



Communication and Behaviour Support for Nurses - Practice Package

Summary: This package has been designed to provide information on the Communication and Behaviour Support for Nurses that guides nurses when working with people with disability in order to promote consistent and efficient best practice.



Document approval

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1. INTRODUCTION

1.1 Introduction and purpose

Welcome to the Communication and Behaviour Support for Nurses practice package. This resource was developed by Clinical Innovation and Governance, within Ageing, Disability and Home Care, Department of Family and Community Services, New South Wales, Australia (FACS).

This practice package has been developed to support nurses who are working with people and their families who support people with a disability. It has been designed to provide information on the Communication and Behaviour Support for Nurses that guides nurses when working with people with disability in order to promote consistent and efficient best practice. It outlines current principles around good practice in the Communication and Behaviour Support for Nurses. This practice package is designed to complement organisation policies and procedures, rather than replace them.

This practice package can be used in a number of different ways:

- As a basis for self directed learning
- As part of core standards learning
- For reference and clarification
- For part of the induction of new staff
- In conjunction with professional supervision
- With student nurses in placements
- With other professions and disciplines

This practice package forms part of the supporting resource material for the [core standards program](#) developed by Clinical Innovation and Governance. Please note that the information contained in this package is specific to all nurses working with people with a disability in New South Wales, Australia.

1.2 Common core standards

FACS has developed four practice packages that support the common core standards for nurses who provide support to people with a disability. These are located on the FACS/[ADHC website](#).

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

- Professional Supervision
- The Working Alliance
- Intellectual Disability: Philosophy, Values and Beliefs
- Service Delivery Approaches.

1.2.1 Nursing and Health Care Practice Packages

The following Nursing and Health Care practice packages have been organised according to the order they should be read. The information is further organised according to domains of practice within those standards as follows:

- **Person-Centred Health Care Assessments and the Development of Health Care Plans Practice Package**
 - Health Assessment
 - Health Planning
- **Communication and Behaviour Support Practice Package**
 - Communication
 - Behaviour Support
- **Working with People with Chronic and Complex Health Care Needs Practice Package**
 - Health Care and Support
 - Teaching and Coaching
 - Advocacy and Co-ordination
 - Education, Research and Evaluation
- **Mealtime Management Practice Package for Nurses**
 - Nutrition for Health and Wellbeing
 - Managing Dysphagia
 - Enteral Nutrition

These core standards represent fundamental areas of knowledge, skills and attitudes required by Registered and Enrolled Nurses when working with people with disability, their families and carers. The standards are not intended to restrict practice nor imply boundaries. Rather, they are intended to enhance core skills that underpin practice. Information presented in this practice package provides access to key information and resources thus contributing to FACS's knowledge translation program.

The Nursing and Health Care Core Standards are intended to provide information that is particularly useful to Registered and Enrolled Nurses new to the area of practice in disability. These may include:

- FACS staff
- NSW Health staff
- non-government agency staff (NGO)
- practice nurses working with GPs
- nurses working in specialist clinics
- private agency staff
- nursing students.

Practice contexts include:

- family homes
- general practitioner surgeries (GPs)
- residential/accommodation services
- community health services
- specialist teams
- hospitals
- nursing homes.

1.3 Copyright

The content of this package has been developed by drawing from a range of resources and people. The developers of this package have endeavoured to acknowledge the source of the information provided in this package. The package also has a number of hyperlinks to documents and internet sites. Please be mindful of copyright laws when accessing and utilising 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 package has been developed for support nurses who are working with people with a disability. It has been designed to promote consistent and efficient best practice. It forms part of the supporting resource material for the Core Standards Program developed by FACS.

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

Access to this document for nurses working outside of FACS has been provided in the interests of sharing resources. Reproduction of this document is subject to copyright and permission. Please refer to the website disclaimer for more details.

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

Whilst the information contained in this practice package 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 does not accept any liability to any person for the information (or the use of such information) which is provided in this practice package or incorporated into it by reference.

2. The Definition of Disability

In order to understand how the conceptualisation of disability has changed, it is first important to define what disability is.

[The Disability Discrimination Act 1992](#) (Australasian Legal Information Institute, 2010) defines disability as:

- total or partial loss of the person's bodily or mental functions
- total or partial loss of a part of the body
- the presence in the body of organisms causing disease or illness
- the malfunction, malformation or disfigurement of a part of the person's body
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction
- a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment, or that results in disturbed behaviour and includes a disability that:
 - presently exists
 - previously existed but no longer exists
 - may exist in the future
 - is imputed to a person (meaning it is thought or implied that the person has disability but does not). (AustLII, 2010)

Please note that the target group of people with disability is under review in the Disability Inclusion Bill (2014).

There are many different causes of disability for example accidents, illness or genetic disorders. A disability may affect a person's movement, their ability to learn, or their ability to communicate. Some people have more than one disability. Although some people are born with disability, many people acquire a disability. Not all disabilities are permanent and conditions which cause disability increase with age (Australian Network on Disability, 2013).

2.1 The definition of intellectual disability

A person has an intellectual disability if they have the following:

1. An IQ that is 2 standard deviations (SD) below the mean (approx. 70, as average IQ is 100 and the SD is 15) and:
2. A significant deficit in at least one area of the following domains of adaptive functioning:
 - conceptual domain- reading writing, reasoning and knowledge
 - social domain – empathy, social judgement and making friendships
 - practical domain – personal care, daily living skills.
3. These problems must be manifest in the developmental period.
(American Psychiatric Association, 2013)

Based on the functional deficits, intellectual disability can be mild, moderate or severe and factors such as personality, coping strategies and the presence of other disabilities (motor, social or sensory) will influence a person's requirement for support with daily living.

(Centre for Developmental Disability Health, 2013)

3. Communication and Behaviour Support

Communication and behaviour support are addressed together as a Nursing Core Standard because of the links between communication and people's behaviour. There is ample evidence to support a significant link between communication difficulties and challenging behaviour.

3.1 Communication

Communication is an interactive process between two or more people. It is usually described as the exchange of information, ideas or meanings between people. For this exchange to occur, we need to be able to **express** (send) and **receive** messages using a shared system of symbols, signs and behaviour.

Information and ideas are usually exchanged in language which may be in:

- words – spoken, written, signed
- pictures

These are symbols for the actual information and ideas. For example, the word 'truck' is not a truck. A picture of a truck is not a truck. They are symbols for a truck that convey a shared meaning.

Words alone (or pictures) do not always convey full meaning, but are added to by:

- context
- bodily movements
- gestures
- facial expressions
- tone of voice
- behaviour.

Expressive communication refers to the ways we send messages to other people. Usually we do this by putting words together in speech, writing or signing to convey information, thoughts and feelings – this is called expressive language. It also includes body language, voice and face expressions and the use of augmentative and alternative communication (AAC) systems such as symbol boards and voice output communication devices

Receptive communication (comprehension) refers to receiving and understanding messages from others. Receptive language refers to the ability to receive, process, comprehend and integrate spoken language. Understanding may be enhanced when words are accompanied by body language and other cues such as pictures.

It is important not to reduce communication simply to messages sent and received. Rather, communication is an **interactive process** that is the primary means for people doing things together. Meanings evolve and change according to interpretations (and misinterpretations), changed circumstances and because of individuals involved. We all bring different views and experiences to any interaction and therefore individuals might interpret things very differently. We also read things into what people say based on our knowledge of them.

3.1.1 Language Development

Language and communication are extremely complex processes involving the senses and brain. Not only do we need to see, hear and feel messages, but also interpret and process the messages so they may be understood. This processing occurs in the brain and develops from infancy. Such brain development involves the processing and interpretation of massive amounts of sensory input from the body and the environment. As infants develop, reflexive, disorganised and haphazard movements and sounds become more organised and purposeful.

Many brain impairments interfere with this processing and integration, so input is not perceived normally. For such people, input does not make sense and may cause confusion and distress. People with intellectual disability have brain impairments and many have accompanying sensory impairments (vision, hearing, touch, proprioceptive) that interfere with language development. People with profound and multiple disability have obvious problems with language. However, many people with milder levels of disability also experience problems with the understanding and expression of language.

It is vital to understand that people with intellectual disability have impaired communication – this ranges from mild and subtle to severe and obvious.

3.1.1.1 Levels of Communication

Communication development goes through many stages that can be broadly broken down to three levels: unintentional, intentional, and symbolic.

Unintentional (or preintentional) communication has the following characteristics:

- the person is not deliberately communicating
- facial expressions, eye movements, body movements, vocalisations are non-specific means of communication
- person does not use communication as a tool to obtain a goal
- communication is not directed at a listener
- listener needs to figure out what the message is
- in normal development, occurs from birth – 6 months.

Intentional communication has the following characteristics:

- the person is deliberately communicating to a listener
- communication becomes more specific – pointing, eye contact, guiding
- the person uses communication as a tool to obtain a goal
- more people can understand the message, but it still needs some familiarity and interpretation

- in normal development, occurs around 6 – 12 months.

Symbolic communication has the following characteristics:

- the person is deliberately communicating a message to a listener
- the person uses a formal symbol system (language) to communicate their message – speech, words, signing, pictures, etc.
- the message is readily understood by those familiar with the language
- in normal development, begins around 12 months. (After Bloomberg & West, 2009)

As children acquire language, they are able to say firstly, what they want, and later, what they mean. Many people with severe and profound intellectual disability may never develop the ability to even signal their intentions. Even those who have some capacity for intentional communication may have difficulties because of physical or sensory problems that make their signals hard to recognise. For example, intentional eye gaze or nodding the head for yes might be beyond the motor control of someone with cerebral palsy.

The classification is useful when considering the communication capacities of people with disability you work with. A Speech Pathologist may break down these basic levels for further identification of communication competencies during assessment. In this way communication strategies can be targeted specifically for individuals.

People with profound and complex disability are dependent on others to interpret their needs and choices through observation, assessment and getting to know them. Their communication is expressed on their faces, and through vocal sounds, body movements and behaviour. By getting to know people with profound disabilities, we can develop some effective ways to respond and communicate.

3.1.2 Communication Plans and Profiles

Following assessment Speech Pathologists develop Communication Plans that identify strategies and systems to support individuals. These plans need to be implemented in a consistent manner by all people working with people with disability. Communication Plans should be reviewed annually for children and every second year for adults. Review should be considered if there is significant change in a person's behaviour.

Communication Profiles are useful tools to provide quick snapshots of individuals' communication such as levels of understanding and the expression of pain and emotional states. A communication profile can be particularly convenient when support is provided in an unfamiliar environment, e.g., during hospitalisation. For a useful example building a communication profile the hyperlink below.

For further information see:

[Building a Communication Profile](#)

[http://www.adhc.nsw.gov.au/_data/assets/file/0006/258684/Lifestyle_Planning_Communication_profile.pdf]

3.1.3 Augmentative and Alternative Communication (AAC)

Augmentative and Alternative Communication (AAC) strategies provide communication options and support for people with complex communication needs. AAC may be used to support an individual's understanding of communication, as well as to promote expressive communication.

Augmentative Communication strategies support existing speech. Strategies include gestures, eye pointing (gaze) and body language.

Alternative Communication strategies are designed to replace speech when normal speech is not possible. Strategies include pointing to symbols, signing and spelling.

AAC devices range from simple communication boards to symbolic picture systems to electronic devices. Technology is rapidly evolving to support AAC with apps for smart phones and tablet computers. Speech Pathologists assess and formulate appropriate systems for individuals.

For further information see:

[Novita AAC](#)

[<http://www.novita.org.au/Content.aspx?p=64>]

[Speech Pathology Australia Position Paper AAC](#)

[http://www.speechpathologyaustralia.org.au/library/Clinical_Guidelines/AAC.pdf]

[The Hospital Communication Book](#)

[<http://www.surreyhealthaction.org/assets/files/Hospital%20Communication%20Book%20-%20version%202%20-%20web.pdf>]

[The Clear Communication People. Health Communication Resources](#)

[<http://www.communicationpeople.co.uk/subjects/health/>]

ADHC (2013) Speech Pathology Practice Package

[Available to ADHC staff on intranet.]

3.1.4 Communicating with People with an Intellectual Disability

The person with a disability must remain the primary focus of the communication even when accompanied by a communication partner such as family member, carer, support worker, or advocate. Following are some useful strategies.

To enhance **receptive communication**:

- speak slowly and use pauses to allow person to process words
- try and present only one concept at a time – too many concepts are muddling
- ask one question at a time – provide time for reply
- use short, clear sentences – avoid complex and technical words and jargon
- if necessary to obtain history from a carer, maintain focus on the person through eye contact, touch and body language
- use visual cues, such as objects, pictures, diagrams, to get your message across
- if a communication device is used, ensure access, read the instructions, and use jointly with the person

To enhance **expressive communication**:

- provide adequate time for person to formulate responses and questions
- explore statements and questions to ensure you understand the person's meaning
- use visual cues, such as objects, pictures, diagrams, to enhance meaning
- note expression and body language to interpret meaning and explore if necessary

Never pretend to understand. Use exploratory techniques clarify meanings. If you still don't understand, then apologise.

When working with people who **cannot communicate intentionally**, observe facial expression, body language and behaviour. Even though it is necessary to communicate with accompanying carer, the person with a disability must retain a central place in the conversation through eye contact, body language and touch.

For further information see:

[CDDH \(2008\) Working with people with intellectual disabilities in healthcare settings. Fact Sheet. Centre for Developmental Disability Health, Melbourne.](#)

[<http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf>]

[RoyalCollegeofNursing \(2010\) Mental health nursing of adults with learning disabilities: RCN guidance. RCN: London.](#)

[http://www.rcn.org.uk/_data/assets/pdf_file/0006/78765/003184.pdf]

[idmh e-Learning. ID and Mental Health UNSW. Communication Module](#)

[<http://training.idhealtheducation.edu.au/>]

3.1.5 Communicating with People with Sensory Impairments

Many people with an intellectual disability have sensory impairments related to **vision** and/or **hearing**. These range from total loss or lack of development of the senses, such as in cortical blindness or sensorineural hearing loss, through a continuum of problems that reduce hearing or visual acuity and result in low hearing or vision.

Vision and hearing impairments have a major impact on communication. Impairments that inhibit the development of sight and/or hearing, such as congenital cortical visual impairment or congenital sensorineural hearing loss, cause the greatest problems with the development of communication.

Some vision and hearing impairments are responsive to correction with glasses or hearing aids, but many are not. Intellectual disability compounds the impact of sensory impairments on communication development and ability. Cochlear implant technology is not available to people with an intellectual disability due to lack of cognitive capacity to adapt.

Deaf blindness is the term used when people have combined hearing and vision loss or impairment. It very isolating because it significantly affects communication, socialisation and daily living.

Sensory integration disorders are an outcome of developmental sensory impairments. These may result in:

- sensory seeking

- under responsiveness to sensory stimulation
- over responsiveness to sensory stimulation (e.g., tactile defensiveness).

Such responses may be interpreted as stereotypic and/or challenging behaviour. The interpretation of these responses is particularly challenging when communicating. For example, withdrawal from touch might be interpreted as 'go away' or 'I don't want that'. However, such withdrawal may be tactile defensiveness.

Various communication strategies are used with people with vision or hearing impairments or who are Deaf blind. These include:

- speech
- oral/aural communication
- various forms of sign language, including tactile
- Deaf blind fingerspelling
- alternative and augmentative communication (AAC)
- print/Braille
- sensory integration therapy

However, the use of some strategies is limited with people with intellectual disability.

Sensory integration activities are the most effective strategies when communicating with people with severe disabilities and sensory impairments. **In general, deeper touch is more acceptable than light touch.** Getting to know the person is vital – families and carers (including support staff) are the best sources for the interpretation of communication.

Speech Pathologists and Occupational Therapists assess and develop plans for people with sensory impairments.

For further information see:

[Royal Institute for Deaf and Blind Children](http://www.ridbc.org.au/)

[<http://www.ridbc.org.au/>]

[DeafBlind Association \(NSW\)](http://www.dbansw.org.au/)

[<http://www.dbansw.org.au/>]

[Australian DeafBlind Council \(ADBC\)](http://www.deafblind.org.au/index.asp)

[<http://www.deafblind.org.au/index.asp>]

[Cortical Visual Impairment](http://www.childrenshospital.org/az/Site2100/mainpageS2100P1.html)

[<http://www.childrenshospital.org/az/Site2100/mainpageS2100P1.html>]

[Australian Hearing](http://www.hearing.com.au/types-of-hearing-loss)

[<http://www.hearing.com.au/types-of-hearing-loss>]

[Sensory Integration Activities](http://www.ot-mom-learning-activities.com/sensory-integration-activities.html)

[<http://www.ot-mom-learning-activities.com/sensory-integration-activities.html>]

[Sensory Integration and Sensory Motor Activities](http://www.tsbvi.edu/component/content/article/1727-sensory-integration-and-sensory-motor-activities) (Texas School for the Blind and Visually Impaired)

[<http://www.tsbvi.edu/component/content/article/1727-sensory-integration-and-sensory-motor-activities>]

[Sensory Integration](http://old.nationaldb.org/ISSelectTopics.php?topicCatID=864) (National Consortium on Deaf-Blindness)

[<http://old.nationaldb.org/ISSelectTopics.php?topicCatID=864>]

ADHC (2013) Speech Pathology Practice Package

[Available to ADHC staff on intranet]

3.1.6 Communication Between Health Professionals, People with Disability, their Families and Carers, Schools, Day Options

Effective communication between health professionals, people with disability, their families and carers, schools and day options is essential. Communication should always be supported by written information that is evidence-based and tailored to an individual's needs. All support, and the information that accompanies it, should be culturally appropriate. It should also be provided in formats accessible to people with specific needs such as sensory and cognitive impairments.

The notion of **partnerships** is essential to effective communication between all parties. This means that people with disability and their families share power, knowledge, and information. Professionals recognise that people with disability and their families hold important knowledge about their own needs, and about how best to meet them. With constructive communication, communication and behaviour support for nurses are created at both interpersonal and practical levels.

Nurses play an important role in:

- facilitating partnerships
- interpreting health information for people with disability, their families, carers, support workers, teachers and program co-ordinators
- co-ordinating health information, advice and recommendations
- liaising with GPs, specialists, dentists, and allied health professionals about complex health issues
- following up on health actions recommended by GPs and other health professionals
- providing support to people with disability, their families, carers, and support workers during complex medical consultations. This includes interpreting information and seeking further explanations and advice when necessary.

For further information see:

[Working in Person Centred Ways: A Resource Book for NSW Advocacy and Information Services.](#) [

http://www.adhc.nsw.gov.au/_data/assets/file/0013/250033/Working_in_Person_Centred_Ways_Resource_Book.pdf]

3.1.7 Communicating with Families of People with Disability

Families of people with disability, especially parents, have often experienced negativity when dealing with health professionals and health systems. They often experience ongoing grief, stress and anxiety related to practical and emotional difficulties encountered because of their child's disability. Communication may be affected because of negative experiences, misunderstandings, and ongoing anxiety and distress. Many families struggle to cope. When communicating with families, it is important to remember that they know their child better than other people and are the experts in care and support.

Older parents with adult children have likely experienced a lifetime of distress. Many experience anxiety related to the future wellbeing of their adult children.

When working with families, nursing roles include:

- recognition of the impact of disability on parents and families
- active and non-judgemental listening, openness and honesty, open-ended questions
- working with families as partners
- promoting family-centred support
- referral to relevant services, including counselling if necessary
- advocacy for people with disability and their families
- enabling others to understand patterns of ability and difficulty, along with implications for learning and living.

For further information see:

[Raising Children Network: Children with Disability](http://raisingchildren.net.au/children_with_disabilities/children_with_disability.html)

[http://raisingchildren.net.au/children_with_disabilities/children_with_disability.html]

[Raising Children Network: Communicating with Parents](http://raisingchildren.net.au/articles/communicating_with_parents_the_basics.html/context/531)

[http://raisingchildren.net.au/articles/communicating_with_parents_the_basics.html/context/531]

Parent Line 1300 1300 52 [Parent Line: Special Needs](http://www.parentline.org.au/Page.aspx?element=704&category=9)

[<http://www.parentline.org.au/Page.aspx?element=704&category=9>]

[ADHC: Older Parent Carers](http://www.adhc.nsw.gov.au/individuals/caring_for_someone/older_parent_carers)

[http://www.adhc.nsw.gov.au/individuals/caring_for_someone/older_parent_carers]

3.1.8 Communication and Behaviour

Communication is the way we learn, make choices and become independent. It is the way we express our feelings, thoughts and emotions. It is the way we make sense of the world around us. Communication is the means by which we relate to others, make friends, live meaningful lives and develop as people.

Shared communication is fundamental to being included in a society. Our society expects everyone to speak, understand, read and write as the main forms of communication. Lack of common language leads to misunderstanding, mistrust and segregation. People with an intellectual disability have problems with communication because of cognitive impairments. Sensory impairments further complicate the situation. People with profound and complex disabilities are not able to communicate in the usual manner.

Lack of effective communication leads to frustration. Frustration leads to withdrawal or anger and aggression against self or others. This is seen as 'challenging behaviour' and may lead to further exclusion. People with profound disabilities are dependent on others to interpret their needs and choices through observing and responding to their communicative behaviour.

Remember: nothing can be done without **consent** from person with intellectual disability or substitute consent from 'person responsible'. (See: your organisations Decision Making and Consent Policy and Procedures).

(Sources used :ADHC, 2012; Balandin, 2002; Baladin *et al*, 2007; Ballin & Baladin, 2007; Bloomberg & West, 2009; Buzio, Morgan & Blount, 2002; CDDH, 2008; Ellis, Sherwin & van Dam, 2011; Grove *et al*, 2000;Hemsley *et al*, 2001; Iacano *et al*, 2009; Kearney & Griffin, 2002; King *et al*, 1999; Mencap, undated; Tadema & Vsalcamp, 2010; Therapeutic Guidelines, 2012; Whittingham *et al*, 2013).

3.2 Behaviour Support

Behaviour is a form of communication. For example, crying behaviour might be a way of communicating hunger, loneliness, pain, discomfort, frustration, grief, sadness. Reaching for a cup might be a way of communicating “I’m thirsty” or “I want to see how this object feels” or “I like the bright colour of this thing” or “I want to throw this cup”. Behaviours perceived as challenging also serve a communicative function. In this section, we look at the relationship between challenging behaviour and communication, and our role as nurses in the assessment and management of challenging behaviour.

3.2.1 Challenging Behaviour

Emerson and Einfeld (2011, p.7) define challenging behaviour as:

...culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.

The [ADHC Behaviour Support Policy](#) (revised 2012) states the following:

Any behaviour displayed by a person which is considered challenging or inappropriate by others, or which gives rise to reasonable concern, may be considered as challenging. However, the use of the term challenging should be understood in terms of the social context in which behaviour occurs, rather than a symptom of individual pathology.

Often the Service User who presents with challenging behaviour is considered to be challenging as a result of their behaviour. However, challenging behaviour is a **social construct** which is a product of an interaction between an individual and others in their environment. Challenging behaviour should not be interpreted automatically as an expression of deviance or abnormality inherent in the individual, but viewed rather with reference to much wider contextual factors (ADHC, 2012, p.5).

Perceptions of challenging behaviour are partly governed by rules of what is considered appropriate behaviour in various **social contexts**. For example, the behaviour of fans at a football match would be considered inappropriate (and therefore ‘challenging’) at a funeral.

It is important to remember that challenging behaviour challenges not only the person, but also families, carers, people in a person’s support network and service providers. Responses to challenging behaviour often:

- prevent a person from participating fully in life and the community
- undermine the individual’s rights, as well as others’
- threaten dignity
- reduce quality of life
- pose safety risks to the person and others.

Challenging behaviour often has a significant impact on the person's health, lifestyle and wellbeing, and on relationships with families, carers, friends and the wider community. Negative perceptions and non-acceptance of people with challenging behaviours are common.

3.2.1.1 Links between Communication, Challenging Behaviour and Ageing

The links between communication difficulties and challenging behaviour are well established. If persons with an intellectual disability do not have a formal way of communicating their wants, needs, likes and dislikes, they may use other behaviours to get their message across.

Evidence suggests that problems with receptive communication (comprehension of information) are more closely associated with challenging behaviours than expressive communication skills. When language is too complex to be understood, people may engage in challenging behaviours because they are scared, confused or frustrated. When carers overestimate people's receptive language skills, they inadvertently create potential situations for challenging behaviour. Therefore, it is essential to adapt communication and use techniques to enhance understanding.

When people age, the possibility of advancing cognitive decline or dementia may also affect their ability to communicate and further influence behaviours.

For further information see:

[Dementia and People with Learning Disabilities](#)

[<http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf>]

[Down Syndrome and Alzheimer's Disease](#)

[<http://www.cddh.monash.org/assets/dsad-booklet-final.pdf>]

3.2.1.2 Some Causes of Challenging Behaviour

Although not necessarily deliberate and planned, behaviour occurs for a reason and serves a function. Identifying reasons for behaviour is necessary if we are to work effectively with people with disability. Many factors contribute to challenging behaviour, but sometimes they cannot be identified. Challenging behaviour is more likely to occur in people with limited or no verbal skills.

Broadly speaking, the causes of challenging behaviour are classified into four areas:

1. **physical causes** – health problems causing pain and discomfort
2. **environmental causes** – interactions with family, staff and others; lack of control over environment; changes to routines; loss and grief
3. **psychiatric causes** – psychiatric disorders more prevalent in people with intellectual disability
4. **behavioural phenotype** – some behaviours may be associated with specific syndromes, e.g., skin picking and Prader-Willi syndrome

Common contributors to challenging behaviour include (but are not limited to):

- health problems, e.g., psychiatric illness, substance abuse, medication, pain, discomfort, epilepsy, GORD, dental problems, osteoporosis, pneumonia, constipation, ear infection, urinary tract infection – it is important to rule out any underlying health problem before looking for other causes of challenging behaviour
- abuse – physical, sexual and psychological

- life and environmental changes, e.g., school or accommodation changes, change in house mates, changes in routine, death in the family, staff changes, siblings leaving home, divorce
- communicating needs and wants, e.g., food, drink, activity
- communicating need for social interaction – sometimes negatively referred to as ‘attention-seeking’
- communicating avoidance and escape, e.g., avoiding situations that are unpleasant or disliked
- limited understanding of social norms
- a need for sensory stimulation
- difficulties with regulating emotions
- boredom
- anxiety
- frustration
- confusion

Some apparently negative behaviours may be a positive coping strategy. For example, if Joe is anxious in social situations, rocking and humming provide sensory comfort and distraction from the disliked situation.

3.2.1.3 Examples of Challenging Behaviour

Challenging behaviours may be self-directed or outward-directed.

1. **Self-directed behaviours** include:

- self-injury
- withdrawal
- repetitive (stereotyped) behaviour

2. **Outward-directed behaviours** include:

- agitation (e.g., pacing)
- aggression (e.g., hitting out, destruction of property)
- socially inappropriate behaviour (e.g., sexualised behaviour in a public place)
- noncompliance (e.g., refusing to follow directions)

Some examples of common challenging behaviours include:

- a person hitting himself about the face and head causing bruises and wounds
- ingestion or inhalation of foreign objects, e.g., pica
- lack of cooperation and abuse towards support staff
- running away in public places
- withdrawal and lethargy that might be accompanied by complaints of stomach pain and nausea

(Therapeutic Guidelines, 2012)

3.2.1.4 Impact of Challenging Behaviour

It is important to understand that it is the **impact** of the behaviours that makes them challenging, rather than judgements about appropriateness of the behaviours.

Challenging behaviours have a wide range of impacts on:

1. the quality of life of persons with the behaviours, and
2. the people who live and work with them.

Challenging behaviours may:

- cause danger to self and others
- cause stress and distress to self and others

- result in social exclusion that may lead to loneliness and depression
- interfere with learning and social development
- have negative effects on social, domestic and employment opportunities.

There is a risk that challenging behaviours may lead to exclusionary and restrictive practices.

For further information see:

[Finding the Causes of Challenging Behaviour](#)

[<http://www.challengingbehaviour.org.uk/learning-disability-files/02---Finding-the-Causes-of-Challenging-Behaviour-Part-2.pdf>]

[CDDH Challenging Behaviour Information Sheet](#)

[<http://www.cddh.monash.org/assets/chabev.pdf>]

[CDDH Challenging Behaviour](#)

[<http://www.cddh.monash.org/assets/fs-challengbev.pdf>]

[Challenging Behaviour and Disability](#)

[<http://www.scope.org.uk/help-and-information/cerebral-palsy/challenging-behaviour-and-disability>]

[Pain, Low Mood and Challenging Behaviour](#)

[http://etheses.bham.ac.uk/3902/1/Davies_12_ClinPsyD_Vol1.pdf]

3.2.2 Positive Behaviour Support

Positive Behaviour Support is both a philosophy of practice and a comprehensive approach to assessment, planning and intervention that focuses on addressing a person's needs, environments, and quality of life. It is an evidence-based approach that includes families and carers to develop shared understandings about why a person uses challenging behaviours. It has:

- a primary goal – to enhance a person's quality of life, and
- a secondary goal – to decrease the frequency and intensity of a person's challenging behaviours (Disability Services Commission, 2012).

Positive Behaviour Support has four core components.

1. Ensuring the person is living the best life that he or she is able to – sometimes this is all that is required. However, if the person is leading a good life and challenging behaviour continues, then the following strategies should be used.
2. Understand why the person uses challenging behaviour.
3. Find causes for the challenging behaviour and modify them.
4. Teach the person new skills to meet needs. The new skill should be more functional than the challenging behaviour (Centre of Excellence for Behaviour Support, 2012).

Positive Behaviour Support employs the following strategies and approaches:

- person-centred approaches
- inclusion of relevant stakeholders
- assessment based intervention
- behaviour support plans
- reduction in aversive, restrictive and punishment approaches
- skill building
- staff development
- environmental redesign
- systems change (DSC, 2012).

3.2.2.1 Assessment of Behaviour

Before intervention can occur, assessment of behaviour considered to be challenging must be conducted. This is in order to identify its **function** and any variables that elicit, maintain and reduce the behaviour. Once factors such as triggers, setting events and consequences are understood, a Behaviour Support Plan can be developed with the aim of reducing the behaviour and replacing it with a more functional way of achieving the goal. See [ADHC Behaviour Support Policy \(2012\)](#). This is usually prepared by a Behaviour Support Practitioner.

3.2.2.2 Behaviour Support Plan

A Behaviour Support Plan (BSP) is designed to enhance the person's quality of life and minimise the challenging behaviour and replace it with more adaptive alternatives. It reflects the components and strategies of Positive Behaviour Support approaches outlined in the preceding section.

Behaviour Support Plans consider biological, social, psychological, and environmental variables as interrelated.

All aspects of interventions must be described in a BSP to ensure a **consistent approach** to behaviour support.

Behaviour support must take account of the following:

- Is there an underlying medical diagnosis? For example, consider pain, tooth abscess, constipation, urinary tract infection, itch, gastro-oesophageal reflux disease (GORD), painful menstrual periods, or a broken bone. Pain is a major contributor to challenging behaviour
- Is there a psychiatric diagnosis? Consider depression, psychosis, etc.
- Are there emotional issues? Consider grief and loss, anxiety, distress, relationship problems.
- Have environmental or other triggers been identified and addressed? What is happening in the person's environment? Have there been changes?
- What is happening in the person's relationship circles? Have there been changes?
- Does the behaviour constitute a serious risk to the person or to others?
- Are medications causing adverse effects? Are there medication interactions?
- Assess polypharmacy side effects or not working well together? Medications for the primary management of challenging behaviours should be considered only after the exclusion of underlying diagnoses and any environmental or other relevant triggers. They may be considered in situations where the behaviour presents a significant danger to the person or others or for the management of diagnosed depression and other disorders.
- Has the GP reviewed all medications, including those currently used to manage behaviour? Have medical specialists been consulted, e.g. a neurologist, if the GP suspects that the person has epilepsy or a psychiatrist for a mental disorder?
- Consider early dementia in people who become less cooperative and whose functional levels decline, e.g., particularly significant in people with Down syndrome.
- What are the person's communication support needs? Are they being addressed or met?

- Has there been collaboration with the behaviour support specialists regarding other interventions that might be effective in place of medications?
- Would the person benefit from a Behaviour Support Specialist review?

3.2.2.3 Restrictive and Restricted Practice

Where a documented Behaviour Support Plan recommends the use of certain practices or strategies that impose restrictions on a person's rights or freedoms, these must be justifiable and may be considered for implementation only with legal consent. Such strategies may be wide-ranging and are referred to by FACS as **Restrictive Practices**.

A number of practices have additional safeguards and are called **Restricted Practices**. These include:

- exclusionary time-out
- physical restraint
- psychotropic medication (for PRN use)
- response cost – the withholding of valued items or activities
- restricted access
- seclusion

Such practices are informed by strict guidelines which provide clear conditions and limitations for use (ADHC, 2012). It is essential that you have a clear understanding of issues related to restrictive and restricted practices.

For FACS staff, the *Positive Approaches to Behaviour Support Core Standard* of the Practice Improvement Framework (PIF) can be accessed at My ADHC Learning website via <https://myadhclearning.nsw.gov.au>.

The PIF e-learning course will soon be available for non-FACS staff. Please email PIF@facs.nsw.gov.au for further details.

For further information see:

http://www.adhc.nsw.gov.au/sp/delivering_disability_services/core_standards

[The Challenging Behaviour Foundation](http://www.challengingbehaviour.org.uk/)

[<http://www.challengingbehaviour.org.uk/>]

[Centre of Excellence for Behaviour Support \(CEBS\)](http://www.centreofexcellenceforbehavioursupport.com.au/Home.aspx)

[<http://www.centreofexcellenceforbehavioursupport.com.au/Home.aspx>]

[What is Positive Behaviour Support? CEBS](http://www.centreofexcellenceforbehavioursupport.com.au/Portals/0/Practice%20Leadership/Practice%20Guides/No1b.pdf)

[<http://www.centreofexcellenceforbehavioursupport.com.au/Portals/0/Practice%20Leadership/Practice%20Guides/No1b.pdf>]

[Positive Behaviour Support: Getting it Right from the Start. DHS Victoria. Various Resources](http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/positive-behaviour-support-getting-it-right-from-the-start)

[<http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/positive-behaviour-support-getting-it-right-from-the-start>]

[Positive Behaviour Support. Synapse.](http://synapse.org.au/get-the-facts/what-is-positive-behaviour-support-fact-sheet.aspx)

[<http://synapse.org.au/get-the-facts/what-is-positive-behaviour-support-fact-sheet.aspx>]

[Positive Behaviour Support: Information for Disability Sector Organisations. DSC, Government of WA](http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/positive-behaviour-support-getting-it-right-from-the-start)

(Sources used: ADHC, 2012; ADHC, 2009; Balandin, 2002; Ballin& Balandin, 2007; Bott, Farmer & Rhode, 1997; DSC, 2012; Emerson & Einfeld, 2011; Kevan, 2003; McClintock, Hall & Oliver, 2003; Sigafos, 2000; Therapeutic Guidelines, 2012)

3.3 *What does this mean for your nursing practice?*

Practice Points: COMMUNICATION and BEHAVIOUR SUPPORT
<ul style="list-style-type: none">• Effective communication and behaviour support are core components of nursing practice.• There are significant links between communication difficulties and challenging behaviour.• Communication is an interactive process. Communication meanings are not static – they evolve and change.• Sensory impairments interfere with language development.• People with an intellectual disability have impaired communication – this ranges from subtle (and difficult to identify) to severe and obvious. Nurses must be aware of potential problems.• Knowledge of levels of communication – unintentional, intentional, symbolic – enhances understanding of communication capacities and the development of appropriate strategies.• People with profound and multiple disabilities are dependent on others to interpret their needs and choices through observation, assessment and getting to know them.• Communication Plans must be implemented in a consistent manner. They must be reviewed by a Speech Pathologist regularly or according to need.• Communication Profiles are useful snapshots of individuals' essential communication. They are convenient for unfamiliar environments such as during hospitalisation.• The person with a disability must be the primary focus of communication.• Use strategies to enhance both receptive and expressive communication.• When working with people who cannot communicate intentionally, observe facial expression, body language and behaviour.• The notion of partnerships is essential to effective communication between health professionals, people with disability, their families and carers, schools and day options programs.• Nurses play an important role in facilitating partnerships, interpreting health information, co-ordinating health practice, and liaising with other health professionals.• Nurses support families by using family-centred and partnership approaches, and through advocacy of people with disability and their families.• Lack of effective communication leads to frustration. This may result in challenging behaviour.• Behaviour is a form of communication that serves a function.• Perceptions of behaviour are governed by social contexts.• Challenging behaviour challenges not only the person, but also families, carers, people in a person's support network and service providers.

- Problems with receptive communication are more closely linked with challenging behaviour than expressive communication skills.
- Carers often overestimate people's language skills. Nurses must assess and educate families, carers and support staff.
- Nurses are responsible for initial assessment of causes of challenging behaviour. Always consider pain and health conditions first. Assess for other causes. Refer for further assessment when indicated.
- Adopt the principles of Positive Behaviour Support into your nursing practice.
- Advocate for the best possible life for people you work with.
- Refer to Behaviour Support nurses when indicated.
- Ensure consistent implementation of Behaviour Support Plans (BSP). Educate families, carers and staff.
- Ensure avoidance of any restrictive and restricted practices unless included in a documented and approved BSP .
- Ensure familiarity with organisational and service behaviour support policies and practices.

3.4 Readings and Resources for Communication and Behaviour Support

- ADHC (2009) Behaviour support policy and practice manual. Guidelines for the provision of behaviour support services for people with an intellectual disability. NSW Government, Sydney.
http://www.adhc.nsw.gov.au/_data/assets/file/0003/228360/341_Behaviour_Support_Policy_and_Practice_Manual_Part_1_web.pdf
- ADHC (2012). Health care: policy and procedures. Sydney: NSW Government.
http://www.adhc.nsw.gov.au/_data/assets/file/0007/228094/Health_Care_Policy_and_Procedures_April_2012.pdf
- ADHC (2012). Lifestyle planning guidelines. Sydney: NSW Government.
http://www.adhc.nsw.gov.au/_data/assets/file/0005/258584/Lifestyle_Planning_Guidelines_Aug_2012_web.pdf
- ADHC (undated). Building a communication profile template.
http://www.adhc.nsw.gov.au/_data/assets/file/0006/258684/Lifestyle_Planning_Communication_profile.pdf
- Balandin, S. (2002) Editorial. *ISAAC Bulletin*, 67, 2.
- Balandin, S., Hemsley, B., Sigafos, J. & Green, V. (2007). Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs. *Applied Nursing Research*, 20(2), 56-62.
<http://dx.doi.org/10.1016/j.apnr.2006.03.001>
- Ballin, L. & Balandin, S. (2007) An exploration of loneliness: Communication and the social networks of older people with cerebral palsy. *Journal of Intellectual and Developmental Disability*, 32(4), 315-326.
<http://informahealthcare.com/doi/abs/10.1080/13668250701689256>
- Balandin, S., Hemsley, B., Sigafos, J. & Green, V. (2007) Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs. *Applied Nursing Research*, 20(2), 56-62.
- Balandin, S., Hemsley, B., Hanley, L. & Sheppard, J.J. (2009) Understanding mealtime changes for adults with cerebral palsy and the implications for support services. *Journal of Intellectual and Developmental Disability*, 34(3), 197-206.
- Bloomberg, K. & West, D. (2009) *The triple C checklist of communication competencies*, SCOPE Vic. Ltd, Box Hill, Victoria.
- Bott, C., Farmer, R. & Rohde, J. (1997) Behaviour problems associated with lack of speech in people with learning disabilities. *Journal of Intellectual Disability Research*, 41(1), 3-7.

- Buzio, A., Morgan, J. & Blount, D. (2002). The experiences of adults with cerebral palsy during hospitalisation. *Australian Journal of Advanced Nursing*,**19**(4), 8-14.<http://ajan.com.au/Vol19/Vol19.4-1.pdf>
- CDDH (Centre for Developmental Disability Health) (2008) Working with people with intellectual disabilities in healthcare settings. Fact Sheet. Centre for Developmental Disability Health, Melbourne.
<http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf>
- CDDH (2013) Centre for Developmental Disability Health Victoria. Accessed: 2 June 2013 <http://www.cddh.monash.org/index.html>
- Centre of Excellence for Clinical Innovation and Behaviour Support (2012)
<http://www.communities.qld.gov.au/disability/key-projects/positive-behaviour-support/centre-of-excellence-for-clinical-innovation-and-behaviour-support>
- Communication Aids. Scope Victoria.
<http://www.scopevic.org.au/index.php/site/resources/communicationaids>
- Department of Human Services(DHS) (undated) *Supporting people who have complex communication needs*. Victoria: DHS.
http://www.dhs.vic.gov.au/_data/assets/pdf_file/0003/596721/Disability_supporting_people_complex_comms_needs_workbook_pdf_030310.pdf
- Disability Services Commission (2012) Positive Behaviour Framework Disability Sector Update October 2013.
<http://www.disability.wa.gov.au/Global/Publications/For%20disability%20service%20providers/Guidelines%20and%20policies/Behaviour%20Support/Positive-Behaviour-Framework-Disability-Sector-Update-October-2013.pdf>
- Ellis, J., Sherwin, J. & van Dam, T (2011). *Working in person centred ways: a resource book for NSW advocacy and information services*. Sydney: ADHC, FACS..
http://www.adhc.nsw.gov.au/_data/assets/file/0013/250033/Working_in_Person_Centred_Ways_Resource_Book.pdf
- Emerson, E. & Einfeld, S.L. (2011) *Challenging behaviour*, Cambridge University Press, Cambridge.
- Grove, N., with Bunning, K., Porter, J. & Morgan, M. (2000) *See what I mean: Guidelines to aid understanding of communication by people with severe and profound learning disabilities*. Worcestershire, UK: BILD. [Order at: <http://www.bild.org.uk/our-services/books/communication-is-a-human-right/see-what-i-mean/>]
- Hemsley, B., Sigafos, J., Balandin, S., Forbes, R., Taylor, C., Green, V.A. &Parmenter, T. (2001) Nursing the patient with severe communication impairment. *Journal of Advanced Nursing*,**35**(6), 827-835.
<http://dx.doi.org/10.1046/j.1365-2648.2001.01920.x>

- Hemsley, B., Balandin, S. & Togher, L. (2007) Older Unpaid Carers' Experiences Supporting Adults with Cerebral Palsy and Complex Communication Needs in Hospital. *Journal of Developmental and Physical Disabilities*, **19**(2), 115-124. <http://dx.doi.org/10.1007/s10882-007-9040-1>
- Hemsley, B., Balandin, S. & Togher, L. (2008) Professionals' views on the roles and needs of family carers of adults with cerebral palsy and complex communication needs in hospital. *Journal of Intellectual and Developmental Disability*, **33**(2), 127-136. <http://informahealthcare.com/doi/abs/10.1080/13668250802082898>
- Hemsley, B., Balandin, S. & Togher, L. (2008) 'We need to be the centrepiece': Adults with cerebral palsy and complex communication needs discuss the roles and needs of family carers in hospital. *Disability and Rehabilitation*, **30**(23), 1759-1771. <http://informahealthcare.com/doi/abs/10.1080/09638280701645474>
- Iacono, T. & Davis, R. (2003) The experiences of people with developmental disability in Emergency Departments and hospital wards. *Research in Developmental Disabilities*, **24**(4), 247-264. <http://www.sciencedirect.com/science/article/pii/S0891422203000416>
- Iacono, T., West, D., Bloomberg, K. & Johnson, H. (2009) Reliability and validity of the revised Triple C: Checklist of Communicative Competencies for adults with severe and multiple disabilities. *Journal of Intellectual Disability Research*, **53**(1), 44-53.
- Kearney, P.M. & Griffin, T. (2001) Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, **34**(5), 582-592. <http://dx.doi.org/10.1046/j.1365-2648.2001.01787.x>
- Kevan, F. (2003) Challenging behaviour and communication difficulties. *British Journal of Learning Disabilities*, **31**(2), 75-80.
- King, G., King, S., Rosenbaum, P. & Goffin, R. (1999) Family-centred caregiving and well-being of parents of children with disabilities: linking process with outcome. *Journal of Pediatric Psychology*, **24**(1), 41-53. <http://www.parentline.org.au/Page.aspx?element=704&category=9>
- McClintock, K., Hall, S. & Oliver, C. (2003) Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study. *Journal of Intellectual Disability Research*, **47**(6), 405-416.
- Mencap (undated). Your guide to communicating with people with profound and multiple learning disabilities (PMLD). http://www.mencap.org.uk/sites/default/files/documents/2009-02/2008.292%20Mencap_Guide_Communicating_with_PMLD.pdf
- Pawlyn, J. & Carnaby, S. (2009). *Profound intellectual and multiple disabilities: nursing complex needs*. United Kingdom: Wiley-Blackwell

- Sigafoos, J. (2000) Communication development and aberrant behaviour in children with developmental disabilities. *Education Training in Mental Retardation and Developmental Disabilities*,35(2), 168-176.
- Therapeutic Guidelines Ltd. (2012). *Management guidelines: developmental disability. Version 3*. Melbourne: Therapeutic Guidelines Ltd. (Order from: www.tg.org.au)
- Tadema, A.C. & Vlaskamp, C. (2010) The time and effort in taking care for children with profound intellectual and multiple disabilities: a study on care load and support. *British Journal of Learning Disabilities*,38(1), 41-48.
- Whittingham, K., Wee, D., Sanders, M.R. & Boyd, R. (2013) Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences. *Disability and Rehabilitation*,35(17), 1447-1452.