the opportunities to be motivated/ learn how to break through the barriers to engage with the verbal world.

Meredith Allan, PWUAAC ISAAC Member,
ISAAC-Australia Submission, 2014.

Additional reading and resources

- ABS (2012) Australian Social Trends March 2012 - Disability and Work.
- Human Rights and Equal Opportunity Commission (2005) National Inquiry into Employment and Disability - Issues Paper 1: Employment and Disability – The Statistics.

6.5 Mental Health

Mental health conditions, including depression and anxiety, can co-occur with complex communication needs and related disabilities such as physical disability, intellectual disability, autism and / or acquired neurological / medical conditions. For instance, "31% to 50% of young people with intellectual disability have significant emotional, behavioural, or psychiatric disorders" (White 2011, p162).

It can be difficult to determine whether people with disabilities and complex communication needs are experiencing psychopathology due to many issues. These include:

- diagnostic overshadowing (Bernard & Turk 2009) as the presence of additional physical, sensory, cognitive, emotional and behavioural disturbances may confuse the mental health presentation
- people may not have the ability to understand or a way to communicate their internal states and their difficulties with regulating their emotions and behaviours (White 2011)
- people often do not access generic mental health services and there are limited assessment tools to accurately diagnose psychiatric disorder in this group (Dossetor 2011).

Speech pathologists may be the first people to become aware of emotional or psychological issues an individual is experiencing. It is important to take the time to discuss issues as they arise and to provide advice about where to go for further assistance if support is needed (NSW Council for Intellectual Disability (CID) 2009, updated 2012).

People with complex communication needs will vary in their capacity to identify their needs for assistance related to mental health and their capacity to participate in discussions or counseling about this. It is important to consider that most counseling methods developed to assist people with mental health issues are based on speech and listening processes (Hagiliassis et al. 2011). The Bridging Project in Victoria has developed a number of fact sheets and resources to assist people with complex communication needs and people with disabilities to access mental health services.

Additional reading and resources

- Scope Victoria & CDDH, Victoria, Monash University The Bridging Project.
- NSW Council for Intellectual Disability (CID) (2009, updated 2012). Mental Health Factsheet.

6.6 Criminal Justice System

A recent inquiry in Australia (Australian Human Rights Commission 2014), highlighted the need for urgent action on equitable access to the justice system for people with disability. People with intellectual disability are estimated to be over represented within the prison population. Their disabilities may not always be fully recognised, nor their needs for communication support understood. Research indicates that over 50% juvenile offenders have an underlying language disorder (Caire 2013; Snow & Powell 2012).

Through consultations, the Australian Human Rights Commission (2014) identified barriers and experiences of people with disability including:

- higher risk of being jailed and repeated contact with the criminal justice system
- difficulty identifying disability and responding appropriately
- supports and adjustments not being provided regardless of whether a person's disability is identified
- insufficient personal protection
- becoming a victim of repeated violence
- not being regarded as credible or reliable witnesses
- inappropriate questioning styles being used by police, lawyers and the courts
- being less likely to get bail.

There are significant issues related to communication being understood, acknowledged and respected, particularly for people who are not completely independent communicators. People with complex communication needs may require communication support workers, just as people who are deaf require sign interpreters (Communication Rights Australia 2013; Given 2014; Given & Cranko 2013).

People with complex communication needs are extremely vulnerable to being victims of crime, including crimes perpetrated by people who live or work with them. (Australian Human Rights Commission 2014; People with Disability Australia (PWDA) 2014). People with complex communication needs are often placed in situations where it is difficult for them to communicate what they are experiencing and to seek help. It can be difficult for them to provide a statement that is detailed enough to be considered as evidence. Police can have difficulty working with people who have complex communication needs and even when support is obtained this can take considerable time, which can reduce the chances of the case being pursued successfully (Given 2014).

Experienced speech pathologists may support a person with complex communication needs accessing the criminal justice system. They can assist by ensuring that a person:

- Has a system with vocabulary to enable them to communicate on difficult topics (Collier 2007)
- Has an understanding of the different types of abuse and what their rights are, to assist them to identify if anyone is doing anything that is inappropriate (Collier 2007). Counsellors would also have a major role and may work with speech pathologists to achieve this (Hagiliassis et al. 2011).

Research supporting the need to take into account oral language competence and literacy skills in offenders helps to highlight some of the complex issues involved (Snow & Powell 2011).

Specific strategies are required to assist people with complex communication needs so that others are clear about their capabilities and communication methods. There is an urgent need to provide training to the legal profession about people with complex communication needs.

For more detailed information on how speech pathologists can support people with complex communication needs in the criminal justice system please refer to the *Communication Equality in the Criminal Justice System: A Practice Guide for Speech Pathologists Supporting People with a Disability* (Statewide Behaviour Intervention Service 2015a).

Additional reading and resources

- Sampson (2013). Submission on behalf of AGOSCI Inc. to the Select Committee on Disability Access to the Justice System
- Togher et al. (2006). Development of a Communication Training Program to Improve Access to Legal Services for People With Complex Communication Needs
- Villamanta Disability Rights Legal Service Inc. (2012). People who have an Intellectual Disability and the Criminal Justice System
- NSW Council of Intellectual Disability (CID) (2013). Participants or just policed: Guide to the role of Disability Care Australia with people with intellectual disability who have contact with the criminal justice system.
- Intellectual Disability Rights Service. Criminal Justice Support Network "Getting Arrested, What to do" Kit
- Lawlink: Police and Justice, Department of Attorney General and Justice Going to Court

7 Behaviour and Communication

7.1 Introduction

People with complex communication needs who do not have formal ways of communicating their wants, needs, likes and dislikes may use behaviours to get their message across to others. For example, crying might be a way of communicating hunger, loneliness or pain. Reaching for a cup might be a way of communicating 'I'm thirsty' or 'I want this.' This relies on the communication partner to observe this behaviour, interpret what it means and respond appropriately.

When a person with complex communication needs does not have their communication attempts recognised and responded to, they may give up on communication or try to find an alternate way to get their message across. This may include behaviour such as 'tantrums, hitting, screaming, pushing, various forms of self injurious behaviour, and many others' (Beukelman & Mirenda 2005).

The evidence continues to grow regarding a significant link between communication difficulties and behaviours of concern (Balandin 2002, 2007; Bott, Farmer & Rohde 1997). It is vital for speech pathologists to work with others who are experienced in behaviour support and to receive supervision and mentoring if this is a new area of practice.

7.2 Defining behaviours of concern

Historically, the term 'challenging behaviour' has been used to describe "behaviour… of such an intensity, frequency or duration that it threatens the quality of life and/ or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion" (Banks et al 2007 as cited in Office of the Senior Practitioner 2009a).

In recent years, there has been a shift towards adopting the term 'behaviours of concern' instead of 'challenging behaviour.' This change is to highlight the human rights of people with a disability and that those supporting them should respond with "sympathy and compassion" (Chan et al 2012).

Behaviours of concern can be defined as "behaviours that indicate a risk to the safety or wellbeing of the people who exhibit them or to others" (Chan et al 2012). This term will be used throughout this practice guide.

7.3 Why do people engage in behaviours of concern?

Behaviours of concern are generally acknowledged to be communicative in nature; that the person is trying to tell us something through the use of the behaviours (Carr & Durand 1985; Donnellan et al. 1984; Hansson 2011; Mirenda 1997; Sigafoos, O'Reilly & Lancioni 2009).

> *Reinforcing the social model of disability, behaviours of concern may be a reaction to an inappropriate environment and/or a method of communicating a lack of autonomy, lack of stimulation, frustration at not being understood or over stimulation.*
>
> *Department of Human Services (2011). Positive Practice Framework, p6.*

Behaviours of concern can occur for a variety of reasons. They may occur because a person:

- has not understood what people are saying
- wants an item or an activity
- wants attention
- is expressing feelings about something
- doesn't want to do something
- doesn't like an activity
- finds the demands of an activity too difficult
- wants an activity to stop
- has a medical condition / could be in pain
- has sensory processing difficulties, for instance to sounds, light or touch, making the person react to the environment. An example is that a person with an auditory hypersensitivity may find everyday noises intolerable, such as a vacuum cleaner or hair dryer

(Clinical Innovation and Governance 2014b; Dossetor, White & Whatson 2011; Kevan 2003).

Evidence suggests that receptive language difficulties are more closely associated with behaviours of concern than expressive language skills (Sigafoos 2000). When language is too complex, people may engage in behaviours of concern because they are scared or confused (Kelly, 2000).

Kevan (2003) suggests that the role of receptive language difficulties needs to be looked at more closely. Behaviours of concern often occur where there is a mismatch between an individual's receptive language skills and the language being used by their communication partners. For instance, where someone

overestimates a person's level of understanding, relying on spoken language alone, rather than using visual supports to assist language comprehension.

Behaviours of concern may be a behavioural indicator of a mental health condition (Hansson 2011). People with intellectual disability have a higher prevalence of psychiatric illness compared to the general population, particularly when there are communication difficulties (Therapeutic Guidelines Limited 2012). Behaviours of concern associated with depression can include withdrawn behaviour, irritability and aggressive behaviour; manic depression (now called 'bipolar disorder') may include absconding behaviour, boisterousness and disinhibition (Therapeutic Guidelines Limited 2012).

7.4 Positive Behaviour Support

Positive behaviour support is an approach using applied behaviour analysis that focuses on preventing or decreasing behaviours of concern and increasing an individual's quality of life. It is a recommended alternative to restrictive practices and use of psychopharmological interventions (Australian Psychological Society 2011). Positive behaviour support is implemented using a process of observation and behaviour analysis to work out the skills, supports and changes needed to prevent behaviours of concern. Positive behaviour support is the approach recommended and supported by current literature (Australian Psychological Society 2011; Department of Human Services 2009, 2011; Office of the Senior Practitioner 2009, 2012).

Positive behaviour support is usually implemented by a psychologist, however, a speech pathologist may be a member of a multidisciplinary team adopting this approach. Communication supports should be an inherent part of positive behaviour support. The speech pathologist will play an important role in communication assessment and intervention for a person who has behaviours of concern.

7.5 Risk Assessment – behaviours of concern

Risk assessment identifies any immediate areas of risk of harm to self or others and estimates the nature and degree of the risk that is inherent in the behaviour of concern. Before any intervention is implemented, it is important to analyse the risks involved in working with a person who has behaviours of concern. It is important to put in place measures that will help reduce any immediate risks to the person and others involved and to ensure that a safe environment is established. For instance, it may be important for two people to be present when working with an individual who has behaviours of concern, so immediate assistance is available if required.

A speech pathologist should determine if the person with behaviours of concern has an Incident, Prevention and Response Plan or Behaviour Support Plan. This should be read before meeting the person for the first time. The plan will assist the speech pathologist in being aware of any factors that may trigger behaviours of concern and how to respond if the situation arises.

In organisational contexts, it is important to be familiar with the organisation's behaviour support policies and procedures. These can be requested before commencing a service. It is likely that the speech pathologist is one member of a wider team and there may be another key person who is designated to undertake a risk assessment before any behaviour or therapy intervention. It is essential that this information is available to the whole team. Sole practitioners need to have their own policy and practices to ensure safety. Protective factors and ways to reduce or remove the risks need to be considered.

7.6 Restrictive Practices- behaviours of concern

Restrictive practices involve the use of interventions and practices that have the effect of restricting the rights or freedom of movement of a person with disability. These primarily include restraint (chemical, mechanical, social or physical) and seclusion.

Australian Law Reform Commission (2014). Restrictive Practices. Chapter 8 in Equality, Capacity and Disability in Commonwealth Laws: ALRC Discussion Paper 81, pp195-196.

Restrictive practices are governed by state based legislation and policy. They can only be used in exceptional circumstances. Should a speech pathologist find themselves working where restrictive practices are being used, they should become familiar with the policies and procedures related to use of these practices. Consent is needed for restrictive practices and some practices that are so restrictive they are restricted in their use and require authorisation (Office of the Senior Practitioner 2009). If a speech pathologist is aware of a restrictive practice being implemented with a person, and have any concerns about whether legal requirements are being followed, they should notify a senior manager in their organisation and/or the NSW Civil and Administrative Tribunal (NCAT).

7.7 Functional Communication – behaviours of concern

Functional behaviour assessment is an important aspect of successful interventions to prevent or reduce behaviours of concern. This is supported by extensive analysis of the current research literature (Walker & Snell 2013). Information can be gathered for functional behaviour assessment from people that

know the person well and through observations. Data can be collected using various observational tools, including Antecedent, Behaviour, Consequence (ABC) charts; a Setting, Trigger, Action, Result (STAR) chart, Durand & Crimmins, 1992 (Australian Psychological Society 2011; Department of Human Services 2009, 2011).

Functional communication training is a method of positive behaviour support, based on teaching functionally equivalent communication skills to replace behaviours of concern (Bopp, Brown & Mirenda 2004; Kevan 2003; Mirenda 1997). It is important that the new communication behaviour is as easy as, or easier to perform as the behaviour of concern it is replacing (Kevan 2003; Mirenda 1997; Sigafoos, O'Reilly & Lancioni 2009).

Additional reading and resources

- Australian Psychological Society (2011) Evidence-based guidelines to reduce the need for restrictive practices in the disability sector.
- Bopp, Brown & Mirenda (2004). Speech-Language Pathologist's Roles in the Delivery of Positive Behaviour Support for Individuals with Developmental Disabilities, *American Journal of Speech – Language Pathology*, 13; 1, pp 5 – 19.
- Department of Human Services (2011) Positive Practice Framework: A guide for behaviour support services practitioners.
- Department of Human Services (2009) Positive behaviour support — Getting it right from the start: Facilitators reference manual.
- Hodgdon, L. (2005). *Solving Behaviour Problems in Autism: Improving Communication with Visual Strategies*. Michigan, U.S.A:. Quirk Roberts Publishing.
- Office of the Senior Practitioner (2009) Behaviour Support: Policy and Practice Manual Part 1: Policy and Practice.
- Office of the Senior Practitioner (2009a) Behaviour Support: Policy and Practice Manual Part 2: Procedures and Templates.
- Scope Victoria Communication Assessment for People with Behaviours of Concern. Literature review.
- Scope Victoria Guidelines for using Communication Assessments for people who engage in Behaviours of Concern.
- Scope Victoria, Functional Communication Training Factsheet.
- Statewide Behaviour Intervention Service (2015b). The Practice Improvement Framework: A professional development framework for behaviour support services in the disability sector.

8 Assessment

Communication assessment processes for people with severe- profound disabilities should begin with an acknowledgment that their communication is complex and whether intentional or not, should be respected and valued.

Johnson et al (2012)

Holistic and functional assessment is essential when working with someone who has complex communication needs (Light & McNaughton 2015). In relation to the International Classification of Functioning Disability and Health, a person with complex communication needs is likely to experience impacts across all domains (World Health Organization 2013).

Assessing people with complex communication needs often requires extended time and a practical approach with opportunities to observe and try out strategies within the person's environments as well as with key communication partners and with the individual themselves. When assessing the individual and their communication partners it is essential to find out as much as you can about their strengths – what they can do – rather than only focusing on their difficulties (Light & McNaughton 2015).

Please also refer to Section 6, Assessment in AAC Practice in the Augmentative and Alternative Communication Guidelines (Clinical Innovation and Governance 2014a).

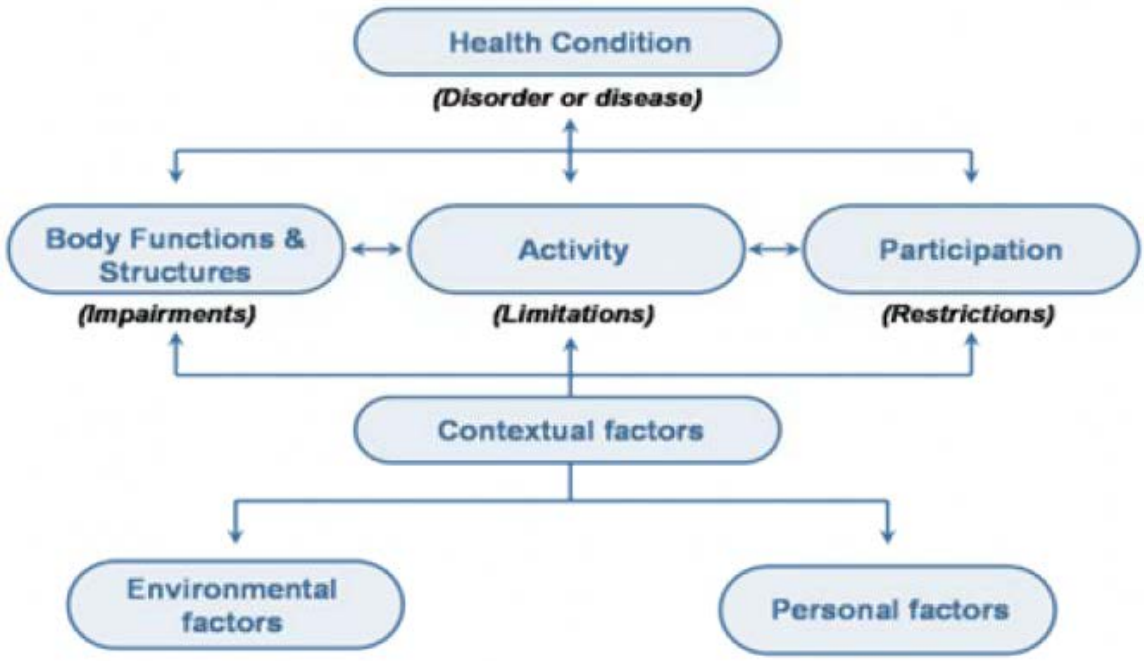
8.1 Assessment framework

The International Classification of Functioning Disability and Health (ICF) is recommended as an overarching framework to guide assessment (Fried-Oken & Granlund 2012). The framework encourages speech pathologists to see the whole person and consider their communication needs within the context of other related factors (Walsh 2011). It also links communication to broader life skills (Threats & Worrall 2004).

Applying the ICF to the clinical practice of speech pathology, practitioners can incorporate both the diagnosis of impairment (body function and structure) and the activity and participation of the individual to assess the impact of the communication and/or swallowing disorder on quality of life.

WHO, 2001, cited in (Speech Pathology Australia 2015), p 4.

Diagram: ICF Domains



The ICF is a conceptual framework and classification system. It is not an assessment tool and does not provide assessment protocols or assist the speech pathologist in identifying which areas to assess or areas of possible intervention. It provides a sophisticated framework and philosophy which highlights the interactions between health conditions, body functions and structures, activities and participation as well as acknowledging the influence of environmental and personal factors (Threats & Worrall 2004).

Additional reading and resources

- Scope of Practice in Speech Pathology (Speech Pathology Australia 2015).
- How to use the ICF A Practical Manual for using the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2013).
- The ICF Checklist and WHODAS Version 2. The 36 item scoring sheet with complex scoring calculation seems potentially the most useful for people with complex communication needs.
- International Classification of Functioning, Disability, and Health (ICF) Resources. ICF and Communication Disorders (American Speech Language Hearing Association, 2014).

8.2 Dynamic assessment

Assessment is a dynamic and ongoing process. Dynamic assessment provides the opportunity to find out the difference between the person's ability unassisted and what they can do when given appropriate supports and scaffolds (Iacono & Caithness 2009). It focuses on discovering what the person can learn to do rather than measuring their performance (Law & Camilleri 2007).

> *Vygotsky (1978) argued that assessments where the examiner does not actively intervene provide data only on the child's past history and present functioning, but not on the child's potential for learning.*
>
> *(Porter 2007), p. 54*

Dynamic assessment considers learning within the social context and helps to evaluate communication partner strategies and resources that enable the person to learn new skills within meaningful contexts (Kublin, Wetherby, Crais and Prizant, 1998, cited in Iacono & Caithness 2009).This process requires time and occurs within a cyclical process of introducing strategies / supports, monitoring, review and evaluation to determine the effectiveness of the strategies.

Additional reading and resources

- Law, J., & Camilleri, B. (2007). Dynamic assessment and its application to children with speech and language learning difficulties. *Advances In Speech Language Pathology*, 9(4), 271-272.
- Snell, M.E. (2002). Using dynamic assessment with learners who communicate nonsymbolically. *Augmentative and Alternative Communication*, 18(3): 163-176.

8.3 Participation model

The Participation Model has guided AAC assessment for many years (Beukelman & Mirenda 2005). It is recommended as a well-constructed, evidence-based model for assessment of communication supports consistent with the ICF (Beukelman & Mirenda 2013; Clinical Innovation and Governance 2014a). Elements of this model can be drawn upon to guide the assessment of a persons communication skills. The Participation Model helps to analyse the person's environments, activities for participation, communication partners and personal factors that either assist communication or make communication difficult.

Additional reading and resources

- A summary of the participation model by Novita Children's Services.

8.4 Person Centred Assessment

Assessment must involve the individual with complex communication needs from the beginning (Clinical Innovation and Governance 2014a). Finding out what the person wants will influence how the assessment is carried out.

For instance, the person may indicate that they want:

- a comprehensive system for communication (e.g. the person doesn't have any recognised formal means at the moment and requires a comprehensive assessment)
- a way to be keep in touch with their friends (e.g. the person may have a specific focus, where they want to learn about how to use social media, and this will lead the speech pathologist to check on skills and needs related to this aspect)
- a way to communicate with unfamiliar people when they are in the community (e.g. the person may have a specific focus to work out strategies, such as community request cards)
- a way to communicate with unfamiliar people when they are at work (e.g. they may want an iPad with a communication app or a speech generating device, when communicating with people who don't know how to sign).

With a child or adult who appears to have very limited communication, and their level of understanding is unknown, it is suggested that the speech pathologist assumes that the person can understand what is being said to them. The speech pathologist should speak directly to them during conversations. Use communication strategies, that may help make your meaning clearer, rather than relying on speech alone (Donellan 1984). The person's reactions, strategies and responses will provide additional information about how much they are understanding, what helps their understanding and how they interact with their carer / family member.

For a person who is unable to participate in discussions directly, involve the person who knows them best. This might be their primary caregiver, parent and/or their guardian/advocate. Gather information about the person's preferences, abilities and communication needs. Supported decision-making frameworks can be used to assist this assessment process (Grove 2000; Watson 2011).

A list of person centred tools that might assist with assessment include:

- Communication profile

- Four plus one
- Good days/ bad days
- Hopes and dreams
- Important to/ Important for
- One page profile

8.5 Collaborative Assessment

Assessments which are person centred and collaborative provide the best chance for a targeted and successful intervention. It is important to understand what other team members are assessing and how the information they gather can inform the speech pathologists' assessment and intervention. It is also important for the speech pathologist to share information about the communication assessment process and findings with other team members.

Awareness of the professional backgrounds and the philosophical frameworks team members bring from their training and experience is essential. Working collaboratively may at times challenge the beliefs professionals may have in relation to people with disability. For instance, are there attitudes and assumptions people in the team have, which may influence their observations during assessment?

A collaborative approach to assessment involves:

- clarity around what people are doing in relation to their roles and responsibilities
- good communication between team members
- using language that everyone understands
- timely sharing of information
- consistent follow through in trying out strategies (Dule et al. 1999; Hunt et al. 2002).

8.6 Cultural considerations

When working with individuals and families from culturally and linguistically diverse (CALD) backgrounds, cultural backgrounds and English language proficiency is a key consideration. If another language is spoken at home, assessments may require the assistance of an interpreter. The interpreter will need to be briefed about the situation if they have not had experience working with people who have complex needs. Interpreters may need some information from the speech pathologist, to assist them to interact appropriately with the

person who has complex communication needs and their communication partners (Korner et al. 2009; Soto & Yu 2014).

When working with people from Aboriginal and Torres Strait Islander (ATSI) backgrounds, it is important to find out about the families' culture, their attitudes to disability and their experience in working with a speech pathologist. An ATSI disability support worker may be able to provide support in relation to communication and cultural knowledge and to help ensure that appropriate strategies are suggested. For instance, eye contact may be considered to be rude in some communities and in some situations, so a lack of eye contact may not reflect a lack of ability, but rather, following a cultural norm within that community.

Taking the time to build good relationships in ways that are culturally sensitive will be valuable with all families and communication partners you are working with and will provide the best chance of achieving the desired outcomes.

8.7 Assessment Methods

Assessment is about joint problem solving. The speech pathologist's role is one of asking questions and working with an individual to find communication solutions. In the preparation stages of assessment, the speech pathologist may need to consider how to answer the following questions:

Self-Awareness

- How self-aware is the person about their own communication abilities?
- How motivated are they to communicate?
- What kind of communication is preferred?

Communication Partners

- Who does the person primarily communicate with? How?
- Who else does the person communication with? How?

Environments

- Is the person able to understand and express him/herself in different environments?
- What are the differences in opportunities for communication in different environments?
- Is the person's communication system present in the environment?
- Is there a way to transport the communication system / device from one environment to another?

Interests

- What is motivating for the person? What engages the person's attention?

Activities / Participation

- How does the person participate within activities?
- How does the person communicate within activities?
- How is the person's participation affected by environment?

Behaviour

- Are there any behaviours of concern? When and where do these occur?

Sensory

- What is known about the person's hearing and vision?
- Does the person have any sensory processing difficulties?

Physical Movement

- Is the person mobile?
- Does the person need mobility equipment, such as a wheelchair?
- What seating does the person have? Does this meet the person's needs?
- Does the person have difficulties initiating movements?
- What functional movements of the head, arms, hands, fingers, legs, knees, feet or toes does the person have?
- What manual dexterity does the person have? (fine movements of fingers)
- Is there a need for a stand or a mounting system to help to position the communication system / device?
- Can the person carry their communication system around with them?

Comprehension

- What does the person appear to understand?
- What level of language does the person seem to be functioning at?
- Does the person understand language related to the "here and now"?
- Does the person understand time concepts?
- Does the person understand humour?
- Is the person understanding topics of conversation that are concrete or abstract?

Expression

- What methods of expressive communication have they tried? How successful were they? Are they still used?
- Does the person have some vocalisations? What do these seem to mean?
- What can the person say? How clear is the speech?
- How clear is the person's signal for 'yes' and 'no'?
- What language functions is the person able to express?
- Are there opportunities to make comments, request information, objects or actions, reject or protest, express preferences?
- What modalities is the person most comfortable using? For example, speech, signs and gestures, non-electronic communication system, high tech speech generating device or mobile technology?

Literacy

- Does the person have any literacy skills? Interest in books or text?

Social media and telecommunications

- Does the person use social media? What sorts of supports do they need to use social media of their choice?
- Does the person use a phone? How are they able to use it? What supports are needed?

8.7.1 Indirect assessment

Assessment will involve using a range of methods to gather information. This may begin with talking to the person and their family / communication partners to find out about the person's background, diagnosis, what support they have received in the past in relation to their communication, what their life experiences have been, their current communication abilities, their current activities and interests and what outcome they are hoping for (Beukelman & Mirenda 2013; Blackstone 2003; Blackstone & Hunt Berg 2003, updated 2012).

8.7.2 Building rapport

Taking the time to get to know the person, without making assumptions about capabilities—but rather with a focus on building rapport and relationships, will enhance the accuracy of assessment (Bevan-Brown et al. 2008).

Building rapport and relationships involves:

- Being well prepared and calm

- Being clear in your own communication – explaining any expressions of terms that may be unfamiliar, avoiding use of jargon as much as possible
- Offering empathy - taking time to demonstrate your understanding of issues from the person's perspective
- Being non-judgmental – having a speech pathology assessment can make people feel uncertain or nervous of being judged. For instance, people could feel that they should have tried an approach at an earlier time. It is really important not to sound judgmental when asking questions
- Being congruent – being authentic and genuine, transparent and open.

(Information adapted from Oakes 2013 and Queensland Council of Social Service, 2013).

8.7.3 Direct assessment

Direct observations will be an important part of assessment. If possible observe the person communicating with their usual communication partners, in their usual environments. This may involve observing them at home, preschool, school, day programs, work and/or during activities in the community. It is important to remember that just being present may affect the way people are interacting. It is important to put people at ease and establish rapport, while trying not to be too intrusive. The speech pathologist can gauge how comfortable people are about their presence during the initial assessment session and check after short initial interactions.

Thorough observation may take place over a number of sessions and environments. Observations can be both informal and formal using published assessments. Using a formal observational checklist or guide is recommended if the speech pathologist does not have experience in conducting observational assessments.

Observations can be face- to-face or video-recorded. For speech pathologists new to observational assessments, video- recording interactions is recommended for later analysis. Videos can provide a chance to look carefully at what both the individual and their communication partners are doing. This may help to identify behaviours that are used for communication, including those that may not have been noticed during the face to face interaction. Videos also provide a record of the person's communication as a baseline measurement.

Video-recording by communication partners may also be a practical strategy when providing services to someone in a rural setting, to allow assessment to

be carried out from a distance. Before recording video it is essential that everyone involved provides consent for this to occur and measures should be taken to ensure that any data is stored securely.

8.7.4 Formal assessment

Although there are a range of formal assessments, these are often not practical for people with complex communication needs (Beukelman, Garrett & Yorkston 2007;Beukelman & Mirenda 2013; Mirenda & Iacono 2009). For instance, children with complex communication needs may have very different experiences to children the tests were designed for and may perform very differently in an isolated "test" situation compared to the child's natural environment (Downing 2009). Physical access to these assessments can also be difficult for those who have a physical and / or sensory disability. Some norm-referenced standardised assessments can be adapted and may provide useful information at times. However, the amount of time taken to administer these needs to be balanced against the information they are likely to provide. Criterion-referenced assessment will usually be more relevant and time efficient (Beukelman & Mirenda (2013), p132–133).

8.7.5 Assessment Tools

The speech pathologist may choose to use a number of tools or checklists to supplement their observations of the person interacting with familiar communication partners during every day routines. There is no single, comprehensive protocol to cover the skills of all people with complex communication needs. Here is a list of suggested tools to help the speech pathologist get started. Please refer to Appendix 2- Assessment tools for a more comprehensive list.

Augmentative and Alternative Communication (AAC) Profile: A Continuum of Learning (Kovach 2009)

The *AAC Profile* can be used to measure the communication competency of both children and adults over time. It uses the communication competency model proposed by Janice Light (Light 1989; Light & McNaughton 2014) to provide a performance profile for baseline assessment and for ongoing assessment and planning. This provides a continuum of learning for monitoring observations of an individual's ongoing development of operational, linguistic, social and strategic skills. This tool assists with the long term planning that is required for many individuals with complex communication needs to achieve communication competence (Kovach 2011). It emphasises the ongoing nature

of assessment and intervention when working with people who have complex communication needs.

Communication Matrix (Rowland 2012; Rowland & Fried-Oken 2010).

This tool is designed for individuals of all ages who function at the earliest stages of communication and who use any form of communication (Rowland 2013). The free online version is designed to be user-friendly and suitable for parents and professionals. The *Communication Matrix* provides a way to record a person's current communication skills highlighting:

- **Level of communication** (e.g., level of intentionality).
- **Reasons to communicate** –refusing things, obtaining things, interacting socially and gaining information which is a scheme consistent with Light (1988).
- **Categories of behaviour** – body language, early sounds, facial expressions, simple gestures, conventional gestures and vocalisations, concrete symbols (photos and objects), abstract symbols (spoken words, signs, written word, braille, 3-D and 2-D abstract symbols, language–combining symbols.

This is a practical tool when assessing early communicators, however, there are some considerations with its use. Although it is designed on a continuum, once a baseline is completed, it is important to take into account all that you know about the individual, communication partners and environments when selecting learning goals, rather than just "filling in" the *Communication Matrix*.

People with complex communication needs do not necessarily follow a developmental pathway to developing their skills (Downing 2009; Porter 2007). Similarly, a person will not necessarily need to follow the hierarchy of skills indicated on the matrix in developmental order (Cress & Marvin 2003; Porter & Burkhart 2010; Romski & Sevcik 2005). A functional adaptation may enable a person to jump some steps. When reviewing progress, this will translate into a positive change in the person's *Communication Matrix*.

Language forms should be selected that suit the individual's requirements, taking into account their physical, sensory and cognitive abilities and their need for language to be available in their environment, using adapted methods. It is suggested that the *Communication Matrix* can be used as a means for initial assessment and for monitoring and review to check on progress.

MOSAIC – A Model of Observational Screening for the Analysis of Interaction and Communication (Smidt 2010).

MOSAIC was developed to provide a framework for gathering information while observing the communication skills of children and adults with a intellectual

disability. It guides the speech pathologist to gather detailed information about the communicative interactions between the person with a intellectual disability and their communication partners in a variety of settings. MOSAIC can be used with intentional and unintentional communicators. It contains forms for collecting information on conversations, partner interactions, capabilities, environmental observations, behaviour observations, summarising of skills and goal planning.

Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners (Blackstone & Hunt Berg 2003, updated 2012).

The *Social Networks* assists in developing a communication profile for people with complex communication needs. It has a focus on the interactions that take place between the person with complex communication needs and their communication partners. It promotes person centred planning by guiding the person and their communication partners to identify the most effective communication strategies for them. *Social Networks* emphasises that all types of communication should be respected as people use a variety of modes of communication, depending on the situation and the communication partners they are speaking with. *Social Networks* also reflects socio-linguistic and cultural issues, with consideration of the interactions between communication partners (Blackstone & Hunt Berg 2003, updated 2012).

The communication groups used in *Social Networks* are:

- **Emerging:** individuals have no reliable method of symbolic expression and use non-symbolic communication such as facial expressions, body language, gestures, vocalisations or other methods. This term is not designed to describe the person's potential, but rather to reflect their current communication strategies.
- **Context-dependent:** individuals have reliable symbolic communication, limited to specific contexts or partners. This may require highly familiar partners or the person has only limited access to appropriate vocabulary. They are dependent on others to select and pre- program vocabulary for them. These individuals communicate most effectively with familiar communication partners.
- **Independent:** Individuals can interact with both familiar and unfamiliar partners, about any topic, in any context. These individuals are typically literate and have the ability to communicate novel messages.

(Blackstone & Hunt Berg 2003, updated 2012)

Triple C Checklist of Communication Competencies, Revised (Bloomberg et al. 2009).

In Australia, the *Triple C Checklist of Communication Competencies* was developed to assess the communication skills of adults with severe –profound levels of intellectual disability.

Levels of communication in this assessment are:

- unintentional passive
- unintentional active
- intentional informal
- symbolic basic
- symbolic established.

This assessment is designed to be used by disability support workers and family members in collaboration with speech pathologists. It is widely used in Australia for training of disability support workers in their understanding of the different ways that people with significant intellectual disabilities and little or no speech can communicate (Bloomberg et al. 2009).

Please note that the *Triple C Checklist of Communication Competencies* is not suitable for adults with more than 50 spoken words, manual signs and/or pictures. It is not designed for assessment of children. Care should also be taken when using this tool with people who have significant physical, visual or hearing disabilities as these impairments may prevent them from being able to complete checklist items.

Additional reading and resources

- Please refer to the Augmentative and Alternative Communication Practice Guide for further information about assessment tools when implementing low and high technology AAC communication systems.
- Iacono, T. & Caithness, T. (2009). Assessment issues. Baltimore: Paul H. Brookes.
- Iacono & Hagiliassis (2010). Communication Assessment for People with Behaviours of Concern — Literature Review. Scope, Victoria.

8.8 Movement

Speech pathologists working with people who have complex communication needs need an understanding of the person's control of their movement.

It is suggested that speech pathologists work closely with professionals who have an understanding of movement, such as occupational therapists and physiotherapists.

Many assessments rely on physical movements, for people with complex communication needs to make their responses. It is vital to understand whether an individual can initiate and consistently make a response, such as pointing to an item.

A person may have reflexes that affect their responses during assessment – for instance, is a movement deliberate or does the person have a startle reflex? Some forms of movement disabilities make it difficult for people to perform movements on request or when a person is anxious or tired.

There may be a need for a person to work on refining their movements to access a communication device or to control a switch. There may be difficulties with movement that vary, depending on levels of fatigue.

Difficulties in consistency of a “yes/no” response may be related to difficulties with control of movement and may require practice and opportunities to learn how to make the movements for the responses to become clearer and more consistent across different situations and environments.

Additional resources

- Occupational Therapy Australia has information about where to find occupational therapists working in private practice
- Australian Physiotherapy Association has information about how to find a physiotherapist
- Therapy Choices is a website for consumers, explaining what various professionals do – this could be a useful resource for all team members.

8.9 Environments

Assessment of communication environments involves consideration of many external factors such as:

- What opportunities are there for two-way communication in the environment?
- What experiences are available for people with complex communication needs?
- How inclusive is the environment?
- What time constraints are there?
- What staff turnover is there?
- What are the attitudes of people in the environment towards people with complex communication needs? Is communication highly valued?

- Are there any policy or practice barriers?

Examples of Policy and Practice Barriers

"We only use PECS at this school"

"Signing is not used in this residential complex any more. Staff don't know how to sign, although some of the residents used to sign"

"I don't understand what he/she is saying – but it's not my problem"

Speech pathologists can foster a climate where team members are open to learning new skills to support people with complex communication needs. This can introduce questions like - How can people in the environment provide time and opportunities for communication? What training is needed? Team work can stimulate creative solutions.

Assessment of the environment also requires consideration of equipment needs, such as ways to physically access a communication system.

For instance:

- What adaptations and modifications are there in the environment to enable participation? Is there a need for new equipment?
- Does the person require any assistance with seating or positioning to be able to use their communication equipment?
- Will changes to positioning make it more accurate and less effortful to use their communication system?
- Is there room in the person's environment for the equipment they need? For example, power wheelchair and mounting system, to enable access to speech generating device
- Are there any issues with transporting equipment from one environment to another?

Assessment should involve consideration of a person's daily environments and may also involve anticipating less familiar environments. Some people with complex communication needs may struggle to communicate in any environment. For others, communication may be adequate in one environment, such as home, but they may struggle in other environments, such as school or community.

Assessment may reveal an upcoming change of usual environment, where visual supports or a social story may be needed to assist with this transition, for instance, preparing to go on a holiday or to go to school for the first time.

Temporary needs related to new environments can sometimes be anticipated. For instance, if you know that a person with complex communication needs is going to have an operation, the speech pathologist can arrange to train staff in the hospital and/ or to make resources for the person to take with them, explaining their methods of communication (Hemsley & Balandin 2014).

Seating and Positioning

People with complex communication needs may have significant physical disabilities, requiring well designed seating and positioning.

The speech pathologist needs to be aware of the different seating and positioning options a person has at home and in their daily environments. It is important to ensure a person is positioned during assessment in ways that enable the person to use their communication system and participate in the activities.

Communication strategies and systems need to be compatible with seating systems.

People have a need to communicate at all times, which means communication strategies and systems are required when a person is not sitting in their wheelchair, as well as when they are.

Occupational therapists and physiotherapists have expertise in seating and positioning for people with disabilities. Specialised seating services are another source of information.

Collaborative teamwork can enable speech pathologists and other team members to understand issues related to a person's seating and positioning.

A Core Standard for Seating and 24 hour Positioning will be available as a resource to teams working with people who have disability.

Assessment of a person's daily environment may involve completing a participation inventory, ecological inventory or routines-based assessment (Beukelman & Mirenda 2013; Downing 2009; Johnson et al. 2012). The person and communication partners or caregivers are asked to relate the individual's daily routine activities. This includes recording the person's level of participation in daily routines and activities, including current opportunities and barriers. The speech pathologist can identify current communication strengths and successes as well as situations where communication supports and strategies are needed.

8.10 Communication Partners

The role of the communication partner cannot be understated within the context of complex communication needs.

> … *"It takes two to tango".*
>
> *Individuals who rely on AAC recount that with some partners communicative interaction is wonderful, and with others it is hell. Following on from this view … a useful beginning point is to view interactions, rather than the individuals involved, as being either successful or impaired. Thus, by looking at communicative interactions between dyads (or a variety of other configurations) as they strive to establish meaning, one is more likely to see how AAC technologies and instructional strategies might support the communication process. Because of this perspective, the range of actual and potential communication partners is a key consideration in the design and development of AAC systems and interventions (Kent-Walsh & McNaughton 2005; Murphy 2004).*
>
> *Blackstone, Williams & Wilkins (2007), p197.*

The Social Networks *Circles of Communication Partners (CCP) Paradigm* (Blackstone & Hunt Berg (2003, updated 2012), pp.10-11), groups communication partners in the following way:

- First Circle: a person's lifelong communication partners e.g. parents /guardians, siblings, grandparents, spouse, children
- Second Circle e.g. close friends and relatives
- Third Circle: acquaintances e.g. schoolmates, colleagues
- Fourth Circle: paid workers e.g. teachers, disability support workers, therapists
- Fifth Circle: unfamiliar people e.g. shop keepers, taxi drivers, waiters.

The *Circles of Communication Partners (CCP) paradigm* helps to analyse the methods of communication that are used with the different communication partners. Research has shown that this varies considerably and needs to be taken into account when planning interventions (Blackstone & Hunt Berg 2003, updated 2012).

> *The CCP paradigm is a dynamic construct. Over time and across a person's life span, each individual's CCP changes. New partners come into one's circles and other partners move out. Such is the nature of human relationships. Also, communication partners may change circles. Unfamiliar partners may well become friends; a relationship with a friend may evolve into marriage, and so a friend becomes family. As people's social networks evolve over time, so do their communication needs and*

the communication technologies, techniques and strategies they may require.

Blackstone (2003). The Circles of Communication Paradigm, Augmentative Communication News, p 6.

Key communication partners within the person's usual environments provide the main support for a person with complex communication needs. These are generally family members, direct caregivers and people in environments where the person spends most of their time, such as staff at pre-schools, schools, day programs and other services. Speech pathologists will work very closely with key communication partners.

Assessment will identify who the key communication partners are and how they are interacting with the person with complex communication needs.

For instance:

- What skills and knowledge do communication partners have?
- What are their attitudes towards the person with complex communication needs?
- How comfortable are they interacting with a person with a disability?
- What is their cultural background and how does this influence them?
- What are their needs?
- Will information and training assist?
- What learning styles will work best?

Working collaboratively with key communication partners is essential. Speech pathologists will gather information about the wider network of communication partners. Key communication partners can provide training and support to the wider network. Speech pathologists can assist in building the skills and confidence of key communication partners, empowering them to provide ongoing support to other communication partners.

9 Intervention

Intervention principles and processes are discussed in this section. Please read this in conjunction with Section 7, AAC Intervention Practices in the Augmentative and Alternative Communication Practice Guide.

Appendix 3 A-Z of Intervention Methods and Resources provides an overview of specific intervention approaches and methods and is designed as a practical resource about the breadth of options available.

9.1 Intervention Principles

The following principles are recommended when developing intervention programs for people with complex communication needs:

- **Everyone communicates** – skilled communication partners support the person with complex communication needs, to enable their communication and, where necessary, to interpret their communication.
- Communication competence will require linguistic, operational, social and strategic competence, resilience and cultural competence.
- **Materials should be age appropriate**. When working with an adult who has severe – profound intellectual disability, materials should be age appropriate. For instance, an adult who enjoys soft objects. Don't use soft objects designed for young children, as this will impact on how other people interact with them. Find soft objects that are age appropriate. All people require respectful, age – appropriate interactions.
- Intervention should be carried out within natural settings as much as possible. Communication is taught as an embedded skill within **natural environments**. Integrate learning within everyday activities, within everyday environments.
- Intervention will be a **collaborative team effort**. It is very important to get everyone on board, so there is consistency in how people are using communication strategies across the various environments.
- Intervention must be **culturally appropriate**, so families, friends and communities are all involved and can engage with the person who has complex communication needs.
- Intervention involves **training communication partners** to enhance their skills in how they interact with the person with complex communication needs. Learning how to communicate using other forms of communication needs to be explicitly taught. Communication partners need to learn to **use the person's communication system and/or strategies** to have **authentic interactions.**

- Intervention will involve using **activity and task analysis**, to work out how a person can carry out a task, when learning a skill.
- Intervention will involve **adaptations** to enable the person with complex communication needs to participate and achieve success. For instance, using a visual symbol display with the steps of the routine to assist a person to learn and carry out an activity on their own.
- The **environment** is set up in a way that supports use of the person's communication. This depends on the individual, but it can include:
    - making communication equipment readily available
    - having appropriate seating and positioning
    - having seating and tables arranged so people can interact with each other
    - minimising distractions in the environment
    - having adequate lighting.
- Good instruction will use **natural cues** and sufficient **scaffolding**, so the person achieves success.

  Natural cues are things that occur in the environment that let a person know it is time for them to do something. For instance, the bell for recess is a natural cue at school, that lets people know it is time to have a snack.

  Scaffolding is a term that describes how a more skilled communication partner can provide assistance to the person with complex communication needs, to enable them to achieve their communication behaviour. There are many ways to provide scaffolding. Examples include:

    - interpreting the communicative meaning of the person's behaviour
    - waiting for the person to respond – giving sufficient time
    - giving the person a hint about what she/he needs to do
    - modelling the response
    - physically assisting the person to achieve the response
    - giving natural feedback about what the person did and how to make the response clearer next time.
- **Prompting hierarchies** can assist use of communication strategies. Examples of prompts are demonstration, verbal prompts and physical prompts, with partial or full assistance.
    - A **"most-to-least"** hierarchy assists when a person is learning a new skill. It is important to use assessment information to determine

the required level of prompting and to not use more prompting than necessary.

  - A **"least-to-most" hierarchy of prompts** works best when encouraging practice of a skill that has already been acquired. It is important to reduce the level of prompting as quickly as possible. This is to avoid the person becoming "prompt" dependent in the long term.

- Communication you are using during instruction should make **pragmatic sense.** Don't ask someone something, when they know you already know the answer.
- **Communication happens all the time**. It is essential for the person to have their methods of communication available at all times.
- **Communication profiles / instructions** about how a person communicates should be **readily available**. This helps new or less familiar communication partners have the information they need to communicate directly with the person.
- **Communication equipment requires ongoing management and maintenance.** Make sure the person with complex communication needs and their key communication partners **/** caregivers have a plan to look after the equipment, program the devices and organise repair, should this be needed.

Instructional Principles have been summarised and adapted from Binger & Kent-Walsh (2010); Blackstone (2008); Porter & Burkhart (2012); Soto & Zangari (2009).

Additional reading and resources

- Beukelman & Mirenda (2013). Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs, Paul H. Brookes.
- Beukelman, Garrett & Yorkston (2007). Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions. Paul H. Brookes, USA.
- Blackstone (2008). *AAC in Today's Classrooms,* Augmentative Communication News, 20 (4). Free download.
- Mirenda & Iacono (2009). Autism Spectrum Disorders and AAC, Paul H. Brookes, USA.
- Soto & Zangari (2009). Practically Speaking: Language, Literacy & Academic Development for Students with AAC Needs, Paul H. Brookes, USA.

9.2 Goal setting and measuring outcomes

It is important to write goals with the person and their family. The process of developing goals together can assist in developing mutual understanding and helps everyone to take active ownership in working towards achieving the goal (Verdon 2015). There may be a need to consider priorities and how many goals can be set at the same time.

Goals must be authentic and written in a way that describes communication they will use in a real situation. It is also important to write a goal in a way that the communication behaviour is under control of the individual and can be measured as being 'observed' or 'not observed' over a period of time and within certain activities.

SMART goals

Goals need to be SMART to measure change:

S	specific – performance conditions and context
M	measurable – acceptable performance criteria
A	activity-based – how and where goal will be achieved
R	review schedule – planned progress reviews
T	time-frame – overall time frame in which goal is achieved.

Adapted from Mogensen & Bowman (2005)

It is essential to evaluate whether an intervention is working. Outcome measures need to be sensitive as improvements and changes can be subtle and slow to emerge for some people. Observing progress can be a challenge in relation to some skills. Short term goals should consist of realistic steps that can be achieved within a fairly short time-frame to determine if the intervention is on the right track.

While improvements for an individual may happen slowly, changes in the person's environment and in their communication partners may occur more quickly.

Measurement of progress can be done using data forms to record observations at regular intervals, to collect feedback about whether a communication behaviour is being demonstrated and the level of assistance needed.

There are some specific skills that may be taught in separate practice sessions. For example, practicing the movements needed for saying "yes" and "no" within a game or a song. This may lend itself to criteria, such as four out of five times within that practice activity. However, most communication goals will

rely on data to be kept over a time period during an activity, over a day or a week, recording instances when the communication behaviour is observed.

Information adapted from Burkhart & Porter (2010)

GAS Goals

Goal Attainment Scaling (GAS) is "a technique for evaluating individual progress toward goals" (Schlosser 2004). GAS can document the implementation of a communication strategy and a way to review whether the strategy is working. GAS is well suited to use with people who have complex communication needs, where every person has their own strengths and challenges.

Steenbeek et al. (2007) found there were potential sources of bias and a reliance on the clinical judgement of therapists when developing the goals. Training in use of GAS and in writing goals was strongly recommended. Steenbeek et al (2007) found GAS worked well as a measure that was more sensitive to change than other standardised ways of measuring outcomes. Recent studies provide further support:

> *We tested assumptions of equality between GAS descriptions for outcome measurement in a randomized trial (i.e., measurability, equidistance, level of difficulty, comparability of behavior samples collected from teachers vs. researchers and live vs. videotape). Results suggest GAS descriptions can be evaluated for equivalency, that teacher collected behavior samples are representative, and that varied sources of behavior samples can be reliably coded. GAS is a promising measurement approach.*
>
> *Ruble, McGrew & Toland (2012), p 1974.*

A useful booklet on Goal Attainment Scaling, designed to provide training on its use within the context of paediatric therapy, is available by McDougall & King (2007). This includes practical information about the use of ICF codes when setting goals.

Goal Attainment Scaling formats can enable all team members to be clear about the behaviours and strategies being suggested. GAS can help to empower the person with complex communication needs and their immediate team as they all know what to do. It is suggested that all key communication partners are involved in the process of developing the GAS goals so everyone takes ownership of them and assists with the implementation.

An example of how this can help is in relation to a child who needs to develop a clear way to indicate "yes" and "no". When GAS goals are developed in consultation with team members at home and at school, agreement can be reached about the target responses, what the steps to achieving these are,

and what cues and prompts should be used to assist the person to learn this skill.

Communication is a complex process. There may be one to three GAS goals focusing on communication at any one time, depending on other priorities that an individual may have. These will be high priority goals, where progress is closely monitored. There may be other communication skills being learnt at the same time for the individual and / or their communication partners that are not documented as formally as GAS goals. These could be written as additional goals or strategies and encouraged during spontaneous communication opportunities, as they arise.

Australian Therapy Outcome Measures

Australian therapy outcome measures (AusTOMs) were developed in Australia and provide outcome measures for occupational therapy, physiotherapy and speech pathology. They were developed as a research project based on Therapy Outcome Measures developed by Pam Enderby in the UK, with input from Australian clinicians, consumers and advocates. They are based on the ICF, covering four separate domains: impairment, activity limitation, participation restriction and wellbeing. (Perry et al. 2004a; Unsworth, Perry & Skeat 2015). The inclusion of the domain for wellbeing is an important addition compared to the original UK instrument and has potential to assist in measuring elements related to psychosocial factors that are an important aspect of measuring progress and success with an intervention. Using the AusTOMs, outcomes can be measured in each domain separately, so it can be sensitive to whether there are improvements in some domains but not others (Unsworth, Perry & Skeat 2015).

These outcome measures can be valuable (Unsworth et al. 2004) but they may require use in conjunction with more sensitive person centred outcome measures when working with people who have complex communication needs e.g. GAS. An area requiring further research is the need for more sensitive measures of communicative participation (Eadie et al. 2006), where communication assessment considers functioning within the social context.

Canadian Occupational Performance Measure

The Canadian Occupational Performance Measure (COPM) was developed as a person-centred tool to enable individuals to identify and prioritise everyday issues that restrict or impact their performance in everyday living (Law et al. 2015). The COPM contains validated measures targeting importance, performance and satisfaction.

Originally designed for use by occupational therapists, the COPM is often used by multi-, inter- and transdisciplinary teams as a tool for the initial assessment interview to assist in identifying and prioritising goals. As communication affects all areas of daily life, asking questions about how complex

communication needs are impacting activities of daily living fits neatly with this tool.

The COPM supports person centred practice as it facilitates the involvement of the person in their own planning, enables people to clearly identify the barriers within their daily life and provides a means to determine which barriers they would most like to overcome.

Individually Prioritised Problem Assessment (IPPA)

Individually Prioritised Problem Assessment (IPPA) is designed to assess the effectiveness of assistive technology.

IPPA assesses effectiveness in relation to those activities that the individual considers relevant. During assessment, the person is asked to identify and rate the activities that he or she has problems with in everyday life. The same activities are rated again, a few months after receiving the assistive technology that aims to assist in addressing the problem. Research (Wessels et al. 2000) has indicated that the IPPA is a usable and valid instrument. IPPA has application for communication technology and other assistive technology, such as environmental control, mobility aids and hearing aids.

9.3 Person Centred Communication Goals

Person centred communication goals will be decided by the individual with complex communication needs, and with their key communication partners / primary caregivers, when required. The speech pathologist provides assistance and advice.

Person centred communication goals involve consideration of:

- Environmental support
- Communication partners support
- Priorities for the person's long term & short term goals to develop communication competence, with as much communication autonomy and independence as possible:
    - Modes / strategies for communication – learning ways to communicate that are specific and clear, so that a range of communication partners can interact with the individual.
    - Linguistic goals — specific needs for language, within and across activities – including pragmatics, receptive and expressive language skills.
    - Operational goals – how to operate devices, use resources, set up equipment so it can be accessed.

- Social goals —friendships, relationships and learning social skills.
- Strategic goals – repairing breakdowns, using communication methods that suit the communication partner and situation.
- Motivation, Attitudes, Confidence, Resilience — having the confidence to communicate using a range of communication modes, including mainstream and specialised resources; having a strong voice within conversations.

Adapted from Light & McNaughton (2014)

9.4 Monitoring Outcomes and Reviewing Goals

Keeping track of whether strategies are working should be built into intervention plans and monitoring should be ongoing. It is important to evaluate progress while providing a service and at the end of a service.

Video sampling and analysis is a recommended method for baseline measurement and then periodic review of communication skills. This can be used to look holistically at particular activities and compare communication skills demonstrated during initial assessment to those being seen three or six months later. This can capture whether there are overall improvements in the quality of interactions, the type of communication being used, the person's responsiveness to their communication partner, their understanding of what the other person is saying, their use of communication behaviours and whether these are informal or formal communication systems.

Progress may be:

- Quantitative – how often did the behaviour occur?
- Qualitative – how was the behaviour performed?

Assessing progress for people with complex communication needs can be difficult. Keep it simple. Data sheets can be included in a person's communication system, so it is easy to record instances of when a communication behaviour is observed. It is important to train communication partners to record what they are doing and observing. A well designed program will include methods of recording data that are simple and effective.

Examples of ways to record data are:

- record the number of times a behaviour is observed over a time period e.g. within a fifteen minute period, an activity, a day or a week
- obtain a language sample
- keep a record of the number of times a communication partner provided a communication opportunity to the person, within an activity

- description of the target behaviour and comments on the quality of the behaviour – how clear was it, what helped, what made it harder, where and when it occurred.

Health, Environment and Personal Factors

There may be additional factors influencing progress and learning e.g. frequent seizures may account for slow progress. Stabilising the medical health of the person may be important initially, to enable further progress on the goals to occur. Other factors could include fatigue, various health conditions, changes in the person's preferences, environmental factors, and changes in a person's life, such as changing schools being on holiday etc.

Monitoring involves making judgements about whether the intervention is working, whether to change the supports, the demands of the task, the context and the communication partners interacting with the individual.

It is generally recommended to change only one variable at a time. However, at times, if no progress is being made, there may be a decision to review the goal and change it completely.

It is important to recognise when a person has achieved a goal, so a new goal can be selected or the service can be completed. Adjustments to the person's program should allow for learning new skills and working towards more complex forms of communication. Aim for a cycle of continuous improvement, where once a goal is achieved, further goals can be developed and worked on. Long term goals should be periodically reviewed against the original assessment frameworks used, to determine the level of achievement and to assist in selecting new goals.

People may decide to complete their service if they feel they have achieved their goals sufficiently at that time. They may want to focus on other life areas. When completing a service, speech pathologists should support people to plan ahead and consider ways they can continue to enhance their communication after formal speech pathology support has finished.

9.5 Applying Evidence Based Practice to Intervention

> *Evidence based AAC practice is the integration of best and current research evidence with clinical/educational expertise and relevant stakeholder perspectives, in order to facilitate decisions about assessment and intervention that are deemed effective and efficient for a given direct stakeholder.*
>
> *(Schlosser & Raghavendra 2004),p 3.*

Developing effective communication interventions requires a multi-pronged approach and there is a need to consider feedback from real world application (World Health Organization 2013).

When reviewing the literature it needs to be acknowledged that there are significant limitations to the range and scope of the current evidence base in relation to complex communication needs (Schlosser 2003, 2004). Much of the published research has been about interventions of limited scope. For instance, research papers related to requesting within a functional communication training paradigm are looking at developing one communicative function. Communication competence involves a lot more than one communicative function.

Good clinical practice translates research into practice. This involves a synthesis of the clinician's knowledge, experience and clinical reasoning. This is informed by reviewing the literature and taking into account 'real-world' feedback from individuals with complex communication needs and their families / caregivers (Schlosser 2004). Intervention methods with a track record of producing the desired outcomes of communication competence can be supported, where there is robust evidence of success through a variety of mechanisms, in addition to being supported by the research literature. For instance, well constructed case studies, peer-reviewed conference presentations and workshops, where outcomes are demonstrated, as well as expert opinion, are reasonable forms of evidence in this field of practice. This can help to identify gaps in the evidence base and the need for future research projects (Schlosser 2003, 2004).

To date interventions for Indigenous Australians with complex communication needs have not been widely reported and this is an area requiring further study.

The ICF can assist in the translation of research into practice. It provides well-defined methods for evaluating progress, taking into account the individual's health, activity and participation, environmental and personal factors:

> *The ICF enables consistent evaluation of interventions, building evidence for effectiveness.*
>
> *World Health Organization 2013, p52.*

Where research has been published, it is important to critically appraise the quality and validity of the research (Schlosser 2003, 2004). Information is needed about the outcomes for people who have used the intervention method, who it was used with and how successful they were in meeting their stated purpose. Some methods are not designed to improve all aspects of

communication, but may be effective in meeting a particular need. Others may be designed as an overall system for developing communication competence.

The speech pathologist will need to determine what will be the most efficient and effective intervention for the particular need or purpose that has been identified through the person's assessment.

Efficiency and effectiveness can be considered within the ICF framework:

Health:

- Is the intervention suited to the individual, given the information you have gathered during assessment?
- Will the intervention enable enhanced functioning for the individual in relation to the person's communication requirements?
- Does the intervention provide a path to developing long term communication competence?

Activity and Participation:

- Does the intervention enable greater participation in everyday activities?
- Does the intervention expand access to activities and participation?
- Does the intervention expand social opportunities for the individual, to enable greater understanding and expression within activities?

Environment:

- Will the intervention make a difference within the person's regular environments?
- Is the intervention effective across a range of environments?
- Is the intervention suited to the environment it will be used for?

Personal Factors:

- Does the individual like the intervention method?
- Does the intervention method enhance the person's confidence?

When selecting an intervention option, consider whether it will be a valuable contributor in moving on the path towards communication competence for an individual (Kovach 2011).

9.6 Accessible Information

Clear communication between the speech pathologist, person with complex communication needs and their communication partners is essential.

Information in handouts, reports and training materials should be provided using Plain English or Easy English.

Literacy is a major barrier for many people. In Australia it is estimated that:

> *2 million Australians struggle to read standard print because of:*
>
> - *Learning Disabilities*
> - *Intellectual Disability*
> - *Brain Injury or Cognitive Impairment*
> - *English as a Second Language*
> - *Literacy Difficulties*
> - *Vision Impairment.*
>
> *(Australian Bureau of Statistics 2003)*

> *46% of the population of Australia might struggle to understand information from newspapers, magazines, brochures, job applications, payroll forms, maps, timetables etc.*
>
> *(The Adult Literacy and Life Skills Survey summary, 2006)*

This might be because of:

- not knowing the topic (jargon, medical terms etc)
- attention difficulties (information is too long)
- vision problems (colour blindness, visual acuity, visual perception)
- educational level (grammar is too complex).

(Turnbull, Burke, Manton, Cummins and Bell,2013)

Additional reading and resources

- ADHC Accessible Information Checklist.
- Fajardo et al. (2014). Easy-to-read texts for students with intellectual disability: Linguistic factors affecting comprehension. *Journal of Applied Research in Intellectual Disabilities, 27(3),* 212-225.
- Hurtado, Jones & Burniston (2014). Is Easy Read information really easier to read? *Journal of Intellectual Disability Research, 58(9*), 822-829.
- Jones, Long & Finlay (2007). Symbols can improve the reading comprehension of adults with learning disabilities. *Journal of Intellectual Disability Research, 51, 7,* 545-550.

- Poncelas & Murphy (2007). Accessible information for people with intellectual disabilities: Do symbols really help? *Journal of Applied Research in Intellectual Disabilities*, 20(5), 466-474.
- Scope Victoria Accessible Information Services.

10 Communication across the Lifespan

Communication is a work in progress for all of us. Throughout a person's lifetime communication needs will change. People with complex communication needs may require specific supports during different times in their lives.

10.1 Life Transitions

People with complex communication needs require:

- **Intensive early intervention.** Provide skilled assessment and intervention while a child is young, so that by the time they go to school, they can communicate effectively, and access their school curriculum.
- **Accessible education.** Education must accommodate the needs a person has for communication and literacy skills. Education needs to suit an individual's needs, whether these are due to physical, sensory and/ or cognitive challenges. Communication strategies, technology and augmentative and alternative communication systems must be available to students at school and must be actively developed to accommodate their needs to learn language, literacy and communication competence at school, with their friends, family and with the wider community.
- **Adult learning.** People with complex communication needs should continue to actively engage in learning as adults. They should have communication systems that are robust enough for them to be able to communicate with people who are unfamiliar. If their communication is idiosyncratic or requires training, they may need to have supports in place with people trained to assist them when they wish to communicate with unfamiliar people.
- **Planning for all life transitions.** Looking ahead and planning for change will empower people to have the communication they need throughout every stage of their life.

10.2 Peer Support

Developing networks with others who have similar experiences can be very valuable. Mentoring from more experienced people who use AAC has been demonstrated to be beneficial (Ballin, Balandin & Stancliffe 2013a; Ballin, Balandin & Stancliffe 2013b).

Forms of peer support include:

- Associations for information sharing and networking for professionals and individuals with complex communication needs (e.g., AGOSCI, ISAAC – Australia, ARATA). These organisations provide listserves, workshops and conferences that enable people with complex communication needs to mix with their peers and with a range of professionals involved in the field – each enhancing the understanding of the other about the issues that people with complex communication needs face.
- Advocacy and social interest groups (e.g., Communication Rights Australia, AAC Voice).
- Peer mentoring (Ballin et al. 2010) – it is highly valuable to younger people with complex communication needs to gain advice and wisdom from older people with complex communication needs, drawing from their life experiences. Parents can also support and mentor each other e.g. the advice of a parent who has experienced having a child with a complex communication needs may be invaluable to another parent who is grappling with his / her child's diagnosis in the early stages.
- People with complex communication needs can train other people with complex communication needs and professionals, as well as having opportunities to receive training. People with complex communication needs can develop their skills to be person-centred champions, providing peer support, mentoring and leadership to others.

Please also see section 9.6 Mentoring in the Augmentative and Alternative Communication Practice Guide.

11 Future Directions

The silence of speechlessness is never golden. We all need to communicate and connect with each other – not just in one way, but in as many ways as possible. It is a basic human need, a basic human right. And more than this, it is a basic human power ….

Much has changed since I grew up. I doubt, for example, that anyone with my level of speech disability would get 10 years of speech therapy today without at least questioning if that person should have access to an augmentative means of expression. But far too much has also remained the same. For example, what is still not certain is whether the same person will gain access, not just to the device, but to the training and support which he or she will need to communicate effectively. We may have torn down some of the communication barriers that exist; however, much of the brick wall that many people with disabilities must break through remains very much intact.

Access to assistive technology and other effective means of expression is vital. Having the power to speak one's heart and mind changes the disability equation dramatically. In fact, it is the only thing I know that can take a sledgehammer to the age-old walls of myths and stereotypes and begin to shatter the silence that looms so large in many people's lives …

Why are so many people consigned to lead lives of needless dependence and silence? Not because we lack the funds, nor because we lack the federal policy mandates needed to gain access to those funds. Rather, many people lead lives of silence because many others still find it difficult to believe that people with speech disabilities like my own have anything to say or contributions to make.

It is this perception and the stereotypes and prejudices that fuel it that we need to challenge. There must be a radical shift in attitudes and expectations. Fortunately for some of us, that shift occurred early in life. My family and I both expected me to communicate, and we did whatever it took to make that happen. The same radical shift in expectations and life experiences can and must occur in others' lives as well.

Bob Williams 2000, in his essay "More than an Exception to the Rule", USA.

Excerpts from pp248-250.

11.1 National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is bringing about a major change in how services are provided and funded for people with complex communication needs. It is hoped this will make a real difference to the life experiences that people have in the future. Changes in attitudes and expectations is needed to ensure that all people with complex communication needs have the supports they need so they can communicate to their full potential.

The processes that have been recommended in these guidelines are consistent to the approach being taken by the NDIS. There is an emphasis on person centred planning, decision making, use of evidence based approaches, and measuring outcomes.

Therapy services will receive continued funding where results are demonstrated in the following areas:

- optimising the ability to understand information and communicate thoughts and needs
- development of skills of communication partners to support participation
- recommendation, assessment and training on augmentative communication equipment for people with vision, hearing or communication impairments.

These are the outcomes emphasised for speech pathologist providing services for supporting people with communication difficulties in the NDIS schedule (National Disability Insurance Agency (NDIA) 2014b).

The move to the NDIS and disability services becoming a Federal Australian Government responsibility, rather than a State Government responsibility, will involve many changes. There is a shift from having block funded government and non-government services, to a fee-for-service, individualised funding model. Many speech pathologists will be setting up their own businesses, to take on the work for people being funded through the NDIS. Non-government not-for-profit services are changing their model of services to fit in with the changes to funding.

While this has great potential for the sector, there will also be areas where systems need further development. Speech pathologists will need ways to:

- Continue to develop their professional skills and knowledge, with supervision, mentoring and support by other speech pathologists with experience in working with people with complex communication needs.
- Work collaboratively with other team members, including the person with complex communication needs themselves, families, carers,

teachers and learning support staff, occupational therapists and physiotherapists, audiologists, vision specialists and doctors, to deliver the required services to people with complex communication needs.

11.2 Communication Participation in Everyday Life

Technology has taken a great leap forward over the last few years and opened up a range of possibilities for people with complex communication needs. Communication solutions are becoming integrated within mainstream devices, such as computers, iPads / smart tablets and smart phones.

People in the wider community are using technologies developed in the field of augmentative and alternative communication in their everyday lives. This includes word prediction, using a variety of modalities and an increased use of SMS texting rather than voice phone calls (Newell 2011). This means increased understanding and knowledge in the community and less emphasis on “difference”. We all use multi-modal ways of communicating.

Areas for improvement in Australia to enable greater communication participation in everyday life are outlined below.

Digital Literacy

Everyone needs to be able to communicate online in order to maintain their social networks. They need to be able to use a variety of social media, be able to talk to other people using various methods of telecommunications, know how to find information, how to participate in leisure activities and games, and to do many daily tasks such as shopping and banking. Being able to manage all of this, as well as knowing how to stay safe when using the internet and learning efficient ways to use computers, are all learnt skills.

People with complex communication needs can greatly benefit from having access to the internet and computers. However, there is also a need for additional options for people who have alternative access needs and for people who are not literate. Computer access, accessible websites and inclusive software can enable people with complex communication needs to access the curriculum in educational settings.

All these options exist and many will improve. Training and a recognition of the importance of this area is a future direction for the field.

Smart Technology and Specialised Assistive Technology

Smart phones and tablets have transformed the area of high tech augmentative and alternative communication.

Mobile devices have made technology:

- mainstream
- user-friendly
- affordable
- widely available.

(McNaughton & Light 2013).

Many people have become aware of communication solutions through the use of mobile technologies. Many people with complex communication needs have been more comfortable using mainstream devices for communication because they do not look “different”.

However, there continues to be a need for specialised technologies. Dedicated speech generating devices were developed to cater for very specialised needs. There will need to be ongoing support for further research and development of specialised solutions, where these enable people to access communication in ways that mainstream solutions cannot.

In the future, it is likely that the differentiation between mainstream and specialised technology will blur even more. It will become easier to customise devices and technology to meet an individual’s particular needs. It will be important that access and programming options that are efficient and effective for people with complex communication needs are not lost, but continue to be improved.

Improving Knowledge about Efficent and Effective Methods

There are a wide range of interventions for people with complex communication needs. In the future, there will be increasing awareness of the most efficient and effective methods for developing communication solutions. Time is a valuable resource. The more efficient we are in knowing what interventions are likely to work for particular individuals, the more quickly priorities for developing communication competence can be set.

Whatever stage of learning people are at, communication interventions will need to consider the various aspects of communication competence for individuals, their communication partners and the barriers and opportunities in the environment.

Further translation of research into practice will help us to have clearer benchmarks so we know when even those people with the most severe disabilities are on track to developing long-term communication competence to the fullest extent that is possible for them.

Complex Communication Needs Training and Research

People with complex communication needs, people who live and work with them and professionals who support them need training so that the opportunities for learning communication skills and using communication resources effectively are fully realised.

A continuous cycle of learning is required for people with complex communciation needs, their communication partners and the speech pathologists supporting them. Sarah Blackstone wrote about the Stages of Knowing in an issue of Augmentative Communication News (Blackstone 2009, pp 8-9).

The Stages of Knowing is described as:

- Stage One: "*We don't know what we don't know", developing awareness.*
- *Stage Two:* "We *learn what we don't know", people begin to learn*.
- Stage Three "*We know what we know*", people become more confident about their knowledge through experience and professional development.
- Stage Four: "*We don't know what we know",* where as experts we realise there is so much more to learn – developing a deeper knowledge and realising that we need to learn more.

Training and research opportunities are needed in this exciting area of practice, including online seminars, local workshops, continuous education, graduate education and postgraduate research and education. These should involve people with complex communication needs, following the principle of "nothing about us without us" (Centre for Disability Studies Inclusive Research Network - Affiliate of The University of Sydney 2013).

11.3 Equality of Opportunity for People with Complex Communication Needs

In the future, people with complex communication needs will have equal opportunity in their communities. The following are benchmarks for achievements that will help measure when equal opportunity is a reality:

- Timely and sufficient supports and services enable all people to communicate.
- There is increased community awareness and understanding about ways people with communication disabiliites can communicate.

- Communication is a top priority within all early intervention services, so all children develop communication competence before they start school.
- Students with communication disabilities can access their curriculum and continue to develop their communication competence.
- People with communication disabilities are able to access employment, with flexibility and universal design within workplaces.
- People with communication disabiliites participate in their communities during all stages of life.

12 Resources

Explore this list of resources, suppliers and websites which has many useful links to information and online resources available to help.

Person Centred Planning

The NSW Department of Family and Community Services has a wealth of resources to assist with person centred planning such as My life, My way.

Centre for Disability Studies http://cds.org.au/

Communication Advocacy & Support Groups

AAC Voice www.aacvoice.com

ACCAN https://www.accan.org.au

Communication Rights Australia http://www.caus.com.au/www/home

Communication Interest Groups & Professional Associations - Australia

AGOSCI www.agosci.org.au

ISAAC-Australia http://isaacaustralia.com/

ARATA www.arata.org.au

Key Word Sign NSW www.kwsnsw.com

Speech Pathology Australia www.speechpathologyaustralia.org.au

Communication Information / Services

Communication Inclusion and Resource Centre, Scope Victoria

- Communication Access, Scope Victoria
- Non-electronic Communication Aid Scheme, Scope Victoria

Ability Technology www.ability.org.au

Connexu Foundation www.conexu.com.au

Independent Living Centres Australia www.ilcaustralia.org.au

Independent Living Centre NSW: Everyone Connects

National Relay Service www.relayservice.gov.au

Newell Network www.newell.org.au

Northcott: Assistive Technology www.northcott.com.au/services/assistive-technology

Novita Children's Services AAC Factsheets

TASC Consultative Service www.cerebralpalsy.org.au

Communication Assistive Technology Suppliers

CommunicateAT www.communicateat.com.au

Liberator www.liberator.net.au

Quantum: Reading Learning Vision www.quantumrlv.com.au

Spectronics www.spectronics.com.au

Technology Solutions Australia www.tecsol.com.au

Tobii www.tobii.com

Zyteq www.zyteq.com.au

Useful Apps

AAC Ferret www.spectronics.com.au/ferret

Phone Rights App www.accan.org.au/consumer-info/phone-rights-app

National Relay Service App www.relayservice.gov.au/support/nrs-app

Emergency & Smartphone App Information is available at:http://www.triplezero.gov.au/Pages/EmergencySmartphoneApp.aspx

Useful Websites

AAC-RERC (AAC Rehabilitation Research Centre) www.aac-rerc.psu.edu

Augmentative Communication Inc www.augcominc.com

AAC Intervention www.aacintervention.com

Call Centre Scotland http://www.callscotland.org.uk/

Center for Literacy and Disability Studies www.med.unc.edu/ahs/clds

Communication Matters (UK) www.communicationmatters.org.uk

Creative Communicating www.creativecommunicating.com

First People's Disability Network Australia http://fpdn.org.au/

GARI - Mobile Accessibility Information http://www.gari.info

International Communication Project www.communication2014.com

ISAAC International www.isaac-online.org/english/home

Multicultural Disability Advocacy Association www.mdaa.org.au

Multicultural Health Communication http://www.mhcs.health.nsw.gov.au/: *

** Speech Pathology section includes handout Communication is Not Just Speech*

PrAACtical AAC praacticalaac.org

Patient Provider Communication www.patientprovidercommunication.org

Raising Children Network raisingchildren.net.au

RESNA http://www.resna.org

Simplified Technology- Linda Burkhart www.lburkhart.com

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13 Appendices

13.1 Glossary

Accessible Information – writing information so it is easy to understand.

Activity analysis – working out the component steps that make up an activity and what skills are required to achieve these steps.

Adaptation – making a change to enable a person to complete a task or activity. This may involve equipment or changing the actions required to do the task.

Applied behaviour analysis – a systematic way to learn new behaviour.

Acquired disability – a disability that occurs after the time of birth.

Assent – the expression of approval or agreement.

Audiologist – a professional who specialises in assessment of hearing and management of hearing loss and related disorders.

Augmentative and Alternative Communication (AAC) – methods of communication that supplement or are used instead of speech.

Behaviours of concern – any behaviour that causes physical harm to the person with a disability or another person, or destroys property resulting in the risk of harm to the person or any other person.

Collaborative team – when two or more people (often groups) work together, sharing knowledge and skills, to accomplish a common goal.

Commonwealth and State/ Territory Agreements – an agreement between federal, state and territory governments in Australia that provides the national framework for the provision of government support to services for people with disability.

Communication partners – anyone who a person communicates with.

Communication Support Worker – a person who is trained to assist a person who has a communication disability to communicate. The person acts as an intermediary when the person needs to communicate with a person who is unfamiliar with their communication methods, in a way that is similar to an interpreter. This role may be carried out by a speech pathologist, a disability support worker or a familiar person.

Communicative intent – communicating for a purpose; understanding that communication is two-way and involves conveying meaning to another person.

Complex Communication Needs – difficulty communicating using speech alone, related to one or more possible causes.

Congruence – as a professional, being open and equal in manner with a client, so the client feels comfortable talking to the professional.

Core Activity Limitation – this is when a person needs help, has difficulty or uses aids or equipment with any of the following core activities: communication, mobility and self-care, (Australian Bureau of Statistics, 2012).

Core Vocabulary – a small set of high frequency words that are used in many situations, for many topics. In a language sample 80% of words will be core.

Cortical Vision Impairment (CVI) – a form of visual impairment that is caused by a brain problem rather than an eye problem.

Deafblindness – the condition of little or no useful sight and little or no useful hearing.

Enduring guardian – a person legally appointed to make decisions on a person's behalf, if needed. An enduring guardian considers your views past or present, if known, and assists if a person lacks capacity to make her/his own decisions.

Fringe vocabulary – a large set of words that enable communication of specific concepts relevant to specific situations or topics. In a language sample 20% of words will be fringe. Includes proper nouns and other nouns.

GAS Goal – Goal attainment scaling is a mathematical technique for quantifying the achievement (or otherwise) of goals set. The achievement of each goal can be measured on a 5-point scale ranging from -2 to +2, and there is a method for quantifying the outcome in a single aggregated goal attainment score. Used as a means of measuring outcomes in therapy, teaching and rehabilitation.

High support needs – a person who requires daily intensive, substantial or total assistance with core activities of daily living, that is communication, self-care and/or mobility.

Idiographic approach – of or relating to the study of individuals.

Informed consent – a process for getting permission, in which an individual obtains knowledge about options, understands this and agrees to a decision that involves them or provides information about them to others.

Interdisciplinary – team members act within their professional domains but collaborate actively and frequently in intervention planning and implementation (Guralnick, 2000, cited in Bundy et al. 2008, p 10).

Key communication partners – people who interact regularly with a person who has complex communication needs and take responsibility for adapting their own communication to support the person's communication where this is needed.

Manual dexterity – ability to perform coordinated hand and finger movements.

Mental health condition – a health condition that changes a person's thinking, feelings, or behavior (or all three) causing the person distress and difficulty in functioning.

Mild intellectual disability – This is defined as an IQ between 50 and 70.

Moderate intellectual disability – this is defined as an IQ between 35 and 50.

Multidisciplinary – team members act within their own professional domains and interact only formally with other team members (e.g., in meetings) (Bundy et al. 2008, p 10).

Non-symbolic – does not involve language or conceptual representation; includes facial expression and body language.

Occupational Therapist – an allied health care professional who specialises in enabling people to participate in activities of daily living and to engage in the meaningful occupations of everyday life.

Orthoptist – eye care professionals who detect, diagnose and treat vision and eye disorders in children and adults.

Ophthalmologist – a doctor who is a specialist in medical and surgical eye problems.

Person centred practice – the person with a disability drives decision-making and receives the information and support needed to make decisions; where assistance is required, the views of the person are ascertained and help to drive decisions to the greatest extent possible.

Physiotherapist – an allied health care professional who specialises in physical movement and assists people with physical injury or disability to enable functional movement and mobility.

Predictably associated vocabulary – words that relate to each other are organised consistently to support construction of multi-word phrases and sentences.

Primary communication partner (similar to key communication partner) – the person who communicates with the person with complex communication needs the most.

Psychopharmological – the effect of drugs on the mind and behavior; the use of medications in treating mental disorders.

Psychologist – an allied health care professional who specialises in the mind, the brain and behaviour, emotional disturbance, and behavior problems.

Public Guardian – a statutory official who promotes the rights and interests of people with disabilities through the practice of guardianship, advocacy and education.

Scaffolds / scaffolding – temporary assistance or a framework that is put up for support and access to meaning and is then gradually reduced and taken away as the person learns to do the task.

Schools for Specific Purposes (SSP) – are for students from Pre-school to Year 12 who require intensive levels of support. These schools provide a specialised educational setting in which learning support plans are collaboratively developed, implemented and monitored.

Self-determination – the process of taking control of your own life.

Severe – Profound Core Activity Limitation – sometimes or always requiring personal assistance or supervision with self-care, mobility or communication.

Severe – Profound Intellectual Disability – this is defined as an IQ below 35.

SMART Goal – a well-defined, observable goal.

Special educator – a teacher who has specialised skills in teaching students with disabilities, learning difficulties and other specialised needs.

Speech Pathologist – an allied health care professional who specialises in assisting people with communication and swallowing problems to enable communication and management of eating and drinking.

Supported decision-making – when one person supports another person to be engaged in decision making.

Symbolic – use of language; language representation (symbols), spoken, graphic or text, that convey meaning to another person

Task analysis – working out the component steps that make up a task and what skills are required to achieve these steps. An activity may involve a series of tasks.

Transdisciplinary – Team members overlap and cross over traditional roles. Boundaries between the roles of team members are blurred (Orelove & Sobsey, 1996; Wooster, 2001, cited in Bundy et al. 2008, p 10).

13.2 Assessment tools

Tool name	Author/s and Year	Description
Affective Communication Assessment and the Early Communication Assessment, published in Communication Before Speech	Coupe-O'Kane & Goldbart (1998)	Guide for interpreting the behaviours of a person and assigning a communicative meaning. Focused on pre-intentional communicators.
Assessment of Phonological Awareness	Iacono & Cupples (2000)	Assesses phonological awareness and text

and Reading (APAR)		reading. For people with physical and/ or intellectual disability. Can be used with people who communicate in a range of modalities.
Augmentative and Alternative Communication Profile: A Continuum of Learning	Kovach (2009)	Measures subjective, functional skills for developing communicative competence using AAC systems. Monitors progress. Ages 2-21 years.
Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)	King et al (2004)	Self report measures of children's participation in recreation and leisure activities. For children and young people with a disability (ages 6-21 years).
Children's Communication Checklist (CCC2) - Second Edition	Bishop (2003)	Screen for communication difficulties and pragmatic impairments in children.
Clinical Evaluation of Language Fundamentals - Fourth Edition, Australian Standardised Edition (CELF-4 Australian)	Semel, Wiig & Secord (2006)	Provides information on the child and young persons receptive and expressive language skills. Ages 5-21 years
Clinical Evaluation of Language Fundamentals Preschool - Second Edition, Australian and New Zealand Standardised Edition (CELF P-2 Australian and New Zealand)	Wiig, Secord & Semel (2006)	Provides information on the receptive and expressive language skills in young children. Ages 3- 6;11 years.
Communication Checklist- Adult (CC-A)	Whitehouse & Bishop (2009)	Questionnaire completed by a respondent who has regular contact with the individual and knows them well.
Communication Matrix	Rowland (2013)	Designed for individuals of all ages who function

		at the earliest stages of communication and who use any form of communication.
Comprehensive Assessment of Spoken Language (CASL™)	Carrow-Woolfolk (2014)	Provides information on children and young adults' oral language skills. Ages 3-21 years.
Dementia Communication Difficulties Scale	Talking Mats (2007)	Identifies the communication difficulties that a person with dementia might be having.
Functional Assessment of Comprehension	Ulliana & Mitchell (1997)	Provides a framework for assessing the comprehension skills of children with severe communication impairments.
Functional Assessment of Expressive Skills (FAES)	Ulliana & Mitchell (1999)	Gathers information about how the child expresses themselves. Information provided by someone who interacts with the child on a daily basis.
Functional Communication Profile Revised	Kleiman (2003)	Provides an overall inventory of the individual's communication abilities, mode of communication and degree of independence. For individuals with developmental and acquired delays. Ages 3 years to adult.
Inventory of Potential Communicative Acts (IPCA)	Sigafoos et al (2000)	Structured interview protocol that is designed to identify PCA's in children with developmental disabilities and physical disabilities and severe communication impairment.
MacArthur- Bates Communicative Development	The CDI Advisory Board (2007)	Parent-completed forms that help screen young

Inventories		children's emerging language and communication skills. Includes a CDI: Words and Gestures form and CDI: Words and Sentences form.
MOSAIC: A Model of Observational Screening for Assessment of Interaction and Communication	Smidt (2010)	Provides a framework for gathering information about how a person with an intellectual disability communicates. For children and adults.
Participation Inventory	Blackstien-Adler (2003) published in Beukelman & Mirenda, 2013, p112.	Gathers information about the participation patterns of a person using AAC within regularly-occurring activities.
Pragmatic Profile of Everyday Communication Skills in Children	Dewart & Summers (1995)	Gathers information about how a child communicates in their daily life. Focus on pragmatic aspect of the child's language. Has a pre-school (0-4 years) and school-age (5-10 years) version.
Pragmatic Profile of Everyday Communication Skills in Adults	Dewart & Summers (1996)	Gathers information about how an adult communicates in their daily life. Focus on pragmatic aspect of the adult's language. For adults with developmental disabilities and severe communication impairment.
Preschool Language Scales, Fifth Edition – Australian and New Zealand Language Adapted Edition (PLS-5)	Zimmerman, Steiner & Pond (2012)	Play based assessment of language skills. Ages: Birth- 7;11 years.
Protocol for Culturally Inclusive Assessment of AAC	Huer (1997) published in Beukelman & Mirenda, 2013, p125.	Includes a self evaluation component for team members to assess their own

		multicultural competencies.
Receptive-Expressive Emergent Language Test (REEL-3) Third Edition	Bzoch, League & Brown (2003)	Provides information on the language skills of infants. Ages: Birth – 3 years.
SETT (Student, Environment, Task and Tools) Framework	Zabala (2005)	Provides a structure for making decisions about assistive technology.
SCERTS® Model	Prizant, Wetherby, Rubin & Laurent (2007)	A model for children with autism and their families. Focuses on building competence in Social Communication, Emotional Regulation and Transactional Support.
Social Networks: A communication inventory for individuals with complex communication needs and their communication partners	Blackstone & Hunt Berg (2012)	Gathers information about the person with complex communication needs and their communication partners. Identifies strategies for enhancing communication interactions. For children and adults with severe communication difficulties.
Stirling Understanding Screening Tool (SUST)	Talking Mats (2012) *Based on Derbyshire Language Assessment but adapted for adults.*	Provides a quick way to gauge the comprehension level of adults with a communication difficulty.
TASP: Test of Aided-Communication Symbol Performance	Bruno (2010)	Test for assessing symbolic skills to assist in developing AAC systems. Can be used with children or adults.
Test for Auditory Comprehension of Language Fourth Edition	Carrow-Woolfolk (2014).	Assess a child's receptive language skills. Ages: 3- 12 years.
The Rossetti Infant-Toddler Language Scale	Rossetti (2005)	Assess the preverbal and verbal aspects of communication and interaction in infants. Ages: Birth- 3 years.
Triple C Checklist of	Bloomberg et al. (2009).	Assess the

Communication Competencies, Revised		communication skills of adults with severe – profound levels of intellectual disability

13.3 A-Z of intervention methods and resources

This appendix outlines intervention methods and resources that are used for people with complex communication needs. A description of each method and resource is provided, with links to additional information.

Please note that FACS does not endorse or recommend any particular intervention method or resource.

These methods are currently being used in clinical practice and have varying levels of formal research behind them. Intervention increasingly involves a mix of low and high technology methods (AAC-RERC 2012).Information is provided on ways of interacting with people with complex communication needs to enhance communication and use of unaided and aided communication systems, including non-electronic & electronic methods.

Please read this information in conjunction with the Augmentative and Alternative Communication Practice Guide.

Intervention methods and resources are presented in alphabetical order. The practitioner should critically evaluate the best available current evidence when assessing interventions.

Aided Language Stimulation

Aided language stimulation (Goossens 1989; Goossens, Crain & Elder 1992) is modelling the use of augmentative and alternative communication by providing receptive language input and a rich language model for people with complex communication needs.

Similar systems include the System for Augmenting Language (Romski and Sevcik, 1992 and 1996, cited in Beukelman & Mirenda (2013), Natural Aided Language (Cafiero 2001) and Aided Language Modelling (Drager et al. 2006).

Aided language stimulation and similar methods have been used successfully to people with severe – profound intellectual disability, autism and multiple disabilities including physical, hearing, vision and cognitive impairments. Research has shown that positive outcomes can be achieved using aided language stimulation with young children (Drager et al. 2006), school aged children (Dada & Alant 2009) and adults with intellectual disabilities (Beck, Stoner & Dennis 2009).

In Australia, the Pragmatic Organisation Dynamic Display (PODD) communication system has been developed by Gayle Porter (2007) as a means of operationalising aided language stimulation to enable communication at any time.

> *The system is guided by a set of principles and design strategies for organising symbol vocabulary to support spontaneous communication for a full range of functional purposes in all daily environments.*
>
> *Mirenda (2009), ASHA website*

The CHAT – Now Manual (Porter & Cameron 2007) provides a training package and resources to assist in introducing aided language stimulation with young children.

Additional reading and resources

- Augmentative Communication News, 2006 Vol 18, No 3
- Mirenda (2009). Promising Innovations in AAC for Individuals with Autism Spectrum Disorders, *SIG 12 Perspectives on Augmentative and Alternative Communication,* 112-113, ASHA.

Alternative Access

Intervention must include consideration of alternative access methods where required. For instance, a person is able to point to large items on a display directly, but this will limit the number of messages they can say and they have a need to access a much larger number of messages, then the speech pathologist may consider alternative access options. This should be done in conjunction with the individual with complex communication needs, their key communication partners and other team members with the necessary knowledge, such as an occupational therapist.

Consider the needs the person has for access:

Physical

- What methods of access will work best?
- What are the methods for high tech and the methods for low tech?
- How much time and effort is required to use the option?
- How much learning will be required to use the method effectively?

Options include:

- Partner-assisted scanning – using visual and/or auditory scanning, in a systematic scan of a display (e.g. linear, row-column, encoding) to select vocabulary, to construct a message.
- Switch – to control a scan on a high tech device.
- Eye- gaze –providing a means of direct access, where a person is unable to point with their hands, but has adequate visual skills.

Vision

- Does the person have adequate vision to see the display?
- Does vision fluctuate?
- Would high-contrast symbols make it easier for symbols to be seen clearly?
- What spacing of symbols is required?

Options include:

- High contrast picture communication symbols
- High tech devices with lighting on the display
- Non-reflective laminate, to reduce glare.

Alphabet boards / displays

Alphabet boards can be designed using an “ABC” or a “QWERTY” layout for direct access or partner-assisted scanning. Alphabet boards are also available for people who use eye gaze as a method of access. How a person accesses their alphabet board may vary depending on fatigue or health. Sometimes they may use direct access and point themselves and other times they may be assisted.

Alphabet boards can be designed with some everyday phrases added to reduce time required for frequently used phrases. A number of alternative layouts to reduce keystrokes or increase efficiency of scanning can be used.

Alphabet boards are easy to make but more specialised designs can be purchased. Examples can be found via the AGOSCI website, Independent Living Centres, Scope Victoria, Spectronics and online.

Applied Behaviour Analysis

Applied behaviour analysis in a broad sense is a behavioural approach to teaching that involves task analysis and systematic teaching of skills.

Applied behaviour analysis is a term that is also used to refer to specific approaches to early intervention, where intensive therapy and a very structured approach to teaching is used.

> *Most ABA-based programs incorporate several teaching techniques, which might include* Discrete Trial Training (DTT) *or* incidental teaching*, or using everyday interactions as opportunities for children to learn.*
>
> *Raising Children Network (2014a) webpage*

Additional reading and resources

- Prior et al. (2011). *A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention of Children with Autism Spectrum Disorders*.
- Raising Children Network (2014a), Applied Behaviour Analysis (ABA)
- Roberts (2004). A Review of the Research to Identify the Most Effective Models of Best Practice in Management of Children with Autism Spectrum Disorders.

Assistive Technology (AT)

Interventions for people with complex communication needs may involve assistive technology.

> *AT is an umbrella term for **any device or system** that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed.*

World Health Organization 2004, p14

Assistive technology can be divided into “hard” and “soft” technologies. Communication strategies, such as intervention methods for encouraging interaction skills, can be viewed as “soft technology” compared to the “hard technology” of actual products — software and devices (Waldron & Layton 2008). Devices can be both non-electronic and electronic. A non-electronic communication book is still a “hard technology”. Key word signing would be considered a “soft technology”.

There are many kinds of assistive technology that may be required to implement communication methods and to be as independent as possible. Speech pathologists should be aware of assistive technology options available and can encourage people to review their assistive technology requirements regularly, so individuals have the best possible support for their needs.

Examples of assistive technology are:

- Calendars
- Clocks
- Computer access
- Environmental control systems
- Hearing aids
- Glasses
- iPads and other tablet computers
- Mounting systems
- Non-electronic communication aids
- Personal Alarm Communication Systems / Emergency Call Systems
- Wheelchairs – manual and power chairs
- Speech generating devices
- Switches.

Environmental control systems can be integrated within a communication system. The range of home automation systems with integration of medical care through tele-health, social networking and environmental control of appliances is growing.,

Individuals with complex communication needs may require assistance from an occupational therapist or an assistive technology specialist when considering their needs.

Additional reading and resources

- Ability House and Ability Technology websites.
- Enable NSW has published Environmental Control, Computer Access and Personal Alarm Clinical Criteria, which provides valuable advice.

- Independent Living Centres in the different states of Australia are a free and unbiased source of information about assistive technology.
- Towards Solutions for Assistive Technology — A Discussion Paper suggests future changes in the process for selection and funding of assistive technology in Australia, supporting the shift to empowering consumers. (NDIA 2014).

Core Vocabulary

Core vocabulary is a small set of high frequency words that are used in many situations, for many topics. See description of core vocabulary in the Augmentative and Alternative Communication Practice Guide.

An additional article with additional links to information, is published as an ASHA Leader article Cannon & Edmond (2009) – A Few Good Words on the ASHA Leader website.

Communication books/ boards

Communication boards can be:

- **Static** – one board, with **core vocabulary** and some additional **fringe vocabulary** added in. These are often large displays, putting a lot of vocabulary within range of an individual. They may be designed with small individual items in an attempt to provide a large vocabulary on one level.
- **Multi-level** – a display with many pages, designed to provide a comprehensive vocabulary. These can be designed in a variety of ways, using pragmatic, syntactic and semantic categories. The efficiency of multi-level books varies and is a significant factor when learning to use a system.

  Multi-level books can involve use of a **core vocabulary, predictably associated vocabulary** and **fringe vocabulary** within their design.
- **Topic boards** – designed for a particular topic or activity, providing comprehensive vocabulary to suit a specific situation.

Communication books or boards can be designed for a range of access options, including:

- **Direct access** – pointing with a hand, fist or foot, using a head pointer; using eye gaze
- **Indirect access** – using partner-assisted scanning that is visual, auditory or visual + auditory scanning, with linear, row-column scanning or other variations.
- **Encoding** – using a code to select items, such as colours and numbers.

Communication Dictionaries / Personal Communication Dictionaries

Communication dictionaries are a method of documenting the sometimes subtle and idiosyncratic communication behaviours of people with complex communication needs. This enables the communication partners to identify the person's communication behaviour, interpret the possible meaning and respond to the communication behaviour consistently (Downing 2009).

This strategy can assist in encouraging communication intent by providing consistency in the way people in the environment respond to the person in particular situations (Bloomberg, Johnson & West 2004). It can help a person with non-symbolic communication to communicate as fully as possible within their familiar environments.

Communication dictionaries can also be used as a method for documenting idiosyncratic gestures and signs used by an individual e.g. adaptations of key word signs. This can assist people in the person's environment to "read" their signs when the formal sign has been modified to suit an individual's physical capabilities. Methods of documenting an individual's modifications can be recorded using a combination of digital photo, video and written descriptions (Caithness & Potts 2003).

Communication Diaries

Communication diaries can provide a way of recording vocabulary needs, to enable updating of low tech or high tech communication resources (Beukelman & Mirenda (2013), p35).

Communication Passports / Profiles / Book about Me

Communication passports (Millar 1991/1992, cited on CALL Centre website) or profiles provide an overview of the person's communication methods to assist communication partners to communicate consistently with the person and to interpret their communication behaviours in various situations. Background information for communication partners about the person and their interests, likes and dislikes, can also be included.

Additional reading and resources

- Bloomberg, Johnson & West (2004). InterAACtion Manual.

Communication Support Workers

Just as people who are deaf require an Auslan Interpreter, people with complex communication needs sometimes require a communication support worker to help communicate with people who are unfamiliar with them. This assistance is available in Victoria for some purposes, but is not yet widely available across Australia. People with complex communication needs may identify this need when applying for individualised funding support.

Additional reading and resources

- Collier, McGhie-Richmond and Self (2010). Exploring Communication Assistants as an Option for Increasing Communication Access to Communities for People who use Augmentative Communication.
- Given & Cranko (2013). Communication Support Workers – Helping Us to Connect, Independent Living Journal.
- Communication Rights Australia (2013). Access to justice arrangements for people with a communication disability.

Deaf blindness Communication Supports

Training in use of specialised communication strategies can significantly improve communication for people with deaf blindness. An example in Australia is Ablelink, a project providing e-resources and face-to-face training to support people with deaf blindness and dual-sensory loss.

Additional reading and resources

- Deafblind information, Able Australia, is a webpage with a variety of training resources, including Deafblindness Communication Methods, Able Australia.
- Deafblind information, Senses Australia.

Developmental Social–Pragmatic Model

The Developmental Social–Pragmatic Model uses a naturalistic, developmental approach to intervention. The Developmental Social–Pragmatic Model involves a combination of a developmental model and incidental teaching from an applied behaviour analysis perspective to help children initiate communication and engage in spontaneous communication (Roberts 2004). It also aims to improve social interactions, such as turn-taking (Raising Children Network, accessed on 25 January, 2015).

> *This approach differs from the contemporary ABA approach in its emphasis on sequences of language development and reduced emphasis on eliciting and measuring discrete trial behavioural responses. DSP focuses on successful participation in extended interactions as the measure of success with greater emphasis on enhancing communication abilities within meaningful events and routines. Research indicates there are some advantages to this approach.*
>
> *Roberts (2004).*

DIR®/Floortime™ Model

> *The DIR®/Floortime™ Model is also known as the Developmental, Individual Difference, Relationship-Based Model. It focuses on promoting development by encouraging children to interact with parents and others*

through play. It's thought that this interaction will help children reach milestones in their emotional development.

Raising Children Network, 2014, DIR – Floortime Model webpage

This approach encourages adults interacting with children to follow their lead (Roberts 2004). For children with complex communication needs it is suggested that this approach is implemented in combination with augmentative and alternative communication methods for receptive and/or expressive language.

Ecological Approach / Participation Inventory

An ecological approach involves analysing activities that regularly occur within the environment for people the same age as the person with the disability and working out functional ways to adapt tasks to enable the person with the disability to participate (Rainforth, J. & Macdonald 1992). This approach is used in special education and assists in developing communication goals. It can help to analyse the communication functions needed within the person's activities and environments (Downing 2009).

A Participation Inventory (Beukelman & Mirenda (2013), p111) enables analysis of the person's regular activities across their various environments. It can be used to analyse how independent a person is already, what their needs are and factors that assist or make participation more difficult.

Additional reading and resources

- Downing (2009). Assessment of Early Communication Skills, Chapter 2, pp 32-42, in Soto & Zangari (2009).
- Giangreco, Cloninger & Iverson (2011). Choosing options and accommodations for children: A guide to educational planning for students with disabilities (3rd ed), Baltimore, Paul H Brookes.

Emergency aids

People with complex communication needs can be very vulnerable in times of emergency e.g., medical incident, flood. It is important to plan for these situations in relation to a person's home and other regular environments.

An Emergency Call App was developed in Australia to enable people with complex communication needs to have a means to call, using the functions of their smart phone to enable emergency services to locate them. Another avenue for calling in an emergency is to use the National Relay Service.

Additional reading and resources

- AAC-RERC (n/d-b). Emergency Communication for People Who Have Limited Speech

- AAC-RERC (n/d-a). Disaster Preparedness for People Who Have Limited Speech: Taking Responsibility for Your Safety handout
- National Relay Service (2014a). Calls to Emergency Services - Six ways to contact emergency services.

Facilitated Communication

The International Society of Augmentative and Alternative Communication (ISAAC Ad Hoc Committee on Facilitated Communication, 2014) and Speech Pathology Australia (Speech Pathology Australia 2012) have published guidelines stating that they do not support use of Facilitated Communication, as there is too much evidence of facilitator influence on authorship of messages.

Functional Communication Training

Information about Functional Communication Training is provided in Section 7.7 Functional Communication Training- Behaviours of Concern.

Hanen Programs®

The Hanen Centre® has developed a range of group oriented programs for parents that teach them practical strategies for encouraging their children's learning during everyday activities. The Hanen Programs® most relevant to children with complex communication needs are "It Takes Two to Talk"® and "More Than Words"®. Hanen reflects a family-centred model of early intervention and uses a developmental social-pragmatic approach (Roberts 2004). The Hanen Centre® uses parent training with seminars, video feedback and an adult learning approach to coaching parents to develop their skills (The Hanen Centre®).

Research studies support the underlying approaches to the Hanen Programs® (McConachie et al. 2005; Roberts & Kaiser 2011). A recent study by the Queensland Department of Communities, Disabilities and Community Services supported the use of More Than Words as an effective intervention for children with autism (Adams & Trentepohl 2012).

The Hanen Centre® also has "Allow Me!" which is a book that outlines interactive strategies that help adults with developmental disabilities to engage in communication during daily activities. It addresses a range of communication stages from nonverbal and unintentional to verbal and intentional.

Additional reading and resources

- The Hanen Centre (n/d-a). Hanen Centre – Research Summary: It Takes Two to Talk

- The Hanen Centre (n/d-b). Research Summary: More Than Words® — The Hanen Program® for Parents of Children with Autism Spectrum Disorder.

Intensive Interaction

Intensive Interaction is designed to encourage a person to become aware of interactions with others.. It focuses on following the lead of the individual, finding ways at a basic level of communication to build relationships and work towards expanding the person's early communication skills. Intensive interaction is an approach that can be applied to both children and adults, and is usually used with people who have a severe-profound level of intellectual disability.

> *First and foremost, Intensive Interaction is highly practical. The only equipment needed is a sensitive person to be the interaction partner. The approach works by progressively developing enjoyable and relaxed interaction sequences between the interaction partner and the person doing the learning. These interaction sequences are repeated frequently and gradually grow in duration, complexity and sophistication. As this happens, the fundamentals of communication are gradually rehearsed and learnt in a free-flowing manner. The style of the teacher person is relaxed, non-directive and responsive. In fact, a central principle is that the teacher person builds the content and the flow of the activity by allowing the learner basically to lead and direct, with the teacher responding to and joining-in with the behaviour of the learner.*
>
> *… Much of the development of Intensive interaction was based on reading of the scientific research on the way in which human beings learn to communicate during the first year.*
>
> *Info from Intensive Interaction website: Accessed on 19 January 2015*

Intensive Interaction has been the subject of a number of research studies, since the development of this approach in the early 1990s. It is designed to assist people who are at an "early", "unintentional" or "informal" level of communication. Research has indicated that Intensive Intervention can assist in:

- promoting social contact, improved early and informal communication abilities and 'cuddliness" (Nind 1996)
- increase in student's joint focus, positive affect and interactive involvement, as well as increasing the communicative involvement of the practitioners (Barber 2008)
- promoting social engagement in adults with severe-profound learning disabilities, even for individuals with a long history of social avoidance (Zeedyk, Caldwell & Davies 2009).

Results of a systematic review published online in January 2015 (Hutchinson & Bodicoat 2015) indicated that there have been limitations in these studies, such as the difficulties of conducting research with participants who have a severe-profound level of intellectual disability. A need for more consideration of staff training in interventions was reported. Overall the authors concluded that more research is needed.

Additional reading and resources

- Further information is available at the Intensive Interaction website.
- Hutchinson & Bodicoat (2015). The Effectiveness of Intensive Interaction, A Systematic Literature Review.
- The Hanging Out Program (Forster 2008) is a practical guide for people supporting adults with severe-profound intellectual disabilities
- Goldbart, Chadwick & Buell (2014). Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning disability. *International Journal of Language & Communication Disorders, 49(6),* 687-701

InterAACtion Manual & DVD

This is a practical resource with ideas and strategies found to be effective for functional communication for adults with complex communication needs. The ideas in this manual come from a variety of sources in the literature. The InterAACtion Manual is designed to be used as a training package for disability support workers / communication partners with the accompanying DVD. It can be used with the Triple C Checklist of Communication Competencies. Strategies are related to the person's assessed level of communication.

Reference

- Bloomberg, Johnson & West (2004). InterAACtion: Strategies for Intentional and Unintentional Communicators, Scope Victoria.

Mobile Devices and Communication Apps

Mobile devices, such as smart phones and tablets, have shifted the ground in making augmentative and alternative communication much more widely available and more socially acceptable for individuals with complex communication needs and the wider community (McNaughton & Light 2013).

It is important to know about the range of options and to provide advice about choices that best meet people's communication needs. A smart phone or tablet device will not be a suitable solution for everyone.

Smaller and larger mobile devices are now available and there are a range of built in accessibility options. There are different platforms with different

devices. It is important to ensure that software purchased is compatible with the device.

Some people might be overwhelmed by a smart phone or tablet device and have various operational issues in navigating pages. It is possible to 'lock' a mobile device so it can be used only as a communication device. Some individuals choose to have one tablet for communication and other dedicated or non dedicated mobile devices for other purposes.

It is not necessary to be literate to use a 'smart' tablet. Many apps are designed for people with severe cognitive impairments. Some people will be able to use a device when it is set up to suit them which may include use of specialised interfaces. Tablets can provide a means to access online social media such as Facebook, Twitter, to watch YouTube, to download movie and games and to take and store photos.

There are many communication apps for people with complex communication needs. Since 2010 there has been an important paradigm shift towards use of communication apps on iPads (AAC-RERC 2012). Comprehensive communication apps are most widely available for the iPad, however there are some communication apps available for Android and Windows tablets and this is likely to increase in the future (Harraway & Lo 2011; Korner 2013).

When deciding on a suitable app, it is suggested that the person with complex communication needs should have an opportunity to use the app before purchasing it e.g. trialing a free 'lite' version. The speech pathologist can also do research online to find out about apps and compare features.

Communication apps can be described as symbol / picture systems ; symbol / text systems and text systems (Farrall 2014), accessed 2 February, 2015), where many apps combine features to varying degrees. Some apps can be used with photos with visual scene capabilities. Another aspect to consider is whether communication apps enable connectivity online to SMS, email and social media.

Additional resources

- Everyone Connects is a project of the Independent Living Centre NSW in partnership with the Telstra Foundation.
- McNaughton & Light (2013). The iPad and Mobile Technology Revolution: Benefits and Challenges for Individuals who require Augmentative and Alternative Communication, *Augmentative and Alternative Communication Journal*, 29 (2), 107-116.

Literacy

Literacy is an essential skill for people with complex communication needs. If you can spell, you can say whatever you want..

> *David (Koppenhaver) and Karen (Erickson) highlighted to us that most competent AAC users, will spell out 50% of their messages, and for the other 50% they may rely on symbols, whole words and pre-programmed phrases. As therapists, this tells us that we need to be equally focused on literacy and language development.*
>
> *Kelly Moore, reporting on the 2014 Literacy Intensive*

Literacy needs to be a priority for people with complex communication needs.

> *As therapists, we are often considered to be one of the earliest educators for children with disabilities. Are we building early goals to support emergent literacy considering its close link with communication? As planners, coordinators and support workers, we play a part in supporting adults with disabilities in their personal goal setting. Is further development of literacy being considered a potential goal? When it comes to literacy … it's never too early and it's never too late to start to develop these skills which just might lead to increased independence. Acquisition of literacy skills is within reach for all!*
>
> *Kelly Moore, reporting on the 2014 Literacy Intensive*

Four Blocks is an evidence based comprehensive approach to literacy development that has had success in the USA and Australia with people who have complex communication needs. The Literacy for All Inclusive Learning Technologies Conference 2012 presentation by Jane Farrall and Chris Lennon provided further information about the Four Blocks approach and useful links.

Reading resources can be produced using Tar Heel Reader. This is a collection of free, easy-to-read, and accessible books on a wide range of topics. Each book can be speech enabled and accessed using multiple interfaces, including touch screens, the IntelliKeys with custom overlays, and 1 to 3 switches. Clinicians and teachers can create their own resources to make age appropriate materials that can assist people of any age and any level of ability to learn to read.

People with complex communication needs may require alternative methods to learn to write. Software such as Co-Writer or Texthelp, with predictive text to make writing faster for people with physical disabilities and learning disabilities, are available. It is important that speech pathologists work closely with educators to ensure that people with complex communication needs have the appropriate learning programs and tools needed to develop and use their literacy skills. This will enable students to access their curriculum effectively at school and to develop the skills they will need to be literate adults.

Vision impairments also need to be considered when teaching literacy skills. Instruction may involve alternative methods for presentation of text including use of high contrast large text, backlighting and braille. For people who have multiple disabilities, consider the students' capacity to feel braille or textures, when selecting alternative methods for developing literacy and language.

Vision needs to be assessed to determine if it is contributing to difficulties with reading and writing.

Additional reading and resources

- Center for Literacy and Disability Studies website
- Daves Literacy and Disability Site Soto & Zangari (2009)
- Soto & C. Zangari (Eds.), *Practically speaking: Language, literacy, and academic development for students with AAC needs* (pp. 47–70). Baltimore, MD: Paul H. Brookes
- Quantum Reading Learning Vision – provides devices and software to assist with reading, vision impairment and software for people with learning and reading disabilities.

Marte Meo

Marte Meo is a developmental support program founded by Maria Aarts in the Netherlands (Baeriswyl-Rouiller 2012). The program aims to identify and develop interactional and developmental skills between children, parents, professional caregivers and supervisors, using video analysis and discussion.

A pilot study was carried out by ADHC in NSW in 2009 to promote the capacity and resilience of those who support people with disabilities, including families and group home staff. The project demonstrated application of distance support for families in isolated rural regions.

Picture Exchange Communication System (PECS)

The Picture Exchange Communication System (PECS) was developed by Bondy and Frost in 1985 (PECS Australia website). PECS is a structured applied behaviour analysis program:

> *The PECS teaching protocol is based on B.F. Skinner's book, Verbal Behavior, such that functional verbal operants are systematically taught using prompting and reinforcement strategies that will lead to independent communication. Verbal prompts are not used, thus building immediate initiation and avoiding prompt dependency.*
>
> PECS Australia website*, accessed 26 January 2015*

PECS was designed as a structured method of teaching early communication skills using a verbal prompt-free method, to encourage children with autism and severe intellectual disability to initiate communication. It has been the subject of many research studies; there are a number of systematic reviews and a meta-analysis available (Ganz et al. 2012; Preston & Carter 2009; Prior et al. 2011; Sulzer-Azaroff et al. 2009). These do not all reach the same conclusions, however, overall there is evidence of PECS being a promising intervention (Preston & Carter 2009).

PECS can be a useful strategy for developing early functional communication skills for a range of beginning communicators (Beukelman & Mirenda (2013), p295). Some people who learn PECS go on to develop speech as an outcome of the intervention. However, this is not the case for others (Charlop-Christy et al. 2002; Sulzer-Azaroff et al. 2009).

PECS has limitations as the intervention focuses on requesting with a very structured approach to learning discrimination skills. In many of the research studies participants did not progress through all the levels (Sulzer-Azaroff et al. 2009).

Positive Behaviour Support

Information about Positive Behaviour Support is provided in Section 7.2.

Pragmatic Organisation Dynamic Display (PODD)

PODD (Porter 2007) is a comprehensive system for developing language and was developed in Australia. PODD can be used as a method for developing receptive language and expressive language skills. PODD provides a consistent framework to develop language from the earliest level right through to adult complex language forms (Porter & Cafiero 2009; Porter & Cameron 2007).

Direct access low tech and high tech versions are commercially available. Alternative access versions can be made and commercial resources are currently in development. PODD can be adapted for people with the most severe physical, vision and hearing disabilities.

PODD was developed over many years as a system that translated research into practice (Sennott et al. 2010). The development of PODD communication systems has drawn widely from the evidence base in augmentative and alternative communication (Porter 2007), combined with improvements to design from the feedback of families and people with complex communication needs and from consistent use by clinicians with consumers.

PODD templates have been translated into other languages and implemented in countries such as Norway, Sweden and Finland, France and Germany, as well as the UK, USA and Australia.

PODD was described as a promising practice on the ASHA website (Mirenda 2009) and was included in the recent edition of Beukelman and Mirenda (2013).

PODD has a strong level of social validity, although there is need for more formal research.

Additional reading and resources

- Korner (2011). What is PODD? Pragmatic Organisation Dynamic Display Communication Books, Independent Living Journal, 27, 2, 4-7.
- PODD Communication Books, Novita website
- PODD Information, Linda Burkhart's website

Sensory based intervention

Early indications suggest a significant proportion of with people with disability may have sensory processing issues. They may have reduced sensitivity to sensory stimuli (hyposensitive) or may be over sensitive to sensory stimuli (hypersensitive). However, more high level evidence is required to understand the incidence of sensory processing problems (Clinical Innovation and Governance 2014d).

Occupational therapists will be the team member responsible for providing assessment and intervention for sensory processing difficulties. There is a range of sensory based interventions that an occupational therapist might employ to assist people with a disability to increase their function and participation in daily life. The Sensory Processing Core Standard (Clinical Innovation and Governance 2014d) summarises the research into the effectiveness of these interventions.

Sequenced social scripts

Sequenced social scripts (Farrall 2011a; Musselwhite & Burkhart 2001) provide ways to structure a conversation to increase an individual's participation, through an enhanced understanding of how to begin, maintain and finish a conversation. This can assist with face to face and online communications.

Signing, Key Word Sign and Gestures

Signing and gestures may be part of a multi-modal approach with reliance on other modes while for some people signing may be the main form of symbolic communication that they use. There are a number of different approaches to signing. The approach selected will depend on the needs of the individual and with consideration of their environments and the skills of their communication partners.

When introducing signing to a young child it is essential to create a signing environment. Familiar communication partners need to learn how to incorporate sign and gestures into their own communication, to provide a rich sign language model. Research has found that signing is sometimes associated with increases in vocalisations and speech (Millar, Light & Schlosser 2006).

Speech pathologists and others working with the person with complex communication needs will need to learn the person's system of communication. During initial sessions there may be a need to have a sign interpreter / communication support worker to assist communication.

1. Auslan / Natural Sign Language

In Australia, the natural sign language of the deaf community is Auslan. In other countries other sign languages are used. Sign languages have their own grammatical rules (Johnston & Schembri 2007). Some people with complex communication needs will use Auslan as their language e.g. if they have a severe – profound hearing impairment. Auslan courses are available through TAFE.

Additional reading and resources

- Auslan Signbank is a language resources website for Auslan (Australian Sign Language) and can be used as a resource to learn signs that a person may need to learn.
- Johnston (1998)*Signs of Australia: A New Dictionary of Auslan*. North Rocks, N.S.W.: North Rocks Press.
- Johnston T., & Schembri, A. (2007). *Australian Sign Language (Auslan): An introduction to sign language linguistics.* Cambridge: Cambridge University Press.
- Conexu aims to build a connected and inclusive community for people with hearing impairment and communication impairment.

2. Fingerspelling

Fingerspelling is an important component of signing. There is an Auslan fingerspelling alphabet that is usually used, although this requires use of two hands. The American fingerspelling alphabet is mostly one handed and is sometimes adapted and used in Australia by people who have a hemiplegia and have better manual dexterity in one of their hands. Even if a person is not literate, they may use signs for single letters. For example, a sign for a person may be the first letter of a person's name; some signs involve signing letters, such as "TV".

3. Gestures

As gestures are an important part of everyone's communication, the development of gestural communication is important for people with complex communication needs at all stages from an emerging level of communication up to complete independence (Blackstone & Hunt Berg 2003, updated 2012).

4. Key Word Sign and Gestures

Key Word Sign is the use of manual signs and natural gesture to support communication. Key Word Sign is used to encourage and support language development in children and adults with communication difficulties (Key Word Sign Australia website). Key Word Sign was originally based on Makaton. Key Word Sign Australia coordinates training activities nationally and there are also state-based Key Word Sign not-for-profit organisations.

> *The main principles of Key Word Sign are:*
>
> - *Always use speech together with the sign*
> - *Speak in normal, grammatical sentences*
> - *Sign only the key words in the sentence*
> - *Use facial expression and body language to help support your message.*
>
> *Caithness, Brownlie & Bloomberg (2012)*

Additional reading and resources

- Bloomberg (2014). The Story of Key Word Sign in Australia
- Caithness, Brownlie & Bloomberg (2012). *Getting Started With Key Word Sign.* Newcastle, NSW,: Key Word Sign Australia.
- Bloomberg (2013). Using Your Hands To Talk
- Key Word Sign NSW website.

5. Idiosyncratic Signs and Gestures

There are many reasons why a person may develop their own idiosyncratic signs and gestures. This may occur when:

- signs are too difficult for a person's physical abilities and the sign is adapted
- a movement is recognised as having a specific meaning, so the person starts to use it more intentionally and it becomes a regular part of their communication
- a person uses whatever movements they are able to make.

Idiosyncratic gestures may be very slight and subtle movements, such as a flick of the eye looking up to indicate 'yes' and a brief glance down to indicate 'no'.

Communication partners need to be familiar with idiosyncratic signs and gestures, so they can respond consistently, enabling the person to communicate.

Sign and gesture dictionaries can be created in book form, or as multimedia resources, to assist those who live or work with a person to learn their repertoire of signs and gestures.

More conventional signs and gestures can modelled to the person by communication partners to assist receptive language learning.

Additional reading

- Caithness & Potts (2003). Modification of Sign for Individual with Complex Needs, *AGOSCI News*, 22 (2), 20-24.

6. Signed English

Signed English was developed by teachers of the deaf to teach literacy skills to people who are deaf (Johnston & Schembri 2007) (Deaf Australia Inc. n/d). Signs used in Signed English were mostly taken from Auslan. Some signs are different to Auslan due to historical influences and some signs were invented when no Auslan sign existed for a concept or to provide signs for grammatical markers. It is no longer widely used, but it provides a useful resource, when there is a need to further develop language skills including syntax and grammar. This may assist a person to learn their curriculum at school and with further learning as adults.

Additional reading and resources

- The Auslan Shop — Deaf Australia Inc. resources.

Small Talk

Small talk (Farrall 2009; King et al. 1995) is a strategy that can increase success in maintaining social closeness. Learning how to use “small talk” can allow people to use a relatively small vocabulary to participate more frequently and equally in conversations. Examples of small talk are phrases such as ‘Okay; Good; Hmm; Yeah; Really; Cool; I don’t know; All right; You know; Sure; Thank you’. Small talk varies depending on the age of the person, the person’s cultural background and the situation.

Additional reading and resources

- Farrall (2011b). Small talk, gossip and tall stories: Using AAC socially - workshop notes.

Social Communication, Emotional Regulation and Transactional Support (SCERTS)

The SCERTS model (Prizant et al. 2003) includes consideration of:

- social-communication, including joint attention, communicative intent, communication functions
- emotional regulation, including self-regulation and mutual regulation

- sensory integration therapy, environmental adaptations and supports
- motor planning for daily living skills
- transactional support, including educating and training family members.

The emphasis is on communication, social relatedness, sensory characteristics and family centred practices that reflect acknowledged 'best practices' in contemporary literature on autism (Dawson & Osterling, 1997) ….the SCERTS program draws on the child's developmental strengths and natural motivations to address areas of weakness.

Roberts (2004), p53.

Social Media

Recent research has confirmed that people with complex communication needs have a strong desire to use online social media and that it is beneficial in strengthening relationships, friendships and social inclusion for people with complex communication needs.

The data presented here are part of a larger study, and the findings within this article suggest that participants have a desire to use the internet and online social media as it is perceived to increase opportunities for self determination and self-representation while enriching friendships. The wide diversity of literacy and language skills among participants, as well as accessibility challenges, mean collaborating with others and receiving technical support from educational settings, families and friends are vital.

Hynan, Murray & Goldbart (2014).

Research and feedback from individuals with complex communication needs (Cranko, G. and Given, F. in personal communications, AAC Voice) highlights that online communication, using social media and email, can assist in alleviating turn-taking challenges and reducing the time pressures of face-to-face conversations (Sundqvist and Ronnberg 2010, cited in Hynan, Murray & Goldbart (2014)).

There are options for accessing social media and the internet using symbol based software for people who have not developed literacy skills. There is also a range of accessibility options to assist people with physical and sensory challenges. A barrier to accessing these options can be insufficient services to support set up of assistive technology (Hynan, Murray & Goldbart 2014).

Information and training to strengthen digital literacy is important when assisting people with complex communication needs to use social media. Materials to support cybersafety are available for people with complex communication needs.

Additional reading and resources

- Chedid & Lim (2014). It's a Digital World We Live In – Guide to Digital Literacy and Social Media, Independent Living Journal, 29 (4), 24 – 26.
- Media Access Social Media For People with a Disability handouts.
- Cybersmart ACMA website.

Speech Generating Devices

Speech pathologists can help people with complex communication needs to be actively involved in their selection of communication devices that meet their needs within their various environments (National Disability Insurance Agency (NDIA) 2014a).

Variations in devices include:

- simple single item voice output communication aids, with recorded messages
- rugged devices that can be used with photos or symbols that can take a lot of wear and tear
- rugged devices that require spelling
- sophisticated dynamic display devices with touchscreens, that provide comprehensive language and literacy tools for communication in many environments
- additional features such as connectivity to the internet and environmental control.

For people with complex communication needs, where access has been a difficult issue in the past, new options may become available, that will make it easier for them to use speech generating devices in the future. An example is eye-gaze technology, which has become more affordable and reliable over the past few years. It is important that people revisit their needs as they get older, to ensure they have an efficient set of communication tools to meet their needs.

It is important to be aware of the time and effort required to learn to use speech generating devices. Low technology options need to be available as well as high tech options. Non-electronic communication aids are often easier to use in the early stages of learning, as communication partners can provide support and assistance in a more flexible way than a device (Porter 2007). High tech devices have many operational requirements. Learning to use a speech generating device is often a long-term undertaking and may require sustained effort over a number of years.

Assessment services are available in most states of Australia at a cost. Assistive technology suppliers can also provide equipment for trial.

Advice is available from Independent Living Centres across Australia – these not-for-profit services do not sell devices, so their information is independent of commercial considerations.

Additional reading and resources

- Augmentative and Alternative Practice Guide.
- Enable NSW Communication Assistive Technology Clinical Criteria provide practical advice for issues related to selection of blindness and low vision communication related products, environmental control and computer access equipment, speech generating devices and voice related devices.
- Assistive Technology Guide : Communications and Telecommunications - Choosing Your Device, Independent Living Centre NSW, is a handout written in Easy English to inform people with complex communication needs and their family, carers and other communication partners about communication assistive technology.
- Independent Living Centres Australia.
- Australian Rehabilitation and Assistive Technology Association (ARATA).
- AGOSCI.
- ISAAC – Australia and ISAAC International.
- Communication Matters.

Storytelling

Learning strategies for storytelling can enable people with complex communication needs to participate in extended conversations and to learn to "hold the floor" and take charge of the conversation. It is also a very important element to cultural sharing of information and developing friendships and social closeness. There are many resources and research efforts in this area of practice for both children and adults.

Additional reading and resources

- Grove (2013). Using Storytelling to Support Children and Adults with Special Needs. Transforming Lives Through Telling Tales.
- Storytellers website, based on Nicola Grove's work.

Symbol Systems

Symbols should be selected that will enable a person to:

- communicate as effectively and efficiently as possible
- represent a variety of communication functions to learn receptive language
- have a means of expression
- be quick to make and easily reproducible.

There are many commercially available symbol sets. The following list is intended to be used as a guide only and it is recommended that speech pathologists select a symbol set that best suits the needs of the individual they are supporting. Some commercially available symbol sets include:

- Picture Communication Symbols (Boardmaker software, Mayer-Johnson).
- SymbolStix — often used in communication software and apps.
- Compic – developed in Australia, designed to be acceptable for adults and children, following international symbol conventions.
- Softpics and Fantasticpics – also developed in Australia.
- Pixons – developed as low tech resources to assist learning minspeak icons.
- Commercially available sets of photos are also available. When creating photos, it is important to make them as clear as possible e.g. high contrast between the main item and the background.
- Objects and tangible symbols need to be custom-made. These can include remnants, which can be associated with an activity or an object.

Although much time has been spent by researchers studying the iconicity of symbols, it appears that the most important factor in determining symbol learning is motivation. If a symbol represents a highly motivating concept, it will be easier to learn (Namy, Campbell & Tomasello 2004).

People with severe–profound intellectual disability do not need to progress through a symbol hierarchy (Porter & Burkhart 2010; Romski & Sevcik 2005). Symbols that can be perceived will be easier to learn if they are used for authentic communication (real purposes) and where there is intrinsic motivation.

For people who are at a very early level of communication, it is important that communication partners respond to their behaviours as if they were meaningful to assist in the development of intentional communication (Johnson et al. 2012). This can include communication partners saying the words a person indicates on a communication display, even when they are not sure if the person “meant” to point to it. By interpreting the selection of an item, saying what it is and acting on it, the person has opportunities to learn that their behaviour has an effect on the communication partner. Skilled communication partners use these opportunities to check back to see if their interpretation does seem to be appropriate by observing the reactions and responses of the person with severe-profound intellectual disability. This co-construction is a vital part of the language learning process.

It will be natural for people to use a range of different symbols within their home and community environments, including real objects, photos, pictures, whole words and text. In typical development, children have opportunities to explore sounds and letters, to help build up their idea of what these are long before they learn to speak or spell. In relation to both communication and

literacy, people with complex communication needs require opportunities for learning before they can be expected to use symbols of any kind for expressive use (Erickson & Clendon 2009).

Additional resources and reading

- Porter & Burkhart (2010). Limitations with using a Representational Hierarchy Approach for Language Learning.
- Romski & Sevcik (2005). Augmentative Communication and Early Intervention Myths and Realities.
- Symbol Set Comparison, Spectronics blog, for additional information on symbol sets.

Talking Mats

Talking Mats are a way to structure a conversation and talk about a topic. They provide a visual framework that uses picture symbols to help people with a communication difficulty. They are available as a low tech resource and a Talking Mats app is available on the iPad. They can provide a practical way to apply person centred decision making (Murphy & Boa 2012).

> *The Talking Mats framework is a low-tech communication system that was originally developed at the University of Stirling (UK) to support people with cerebral palsy who used high tech systems. It was designed to help people with communication difficulties of different ages and abilities to express their views about specific topics or issues. It comprises a low-priced textured mat and picture symbols with Velcro attached to the back so that they can be placed on the mat and moved around by the person with communication difficulties to reflect his or her views. Any symbol system can be used; throughout this study, we used three sets of Picture Communication Symbols (PCS):*
>
> - *Topic: whatever participants want to talk about in relation to a specific issue (e.g. activities, environment, relationships, self care)*
> - *Options: relating specifically to each topic (e.g. options, relating to activities might be listening to music, playing card games visiting friends); and*
> - *Visual scale, in order to allow participants to indicate their general feelings about each topic and option (e.g. whether they are happy, unsure, unhappy).*
>
> *Murphy & Boa (2012), p53.*

Research studies have demonstrated the effectiveness of Talking Mats with people who have an intellectual disability (Murphy & Cameron 2008),

people with dementia (Murphy et al. 2010), as well as with a range of acquired communication disabilities.

Additional reading and resources

- Talking Mats website, includes a comprehensive list of research publications and practical resources.

Telecommunications

Telecommunications are a vital part of everyday communication, yet for many people with complex communication needs access to telecommunications is often restricted.

There are a range of phone options for people with complex communication needs.

Specialised landlines are available for people with a hearing impairment and speech impairment e.g. teletypewriters (TTYs), phones with large buttons and picture/ photo dialing for people with physical, hearing, vision or cognitive impairments.

Innovations with smart phones and tablets over the past few years have opened up options, with touch screens and new alternative access options making it easier for people with complex communication needs to use phones via SMS messaging, email or Skype, when alternatives to voice calls are required. Mainstream computers can also be used for a wide variety of telecommunications.

The National Relay Service is an Australia-wide phone service for people who are deaf, have a hearing impairment or a speech impairment. It is a service for anyone who wants to call a person with a hearing or speech impairment. There is no cost for using the National Relay Service – it is one way the Australian Government meets it's obligations to provide equal communications services for all.

People with complex communication needs, just like others in the community, may need assistance to become digitally literate and to avoid the pitfalls of telecommunications, such as bill shock and the need to be aware of cybersafety issues. The Phone Rights App was produced by ACCAN to assist people to manage their telecommunications.

For people with complex communication needs, phones can also provide a backup means of communication, where they may be quicker to access or a preferred option to low tech boards, when brief communication is needed.

Additional reading and resources

- Australian Communications Consumer Action Network (ACCAN).

- Jeenee Mobile is a not for profit mobile phone service is designed to support people with complex communication needs.
- National Relay Service website and National Relay Service app.

Video Interaction Guidance

Video Interaction Guidance (VIG) (Kennedy & Landor 2012), is a strengths-based approach, using adult learning principles, where communication partners analyse short video clips taken during normal interactions with a person who has a communication disability, to identify moments when their interactions are more successful. The Video Interaction Guide is trained to coach the person in analysing the videos, helping the family member or carer to review the video and find what is helping.

> *Video Interaction Guidance™ is an intervention through which a practitioner uses video clips of authentic situations to enhance communication within relationships. It works by engaging clients actively in a process of change towards realizing their own hopes for a better future in their relationships with others who are important to them.*
>
> *Association for Video Interaction Guidance UK, website.*

This technique was originally developed by psychologists, with applications related to counselling for anxiety, attachment and autism. Kennedy & Landor (2012), p27.

Video Interaction Guidance has been successfully applied for people with complex communication needs, including people with severe–profound intellectual disability, to increase positive communications and enhance interactions (Forster 2014).

> *VIG can be used in many different situations. I use VIG with families and support workers who support people with very severe interaction difficulties, such as people with profound intellectual and multiple disabilities, autism, or Down syndrome and dementia. It can be used to help enhance the interactions, and put into words the qualities of interactions that best enable the person with a disability.*
>
> *Sheridan Forster website, accessed 3 February 2015.*

Additional reading and resources

- Forster (2014). What is Video Interaction Guidance (VIG)? Information sheet.
- Association for Video Interaction Guidance UK.
- What is Video Interaction Guidance?

Visual Supports

Visual supports are things that can be seen that support the communication process. They include picture based timetables, routine boards, choice making displays, first/ then strategies, contingency maps and social stories. Use of visual supports to enhance a person's participation within their environment is supported by research and practice (Beukelman & Mirenda 2013; Mirenda & Iacono 2009).

Speech pathologists can assist in gathering information to develop visual supports, including daily schedules, timetables and routines for individual activities (Bopp, Brown & Mirenda 2004). When developing visual routines, activity analysis can be used to work out the steps involved in carrying out an activity and the vocabulary and concepts required. (Bloom & Treloar 1997, updated 2003; Bloomberg, Johnson & West 2004; Hodgdon 1995, revised and updated 2011; NSW Department of School Education 1991).

Additional reading and resources

- Bhargava, D. (2008). Getting Started!!! Using visual systems to promote communication.
- Center for Community Inclusion and Disability Studies. Resources Across the Lifespan - Visual Supports Learning Links and Templates.
- Shane, et al (2015). Enhancing Communication for Individuals with Autism - A Guide to the Visual Immersion System.

Virtual Worlds

Virtual worlds are computer-based simulated environments, where multiple users can interact and communicate with each other using their avatars. An avatar is a digital representation of a real person, often in 3D. Inhabiting a virtual world enables people with to take part in virtual activities, providing experiences they may not be able to enjoy in the real world. Virtual worlds can be modeled on real or fantasy worlds. Avators are able to communicate with each other through the virtual world.

Research has demonstrated that people with lifelong disabilities, including people with complex communication needs, can gain independence and improved social participation and emotional well-being through virtual worlds (Stendal 2013). Virtual worlds can provide an environment for learning new skills that can then be applied to the real world. Balandin (2012) reported that virtual worlds made the most impact for people who could access them independently. Not all participants could take advantage of virtual worlds in the same way; some people require more training and support to access virtual worlds and require ongoing assistance. As with other areas of online

communication, it is important for people entering virtual worlds to have digital literacy skills and to maintain their cybersafety.

Additional reading and resources

- Stendal et al. (2013). Social Affordances for People with Lifelong Disability Through using Virtual Worlds. 2013 46th Hawaii International Conference on System Sciences.
- Balandin (2012) Virtual Worlds – A new tool? Keynote address, ASID Conference 2012.

Yes / No

Having a way to say 'Yes' and 'No' is very important for people with complex communication needs both in relation to answering questions in conversation and as a means for using a communication system to select and confirm messages.

Teaching 'Yes' and 'No' is often a focus of intervention quite early on and interventions can get stuck on this concept. However, sometimes the skills involved in saying 'Yes' and 'No' are not always fully considered.

> *"No" can be used to reject, protest, ask for things to stop, comment on things being absent, gone, missing (e.g. no doll), to deny, to disagree. "Yes" can be used to accept, consent, agree, affirm.*
>
> *Children are able to reject, protest and accept before they are able to use the words "yes" and "no". Parents often know whether their child likes or wants something by her facial expression, cries, happy noises, attention and general body movements (e.g. pushes away, reaches for, becomes quiet, starts to move, etc) …*
>
> *…Children usually learn to use the word "no" to reject and protest before they learn to use "yes". When young children accept something they often just take it, do it, or point towards it, rather than saying "yes".*
>
> *Learning to use words for "No" and "Yes" allows a child to be more specific and the person she is communicating with to feel more confident that she has understood the message. However, there are many other reasons we communicate and a child needs to learn ways of communicating to express many meanings, not just "yes" and "no". Relying on using lots of questions that can be answered with "yes" and "no" has many limitations. E.g. the child has to wait to be asked what she things and has no control over the topic or the choice she can make. Relying on "yes" and "no" can place the child in a very passive role, limiting her options to those thought of by the person communicating with her.*
>
> *Learning to say "Yes" and "No", 1998, in Porter (1998)in Porter (2001).*

If a child or adult does not have a clear "Yes" and "No", then facial expression and body language can indicate their responses in relation to accepting,

rejecting and protesting. It is important to move from reliance on a “smile” for “Yes”. There will be times when a person needs to answer “yes” about something that is “sad”. In these situations, a “smile” is incongruous with meaning associated with “Yes”.

When getting to know a person with complex communication needs, it is very important to know how the person indicates “Yes” and “No” to assist clear communication. Some examples include:

- using a head nod for “Yes” and a head shake for “No”
- looking to one side for “Yes” and to the other side for “No”
- glancing up for “Yes” and down for “No”
- moving one hand for “Yes” and the other hand for “No”
- touching “Yes” and “No” symbols on a tray.

It is essential that a “Yes” and “No” response is clear and easy for communication partners to read. It should not be too fatiguing. It also needs to be able to occur at any time, so it is preferable that it does not rely on looking or touching items on a display as; there will be times when the display is unavailable.

If a response is very idiosyncratic, communication partners can easily get confused. A common problem is when different responses are encouraged in different environments, leading to a person’s “yes” and “no” response being inconsistent.

Yes / No – Additional Considerations when using in conversation

Any system that includes 'yes' and 'no' should have an option for not responding or 'other' e.g., 'I don't know’, ‘ask me later', 'ask that again'. This is because “Yes” and “No” may not always be what the person wants to say. It is essential that people can express when they don’t know the answer, or when they want to change the topic. Closed questions which only allow for a “Yes/No” response can limit the person with complex communication needs to being in a passive role in the conversation.

Using a systematic approach to asking “Yes/No” questions can be an important adjunct to a person’s communication system. Communication partners have an important role and need to think carefully about the form of their yes/no question.

Tips are:

- Provide a way to indicate 'yes', 'no', ‘I don’t know’ and ‘other’/ ‘something else.’

- When asking a yes/no question, do NOT use the word 'OR' in the question. Do not provide a 'choice' in a yes/no question – ask one thing at a time and wait for a response.
- Examples of suitable yes/no questions: Do you have any money? Do you want cake?

Additional reading and resources

- Porter (1998). Learning to say “Yes” and No”, in Porter (2001), Students with Physical Impairments – Augmentative and Alternative Communication, Professional Development Module, Queensland Department of Education.