NSW GOVERNMENT | Justice
Juvenile Justice

# Working with Young People who have an Intellectual Disability or Cognitive Impairment

2016

# Preface

This resource is for frontline staff, including Juvenile Justice Psychologists, Caseworkers and Youth Officers, who work with young people who have or may have an intellectual disability. This resource will help you to identify, refer, understand and work with young people with an intellectual disability or cognitive impairment.

# Acknowledgements

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**Agency Contributions**
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# 1. The role of Juvenile Justice NSW

Young people with an intellectual disability or cognitive impairment may be particularly susceptible to getting into trouble with the law and repeating their offending, as clients with an intellectual disability have been shown to find it more difficult to learn new adaptive behaviours to replace maladaptive behaviours than other clients.[1]

Strategies for the identification of, and interaction with, young people with an intellectual disability are presented here to assist staff in meeting the special needs of these clients, and work with Psychologists to design individualised interventions to reduce the risk of re-offending. We must also ensure that Juvenile Justice's policies and procedures are equitable to young people with an intellectual disability or cognitive impairment.

Staff need to know when and how to make a referral to a Psychologist for further assessment. Identifying an intellectual disability can have significant implications for the young person.

| **Implications for a young person identified with intellectual disability** | |
|---|---|
| Legal | They may be dealt with under special legislation, being diverted from the criminal justice system |
| Financial Support | They may be eligible for Centrelink benefits or services offered by the National Disability Insurance Agency (NDIA) |
| Educational Assistance | They may be eligible for support through the education system |
| Living Support | They may be eligible for assistance with special needs |
| Supervision & Intervention | They may require the adaptation of supervision plans and intervention as appropriate |

The Department's Disability Inclusion Action Plan 2015-2018 outlines our commitment to supporting the needs of young people with disabilities who are in contact with Juvenile Justice NSW.

# 2. The National Disability Insurance Scheme

The NDIS supports people with a permanent and significant disability that affects their ability to take part in everyday activities.

To receive support from the NDIS the young person must to the following requirements:

- have a permanent and significant disability that affects your ability to take part in everyday activities
- be aged less than 65 when you first access the scheme
- be an Australian citizen, a permanent resident or a New Zealand citizen who holds a Protected Special Category Visa

Use the **NDIS Access Checklist** to find out if the young person is able to receive assistance from the NDIS.

If the young person meets the requirements of the Access Checklist they will need to provide evidence of a disability.

Assistance will need to be provided to complete the **Access Request Form** and provide proof of age, residence and evidence of a disability to become a participant of the NDIS.

If required, the NDIS will also fund reasonable and necessary supports that help the young person access services such as behavioural support, recreational support and or assistance with accommodation and employment.

The NDIS plan is specifically tailored to meet the individual needs and goals of the young person.

**NDIS Contact Details – Phone: 1800 800 110**

**Email: nationalaccessteam@ndis.gov.au**

**Website: http://www.ndis.gov.au/**

## 3. Over-representation in criminal system

The 2009 Young People in Custody Health Survey found that 13.6% of young people in custody were assessed as potentially having an intellectual disability. This figure increased to 16.5% in 2015 (in press).

In 2013 over half a million Australians (approximately 3% of the population) have an intellectual disability.[2]

In comparison with individuals without an intellectual disability, people with an intellectual disability are said to be, "...more likely to be arrested, refused bail, convicted, sentenced to imprisonment, receive a longer term of imprisonment and serve a greater percentage of their sentence before being released on parole" (NSW Law Reform Commission, 1992).

There are many theories for this over-representation including:

- People with an intellectual disability can be more likely to engage in delinquent behaviour due to impaired cognitive abilities [3]
- People with an intellectual disability are more likely to be living in community environments where they can become involved in or suspected of committing crime [4]
- People with an intellectual disability may not be more delinquent than others, however they are often found to be so by the courts due to their vulnerability in criminal justice processes [5]
- Lack of identification and insufficient advocacy for young people with an intellectual disability seem to be factors that strongly correlate to their over-representation in the criminal justice system [1]

People with an intellectual disability often display attributes and behaviours that may increase their entry into the criminal justice system. Some of these include:

- A desire for recognition and status
- Difficulty complying with bail conditions or community orders
- A yearning for acceptance and belonging - an often unmet need for meaningful relationships
- Low self esteem
- Poor social skills and inability to deal with problems
- Restricted social networks and lack of family/community support [5]

Aboriginal and Torres Strait Islander people are significantly over-represented within the criminal justice setting at all levels, and around 13 times more likely to be imprisoned during their life than non-Indigenous people.

See the following sections for further information on Aboriginal and Torres Strait Islander young people.

6 Aboriginal and Torres Strait Islander young people
7 Screening an Aboriginal and Torres Strait Islander young person for intellectual disability
13 Working with an Aboriginal and Torres Strait Islander young person

# 4. Definitions

## Intellectual Disability (DSM-5 diagnostic criteria)

Intellectual Disability (Intellectual Developmental Disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains. The following three criteria must be met.

| | |
|---|---|
| 1. Deficits in intellectual functioning | Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing. |
| 2. Deficits in adaptive functioning | Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit function in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work and community. |
| 3. Onset of deficits | Onset of intellectual and adaptive deficits during the developmental period. |

The various levels of severity (mild, moderate, severe and profound) are defined on the basis of adaptive functioning and not IQ scores, because it is adaptive functioning that determines the level of supports required.

## Cognitive Impairment

Cognitive Impairment, Developmental Disability and Developmental Delay are terms that are considered broader than intellectual disability, whilst often relating to similar cognitive and functional deficits. Various conditions can result in an impairment of mental function, difficulty in learning and performing certain daily life skills, and limitations in adaptive skills. There may also be no specific diagnosis. [6]

Cognitive Impairment generally refers to a disability that arises during the developmental period (usually before 18 years of age) and can include conditions such as cerebral palsy, which can also be of a physical rather than an intellectual nature. Some developmental disabilities may be overcome with or without treatment, and may not be permanent. [7]

## Global Developmental Delay

A diagnosis reserved for individuals *under* the age of 5 years who fail to meet expected developmental milestones but are too young to undergo a systematic assessment of intellectual functioning.

## Unspecified Intellectual Disability

A diagnosis reserved for individuals over the age of 5 years when a systematic assessment of intellectual disability (intellectual developmental disorder) is not possible due to co-occurring sensory or physical impairments such as blindness, pre-lingual deafness, locomotor disability, mental health or severe behavioural problems.

## Communication Disorders

A range of disorder associated with difficulties in the acquisition of language and/or deficits in communication (spoken and written) including: Language Disorder, Speech Sound Disorder, Childhood-Onset Fluency Disorder (stuttering), and Social (Pragmatic) Communication Disorder.

### Acquired Brain Injury

An acquired brain injury relates to damage a person has sustained to their brain. This can be through a head injury caused by an accident or violence, through drug and/or alcohol abuse, abuse of other chemicals such as petrol or glue, or serious illness. The acquired brain injury is generally described as having been sustained following a 'normal' development. [8]

Young people who have suffered an acquired brain injury may exhibit the same behavioural and cognitive presentations as a young person with an intellectual disability. Damage to the brain may lead to intellectual and adaptive deficits such that the person would be classified as having an intellectual disability if their onset had been in the developmental period.

- Information Sheet 1: Effects of Substance Abuse
- Information Sheet 2: Alcohol Related Brain Injury

## 5. Causes of intellectual disability

There are many causes of intellectual disability; however in a large percentage of cases, the reasons remain unknown. [3]

Research has suggested that the following factors may have a causative link:

- Brain injury or infection before, during or after birth [4]
- Problems during pregnancy, labour or birth (eg lack of oxygen)
- Drug misuse in pregnancy – including though not limited to smoking and excessive alcohol consumption [9]
- Problems with growth or nutrition during developmental stages [9]
- Genetic conditions/disorders [10]
- Extreme premature birth [11]
- Medical conditions of infancy or childhood (eg any trauma, and/or diseases like cooping cough, measles, meningitis or any infection of the central nervous system) [11]

- Information Sheet 3: Syndromes Associated with Intellectual Disability
- Information Sheet 4: Common Co-Morbid Mental Disorders

## 6. Intellectual disability and mental health

Intellectual disability has been highly correlated with the occurrence of other diagnosable psychiatric disorders. An Australian study found that 40.7% of children and adolescents sampled with an intellectual disability could also be classified as having severe emotional or behavioural disorders.[12]

Differential diagnosis can prove especially problematic with a young person with an intellectual disability. This is due to the frequency that other problems present co-morbidly with intellectual disability. Throughout your assessment, it is important to consider the following as possible co-morbid disorders:

- Physical factors - especially those which may be causing pain, discomfort and frustration
- Sensory impairments - eyesight and hearing problems are common and should be screened for
- Epilepsy and other seizure disorders are frequently diagnosed in those with intellectual disability
- Medication effects

- Other developmental disorders including; autistic spectrum disorders, ADHD, dyspraxia (coordination disorder), tic disorders, specific learning difficulties in communication, reading or writing

- Mental illness occurs at a significantly higher rate in those with an intellectual disability [13]

Individuals with a diagnosis of intellectual disability and co-morbid mental health conditions are at greater risk of suicide. A discussion of suicidal thoughts is essential in the assessment period. The risk of accidental injury is also increased due to greater impulsivity and a lack of awareness of danger or negative consequences.

Information Sheet 3: Syndromes Associated with Intellectual Disability
Information Sheet 4: Common Co-Morbid Mental Disorders
Intellectual Disability Mental Health First Aid Manual (2.74MB) [14]

See the following section for information on Assessment:

9 Assessment

# 7. Aboriginal and Torres Strait Islander young people

Aboriginal and Torres Strait Islander young people with an intellectual disability are highly represented in the Juvenile Justice system, although the disability may not be recognised. This lack of recognition may be due to issues around how Indigenous communities may not recognise disability, masking of the disability by social and economic disadvantages, cultural issues and the lack of training in the criminal justice system. It is impossible to provide generic guidelines for working with Aboriginal and Torres Strait Islander young people with an intellectual disability due to the vast diversity in Indigenous populations. [15]

Information Sheet 5: Aboriginal & Torres Strait Islander Historical Context
Information Sheet 6: Aboriginal & Torres Strait Islander Culture and Language

Definitions of disability differ within Aboriginal and Torres Strait Islander communities from those of western culture. There are of course, individual differences between people and cultural groups, though generally Aboriginal and Torres Strait Islander people may only regard highly visible conditions such as strokes or amputation as a disability. Less visible disabilities (as defined by western medicine) are not generally considered as important as social stigma and socio-economic disadvantage, which tends to take precedence. In some contexts, intellectual disability and hearing impairment may not be considered disabled or abnormal. [16]
Many Aboriginal and Torres Strait Islander people have concerns about having an intellectual disability formally recognised, as this is not seen as beneficial to the person. The label of disability has the potential to further stigmatise an already marginalised person. [17]

The issue of shame is of significant importance to Aboriginal and Torres Strait Islander people, and in particular for young people. One is 'shamed' when they are singled out from the security and anonymity of the group for any purpose. Being identified as having a disability can be seen as a cause of 'shame'. [16]

The use of the term 'cognitive' or 'intellectual' disability is problematic for Aboriginal and Torres Strait Islander people. This is due to the racist implication that Aboriginality is the cause of reduced intellectual ability. Using these terms can further stigmatise or label those who already have to contend with negative attitudes from the mainstream population.

You should always seek specific information through consultation with appropriate Elders, Indigenous persons with knowledge of the young person's cultural background, or the Aboriginal Strategic Coordination Unit.

See the following sections for further information on Aboriginal and Torres Strait Islander young people with intellectual disabilities.

7 Screening an Aboriginal and Torres Strait Islander young person for intellectual disability
13 Working with an Aboriginal and Torres Strait Islander young person

# 8. Screening

It is difficult to provide a complete picture of the presentation of a person with an intellectual disability, due to a vast range of individual differences. Research has shown that young people involved in the criminal justice setting who have an intellectual disability, generally fall within the mild range of disability. They are likely to come from deprived and disruptive backgrounds, have relative impairments of communication and social skills, and are more likely to have had a greater number of care placements outside the family home, than peers without an intellectual disability. [3]

The behaviour of a person with an intellectual disability is sometimes mistaken for that of a person under the influence of alcohol or other drugs, or that they are being deliberately non-compliant. [5]

A large proportion of people with an intellectual disability can function independently. They experience the full range of human emotion, aspire to have varied life experiences, and can learn to adapt to new situations. [11]

| **Common characteristics of a person with an intellectual disability** [18] | |
|---|---|
| May not communicate at age level | ▪ Short attention span<br>▪ Difficulty understanding questions and instructions<br>▪ Responding inappropriately or inconsistently to questions [5]<br>▪ Limited vocabulary; may have speech deficit<br>▪ Difficulty understanding or answering questions<br>▪ Inability to read or write<br>▪ Mimics responses or answers<br>▪ May answer, 'yes' to all questions asked |
| May not behave at age level | ▪ Prefers younger persons (children) for friends<br>▪ Inappropriate interactions with peers or opposite sex<br>▪ Easily influenced by and anxious to please others<br>▪ Difficulty making change, using telephone, telling time, etc<br>▪ Low frustration tolerance |
| May not understand consequences of situations<br>May not understand consequences of situations (cont) | ▪ Doesn't appreciate seriousness of situations<br>▪ May not reflect on actions; acts impulsively<br>▪ May try to please others and disregard legality of actions<br>▪ A follower, often not initiator of criminal activity |
| May not behave appropriately in criminal justice situations | ▪ May not understand rights or issues of mandatory reporting<br>▪ May be overly willing to confess, or discuss offences not charged with<br>▪ Difficulty recalling facts or details of offence<br>▪ Tendency to be overwhelmed by Police/Juvenile Justice authority<br>▪ May not want disability to be noticed |

## Screening an Aboriginal and Torres Strait Islander young person for intellectual disability

The identification of intellectual disability in an Aboriginal and Torres Strait Islander young person can be problematic due to a number of factors including:

- The lack of culturally appropriate screening assessment tools [17]
- The young person and/or their family not recognising the problem as being an intellectual disability, or it being seen as 'cultural difference' by others
- The young person hiding their disability
- Mild intellectual disability can be masked by more evident physical disabilities, substance abuse disorder, or issues caused by disadvantage

Juvenile Justice is currently in the process of validating a screen (CAIDS-Q) for Intellectual Disability in order to assess its suitability and usefulness within an Australian population.

See the following sections for further information on Aboriginal and Torres Strait Islander young people with intellectual disabilities.

6 Aboriginal and Torres Strait Islander young people
13 Working with an Aboriginal and Torres Strait Islander young person

# 9. Referral

If you suspect that the young person you are dealing with may have an intellectual disability, speak to your Manager or supervisor and refer the appropriate flowchart below.

Referral and subsequent actions will depend on the legal status of the young person, whether or no the court has requested a psychological assessment, and where he/ she is situated (community or custody).

- Flowchart 1: Young Person on Bail in Community
- Flowchart 2: Young Person on Remand in Custody
- Flowchart 3: Young Person on a Custodial or Community Order

# 10. Assessment

CIMS referrals can be made to Juvenile Justice Psychologists for specific assessment and intervention planning. Talk to your supervisor about the need to make a referral.

The assessment of a young person with a (potential) intellectual disability can be critical to their legal situation and their management as Juvenile Justice NSW clients.

## Before an assessment is conducted

- As with all psychometric assessment, it is essential to determine if previous assessment has been undertaken
- Determine if you are the correct person to be undertaking the assessment and ensure that you have been appropriately trained to use the psychometric instruments
- Familiarise yourself with the Section 32 (s32) of the Mental Health (Criminal Procedure) Act 1990 guidelines which are discussed in 14 Federal and State Legislation and follow up if the young person has grounds for appeal
- Ensure you have valid consent from the young person. See the section on Valid Consent below

## Valid consent

An issue that often arises when working with young people relates to valid (previously termed 'informed') consent[19]. This can become more problematic when the young person also has an intellectual disability. Generally, the age for providing valid consent for assessment or treatment is 14 years; however the range between 14 and 16 years is often unclear. When the young person has an intellectual disability, it can be difficult to determine if the client has sufficient functioning to provide valid consent, particularly if the assessment to be undertaken is to determine cognitive functioning.

The most significant question in determining issues of consent relates to the individuals' ***capacity*** to make the particular decision.

For a person to have the capacity to take a decision, they must be able to:

- Comprehend and retain:
  - information material to the decision
  - the consequences of having or not having the intervention in question
- Use and weigh this information in the decision making process [20]

It is always helpful to have a parent or carer involved in any assessment process, and utilising their permission can serve as valid consent when you are unsure of the young person's capacity. When clinically engaging a young person with an intellectual disability, the following suggestions may prove helpful:

- Always ensure you explain any proposed assessment or intervention to the young person in a language that they can understand (i.e.: "...these activities will help us find out what you are good at, and how we can help you here")
- Gain parental/guardian consent wherever possible when you are unsure of a young person's capacity
- Young people with an intellectual disability sometimes feel that decisions are made for them. Include the young person in the assessment and intervention process wherever possible
- Explore the young person's ability to paraphrase what has been said and to compare alternatives
- Consider if the young person can apply the information you have provided to his or her own situation [21]
- Always document that you have explored the issue of voluntary participation [22]

## Problems conducting an assessment interview

A young person with an intellectual disability can prove problematic to interview due to issues directly related to their disability. Areas of intellectual disability that may influence the assessment process and subsequent formulations have been identified (see the following table).

**Areas of intellectual disability that may influence the assessment process** [23]

| | |
|---|---|
| Intellectual Distortion | Emotional symptoms are difficult to elicit because of deficits in abstract thinking and receptive/expressive language skills |
| Psychosocial Masking | Limited social experiences can influence the content of psychiatric symptoms (eg: mania presenting as a belief that one can drive a car) |
| Cognitive Disintegration | Decreased ability to tolerate stress can lead to anxiety-induced decompensation |
| Baseline Exaggeration | The severity or frequency of chronic maladaptive behaviours can increase after the onset of psychiatric disorder |

See the following section for further information on intellectual disability and mental health.

5 Intellectual disability and mental health

## Tips for conducting an assessment interview

Interviewing a young person with an intellectual disability will usually take more time than for a non-disabled one. These young people often come from complicated backgrounds, and significant effort can be required to gain information about the systems they have been involved with. Specific considerations for interviewing include:

- Ensure an appropriate environment, minimising distractions
- Ideally, interviewing should be conducted over several shorter sessions due to attention and concentration problems
- Have a family member, carer or familiar staff member introduce you if possible
- Take time to build rapport
- Young people with an intellectual disability are often known to services such as the Department of Education, Community Services, ADHC, Centrelink, and community health. Check with carers or caseworkers as to previous contacts
- Young people with an intellectual disability are often considered to have "special education" needs. A history of school placement in high support classes may have been due to behavioural issues, and an underlying disability may not have been identified [3]
- Young people with an intellectual disability generally resort to memorising information, which becomes problematic as the verbal load increases. Give verbal information in small doses, and check comprehension often [24]

See section 10 Interacting with the young person below for tips on communicating with the young person.

# 11. Working with the young person

While the assessment process may be underway, you still need to work with the young person. Depending on your setting (community or custody) the information contained in these sections may be able to assist you by providing ideas on how best work with a young person with a potential intellectual disability.

## Tips for engaging and interacting with the young person

Remembered the following tips when building relationships and interacting with any young person who has an intellectual disability or cognitive impairment.

***Relax and be yourself***

Try not to worry when interviewing or otherwise interacting with a young person who has an intellectual disability, just be as open and honest as you can. Act naturally and don't monitor your every word and action for fear of saying or doing the wrong things. If you are relaxed, calm and positive you will appear more confident, and will encourage the young person to respond in a similar manner. Adolescents are masters of determining whether or not adults are genuine, especially our clients who tend to have highly tuned survival skills and are experts at 'reading' non-verbal messages including body language. A member of staff who is not being genuine will quickly lose their credibility and the respect of the young person. In the same way, if you don't model respect, the young person can't be expected to respond in a positive, pro-social manner. Model the behaviours you expect young people to display.

***People first***

When interacting with anyone who has a disability (cognitive or physical) or talking to others about a person with a disability, always identify the person first and then the disability (eg "a young person with an intellectual disability" rather than "an intellectually disabled young person"). It may not be relevant to mention the disability, so don't feel obliged to do so. Emphasise abilities rather than disabilities, but without hyperbole. Always avoid labels that stereotype or devalue. Always treat the young person with respect and ensure dignity and privacy. Create a climate where appearing different is accepted and encouraged. Create the space and safety for the expression of that difference.

Information Sheet 7: People First Language

***Use appropriate language***

Speak clearly and slowly in a calm and quiet voice. Use simple, short statements or questions. Be specific and concrete, avoiding jargon or abstract ides (eg "later", "maybe", "soon", "sometimes"). The concept of time can be very difficult for a young person with intellectual disability. Some young people may struggle with questions about the duration of a problem or behaviour over longer periods as they are unable to distinguish a single event from a history of events. Try using an 'indexed event' that has meaning like a birthday, Christmas or court appearance, to establish timelines that make sense to the young person. Use normal tone and don't raise your voice. Don't swear as a way of relating to a young person; maintain your adult stance. Don't use slang terms that aren't within your normal vocabulary. Don't assume that a person with an intellectual disability also has a hearing impairment. Use non-threatening language (including body language). Avoid being judgemental, critical or flippant.

***Never break a promise***

When you make a promise to a young person and follow through, you are fostering a sense of trust (in you and in other adults). Breaking a promise reinforces a young person's belief that adults can't be trusted, that they say one thing and do another. Don't make promises in the pressure of the moment that can't be kept. The work will quickly spread that you can't be trusted or that you can be manipulated under pressure.

***Keep questions simple***

Use open questions when ever possible (eg "How are you feeling?", "Why did you do that?", "What happened next?") or elicit information use "Tell me about …" or "I'm interested in …". Closed questions (ie those that require only a "yes" or "no" response) may be used for clarification, but be careful not to ask leading questions as people with an intellectual disability are often suggestible and will tell you what they think you want to hear or what they think is the 'right' answer. They may just respond with "yes" to everything. Ask one question at a time, as asking multiple questions or a single question with several parts will only confuse the young person. Similarly, only make one request at a time, ensure that what is being requested is achievable and be clear regarding your expectations.

***Check understanding***

Take regular breaks and check the young person understands what is being said by asking them to repeat what they have just heard and understood in their own words. Don't assume that their ability to express themselves is an indication of how much they understand. Similarly, don't pretend to understand something if you don't. Asking a young person to explain a slang term, for example, allows you to experience a dual role, one of teacher and one of student. This helps to create an opportunity for the young person to share knowledge and feel heard. Listen carefully and check back or paraphrase in order to assist your understanding. Ask them to repeat what they have said in another way if they can. They may have a preferred way of communicating that might help. Some young people favour communication through pitchers and written words over spoken language. Writing a list of key words, or drawing pictures, as you go through topics can improve understanding.

***Be patient and supportive***

People with an intellectual disability need sufficient time to respond or otherwise act independently. Be prepared to repeat information as many times as necessary. Don't assume that the young person will be able to generalise skills learned in one context or situation to another. Be supportive. Reassure often.

***Focus on abilities***

A young person with an intellectual disability may have many positive attributes. They may have a good sense of humour, be creative, determined, show a desire to please and/or have artistic or musical talent. If successes can be encouraged whether it is within custody, during a community order or other dealings with Juvenile Justice, the young person can learn and build on small successes.

## Communicating with the young person

Communication can be problematic with a young person who has an intellectual disability. The young person can be overwhelmed with complex requests and answer 'yes' to all questions to avoid looking silly or admitting that they do not understand. Young people may present with varying degrees of intellectual disability. Some of the following tips may not be appropriate for young people with a less severe intellectual disability. [25]

| Things to Consider When Communicating with the Young Person with an Intellectual Disability | |
|---|---|
| In General | ▪ In any situation with all young people, it is important to identify yourself and explain your role<br>▪ A young person with an intellectual disability may need you to briefly re-introduce yourself at each contact several times as they can have difficulty remembering names and faces<br>▪ Minimise distractions - check the environment for excessive heat, light and noise<br>▪ Allow frequent breaks<br>▪ Make eye contact and face the person<br>▪ Talk directly to the person, not through a carer or other staff<br>▪ Use simple language; speak slowly and clearly<br>▪ Be careful not to 'overload' the young person with information<br>▪ Use concrete terms and ideas and check understanding often - ask questions<br>▪ Discuss one topic at a time, don't introduce a new topic until the last one is understood and can be paraphrased back to you<br>▪ Utilise pictures or diagrams if appropriate<br>▪ Avoid questions that tell the person the answer you expect<br>▪ Phrase questions to avoid 'yes' or 'no' answers<br>▪ Break down information into smaller chunks and repeat questions from a slightly different perspective<br>▪ Ask for concrete descriptions and keep the conversation focussed<br>▪ Remind the young person of the topic and re-direct the conversation if they get off track |
| In General (cont) | ▪ Proceed slowly and give praise and encouragement<br>▪ Avoid frustrating questions about time, complex sentences, or reasons for behaviour<br>▪ Never make fun of the person; they will sense it and become less cooperative<br>▪ Be patient and respect the individual |
| Telephone communication | ▪ A young person with an intellectual disability can have particular difficulty communicating over the phone [26]. Firstly, it is essential to establish if they have a hearing impairment that would make phone contact difficult.<br>▪ Don't interrupt or finish the person's sentences<br>▪ Use open questions (avoiding the response of yes or no answers)<br>▪ Use simple words and sentences - one idea at a time |

| Things to Consider When Communicating with the Young Person with an Intellectual Disability | |
|---|---|
| | ▪ Avoid abstract concepts and don't use jargon or acronyms<br>▪ Remember that the young person may need more breaks and shorter sessions<br>▪ Slowly read out information and phone numbers if the young person needs to write them down |
| Written Communication | ▪ Find out about the young person's skill level in reading and writing. If the young person has difficulty in reading, ensure the information is also conveyed in person or over the phone<br>▪ Ensuring carer or staff members are aware of information (with consent) that can assist in reinforcement (such as a appointment letter, conference dates, etc) [25]<br>▪ Use formatting that is easy to read such as 14 or 16 point font as Arial with at least 1.5 spacing. Use headings and dot points<br>▪ Write short sentences and paragraphs in simple, plain language<br>▪ Include only necessary information |
| Observing your own body language | ▪ What message is your body language giving others? Does your verbal communication say one thing and your body language another?<br>▪ Respond to our 'feeling' state, listen to your 'gut' instinct<br>▪ Describe it, (when appropriate) rather than interpret it, be honest with those feelings and in doing so, give young people a structure and format for describing their own feelings |
| Behaviour as communication<br><br>Behaviour as communication (cont) | ▪ All behaviour is communication, whether a young person **shows** as well as describes, or **acts** as well as talks about - all behaviour sends a message to those around us.<br>▪ Many adolescents have problems with verbal communication, and use non-verbal communication as a preferred method of sending and receiving messages to others<br>▪ Examples of non-verbal communication include:<br>– A young person who feels 'out of it' may close their eyes or physically move or withdraw from the group<br>– A young person who feels 'close' to someone may physically move closer or lean toward them<br>– A young person who distracts others by fooling around or arguing may actually feel frightened or uncomfortable with what is currently going on<br>– A young person who puts their arm around another young person in what appears to be a friendly action, may be in fact, threatening or coercing that person<br>– A loud or aggressive young person may actually be frightened<br>– A young person who creates havoc may actually want a nurturing response, but is unable to articulate those needs |

### Running a Group

Young people with an intellectual disability can have significant trouble learning in a group-like environment. Despite this, a group environment can provide the individual with an excellent opportunity to participate socially in a structured way with peers. Opportunities for modelling of interpersonally appropriate behaviour, dealing with various viewpoints; turn taking and negotiation are intrinsic in group process.

The following suggestions may assist you in designing group interventions: [27]

- Be creative with delivery material. Don't just rely on verbal communication, use multi-modal strategies (visual, auditory, tactile, kinaesthetic)
- Provide simple handouts to help reinforce more abstract concepts
- Don't use euphemisms, figures of speech or sarcasm. Keep language clear.
- Use role plays of different situations to facilitate generalisation of social skills
- If the setting allows, use art and music as young people with an intellectual disability often relate to these interventions very well
- When giving verbal instruction, write down visual summary points on a board
- Establish group rules - in conjunction with the group and consistently enforce them
- Remember non-compliance may mean that the message was too ambiguous

### Goals in Social Skills Development

Specific social behaviour skills that can be goals for intervention can include: [28]

- How to negotiate for what you want
- How to accept criticism
- How to show someone you like them
- How to get attention in a positive way
- How to handle frustration, disappointment and fear

## 12. Managing the young person

The table below lists stressors that may trigger problems in individuals with a cognitive impairment or intellectual disability.

A complete evaluation and an individualized treatment plan require attention to the possible short-term and long-term stressors that may be triggering or exacerbating psychiatric disorders or behavioural problems in persons with intellectual disability.

Although none of the stressors listed are specific to individuals with an intellectual disability, each is more likely to occur and cause difficulties in those whose coping skills already are compromised substantially.

Helping the individual, family, and caregivers deal with or eliminate stressors sometimes may be the primary target of treatment, and this often opens the door to a realisation of other treatments that may be necessary.

| Stressors That May Trigger Behavioural Problems [29] | |
|---|---|
| **Type of Stressor** | **Examples** |
| Transitional phases | ▪ Change of residence (eg incarceration)<br>▪ New school or work place<br>▪ Altered route to work<br>▪ Developmental changes (eg, entering puberty) |
| Interpersonal loss or rejection | ▪ Loss of parent, caregiver, friend, roommate<br>▪ Break-up of romantic attachment<br>▪ Being fired from a job or suspended from school |
| Environmental | ▪ Overcrowding, excessive noise, disorganization<br>▪ Lack of satisfactory stimulation<br>▪ Reduced privacy in congregate housing<br>▪ School or work stress |
| Parenting and social support problems | ▪ Lack of support from family, friends, or partner<br>▪ Destabilizing visits, phone calls, or letters<br>▪ Neglect<br>▪ Hostility<br>▪ Physical or sexual abuse |
| Illness or disability | ▪ Chronic medical or psychiatric illness<br>▪ Serious acute illness<br>▪ Sensory defects<br>▪ Difficulty with ambulation<br>▪ Seizures |
| Stigmatisation because of physical or intellectual problems | ▪ Taunts and teasing<br>▪ Exclusion<br>▪ Being bullied or exploited |
| Frustration | ▪ Due to inability to communicate needs and wishes<br>▪ Due to lack of choices about residence, work situation, diet<br>▪ Because of realization of deficits |

## Responding to inappropriate behaviour

- Look for patterns of re-occurring problem behaviour – what, who, when, where, how
- Discuss the behaviour with the young person
  - What is the need that the problem behaviour is trying to meet? (What do they want?)
  - Define problem behaviour objectively – priorities
  - Define target (desired behaviour) objectively – desired outcome
  - Ensure other factors are understood such as age, IQ, mental health, disability, development, setting
- Brainstorming solutions to the problems
  - Consult a psychologist or counsellor
  - Select the behaviour to be learnt
  - Break the desired behaviour into components
- Make a plan
  - Prioritise addressing behaviours that place the client/others at risk
  - Promote pro-social behaviours

Developing a plan can be difficult, particularly when the behaviour is serious (such as inappropriate sexual conduct) or constitutes a minor misbehaviour. In these cases, consequences must be imposed in accordance with the relevant behaviour management/minor misbehaviour guidelines.

A good behavioural intervention should:

- include community caregivers and division staff
- formulate specific treatment goals, remembering what can reasonably be accomplished within the time constraints
- avoid (as much as possible) treatments that cannot be continued in the community, such as medications taken as required or seclusion and restraint
- take into account the crucial importance of variables such as consistency versus change in the patient's environment, greater or lesser supervision of the patient's activities, identification of possible stressors, and implementation of behavioural management strategies
- use therapy, activity groups, or both to bring out the person's capacity for learning and participation (for more cognitively impaired or acutely psychotic individuals, focus groups may be used to improve orientation) [10]

## Approaches to Behaviour Intervention

Multidisciplinary treatment teams use a variety of psychosocial modalities to address behavioural problems experienced with people who have an intellectual disability. The behavioural interventions recommended by the expert consensus panel [29] or most situations are listed in the following table.

| Behavioural Intervention | Description |
|---|---|
| Applied Behaviour Analysis | Techniques that are based on the principles and methods of behaviour analysis and are intended to build appropriate functional skills and reduce problem behaviour include the following:<br>▪ *Behaviour-accelerating procedures*: such as contingent reward for specific behaviours that are incompatible with problem behaviour<br>▪ *Behaviour-decelerating techniques*: such as contingent reward for specified time periods during which the problem behaviour did not occur; extinction; overcorrection; response cost; time-out |
| Behavioural parent and teacher/staff training | To help them function as co-therapists and/or to avoid incidental reinforcement of the problem behaviour |
| Client and/or Family Education | Helping clients and/or families understand more about the behavioural psychiatric problems that may accompany intellectual disability and how to manage them |
| Managing the Environment | Reducing problem behaviours by rearranging physical and/or social conditions that seem to provoke them, for example: changes in activities (*eg*, noise, temperature, lighting, crowding); and/or enrichment of environment through social or sensory stimulation. |

Reactive strategies may provide better ways of handling the problem behaviour when it occurs.

- Manage the situation (ignore, redirect, give feedback, instruction, stimulus change, safe physical management)
- Active listening (or reflective listening) is the single most effective reactive strategy
- Self-control and self-protection (acknowledge emotions, stress/anger management, make safe)
- Match, pace, lead (mirror but guide behaviour)

- Natural consequences (not helpful if they lead to problem escalation)
- De-escalate (towards comfort, de-arousal)

| Behavioural Intervention | Description |
|---|---|
| Environment | Be aware of the environmental factors that could be contributing to the behaviour.<br><br>Take note of lighting, heat, noise and distractions. For example, don't request complex behaviour from an AD/HD child in a distracting environment.<br><br>Ensure that the environment is as safe as possible by removing potential weapons, self-harming implements etc. (particularly dangers and opportunities for natural reinforcers to take over). |
| General Skills Training | Training (positive programming) that will teach skills and competencies to facilitate behaviour changes, that help resolve the problem and also have wider beneficial consequences towards social and community integration (e.g. social, living and communication skills including conflict resolution).<br><br>▪ Communication skills<br><br>▪ Functionally related skills, such as:<br>– how to discriminate<br>– make choices<br>– predictability and control<br>– useful rules (a lot of behaviour is governed by rules, not contingencies)<br><br>▪ Coping skills (desensitisation, shaping, relaxation training) |
| Focussed Support | Focussed support is a learning program that addresses the specific problem behaviour directly. What skills can be learnt that will achieve the person's legitimate goal without the need for the undesired behaviour (work on with the client)? It involves skills training based on schedules of reinforcement (eg Differential Reinforcement of Other Behaviour, Differential Reinforcement of Lower Rates of Responding, and Differential Reinforcement of Alternative Responses, including modelling, practice, reinforcement schedules, star charts, and review).<br><br>Examples of skills are:<br><br>▪ Identify for themselves, and let a trusted person know, when they are feeling unsafe<br>▪ Communicate appropriately<br>▪ De-arousal strategies |

## Implementing the behaviour intervention plan

***Initial Response***

Where the disruptive behaviour (e.g. interruption of an ongoing activity) does not place the young person or others at risk, and has minimal effort on the group, ignore the behaviour (i.e. make no comments about it) and redirect them to an alternative, pro-social activity

When the behaviour is irritating or disruptive, it is appropriate to redirect the young person by focusing on the behaviour you want, not the undesired behaviour. So, for example, you might say "Please speak to me in a softer voice"

Use reassurance with the young person, emphasise that you are there to help them. Use a calm tone of voice and avoid getting into an argument

Reward appropriate behaviour. Give praise when the young person regains composure after an outburst.

***How will the client learn the new behaviour?***

Decide who will be part of the support team (including management) to help the client learn the new behaviour. Is there staff motivation to change practices to achieve this? Do they understand the behavioural perspective? What staff training is necessary to learn how to deliver the program effectively?

Decide how the support team will learn to observe, train the young person, apply the new reinforcement schedules, give feedback to enable program adjustment, etc. Maintain everyone's motivation, role play new strategies if necessary. Communicate the plan to all stakeholders – all must understand and agree to it.

It will be much more effective if the young person understands the program. Use pictures, diagrams, reminders.

Monitor for compliance, with scheduled review meetings. Allow for relapses. Use observation/star chart, to track changes. Review all factors: environment, skills training, focussed support, reactive strategies. Is the plan heading the right way, or needing revision? If the young person moves, or circumstances change, the plan needs to be amended.

***Setting Limits***

Set firm limits and provide the young person with specific instructions regarding expected behaviour.

- Set and reinforce clear limits in plain language, use regular repetition
- Be prepared to listen carefully to the young person, and explain misunderstood concepts
- Try not to demand – explain what you want them to do in clear language
- Ignore negative and critical comments
- Try not to take the behaviour personally

***Warning with Consequence***

When inappropriate behaviour does not place the young person or others at risk, but has an effect on others:

- Give a warning first about the consequence if they continue with the behaviour
- The best consequences are ones that are going to occur naturally (e.g. "Please speak calmly. I will be able to understand you better and help you out if you talk in a softer voice"), but you may need to use ones that result from the custodial environment (e.g. "Please speak to me calmly. Don't yell and swear or you may not earn all your points today")
- Use objective statements that are delivered in a matter-of-fact manner (e.g. "If you continue to swear, you will not gain points and you may be committing a minor misbehaviour")
- Make sure the consequence is one that can and will be carried out

If the young person chooses to continue with the behaviour, staff will have to implement the consequence. It is imperative that consequences occur.

***Feedback to the young person***

Give feedback about both the resident's pro-social and negative behaviours. Be careful to make it clear that it is the behaviour that is not acceptable, and not the person themselves when giving feedback about their negative behaviours. When giving such feedback, avoid giving the young person a sense of rejection from others.

***Rewards for Pro-Social Behaviours***

Give social rewards immediately following the appropriate behaviour. Examples of social rewards: praise, attention, approval, and social activity with staff, social privileges … (Note: Material rewards can be used occasionally if considered it appropriate, and can be arranged)

Any reward must be given IMMEDIATELY. This will ensure they are not unintentionally or incorrectly being rewarded for any negative behaviour, which could have occurred between the time of the appropriate behaviour and the time when they receive the reward.

To maintain pro-social behaviours over a period, staff should periodically give rewards (social/material), rather than ignore these behaviours once they are established.

***Setting Clear Boundaries and Realistic Expectations***

Given the difficulty some young people have in differentiating between fantasy and reality, staff members need to make the boundaries clear with regard to others' personal space and personal details, while acknowledging their emotional need for ties with individuals.

Encourage the young person to have realistic expectations in his/her relationships with others, and in situations (as opposed to fantasizing about such relationships and situations).

Communicate your confidence in your ability to manage the young person's behaviour.

## Dealing with bed time in Juvenile Justice Centres

For many of our clients who have led a disturbed and difficult upbringing, bedtime in a Juvenile Justice Centre will be a time of high excitement, fear and avoidance.

Going to bed (for some young people) may be associated with trauma, drunkenness, violence, being left alone, feeling vulnerable or being sexually abused.

Staff too, may become tense in response to the young person's anxiety, which can in turn lead them to feel angry and act punitively. They may even punish residents by sending them to bed. For some young people, this may be their only association with bedtime and bedrooms.

Young people who fear nightmares and the vulnerability of going to sleep, will often want to stay up late, watch TV, or rush around and create chaos.

The challenge for Youth Officers is how to make bedtime calm and safe in a prevailing atmosphere of chaos and over-excitement. The following may help in this challenge:

- Maintain the essential element of a reassuring, calm, (and to some extent) controlling presence on the unit
- Maintain a well ordered unit, where staff understand, but do not condone acting out behaviour
- Think and plan ahead
- Never expect the young people to be compliant or look forward to going to bed!
- Consider the evening's activities. Young people often feel that their behaviour and lives are out of control, and they need you to be in control! If they do not feel that you are in control, then they will act 'out of control', forcing you to bring some order to the situation
- Ascertain who is working that night and who is the most appropriate person to 'put the unit to bed'
- Think about what happened the previous night, and what if any, is the pattern of the evening and prospective bedtime at the moment
- Know the whereabouts of all residents, either in or out of their rooms
- Provide a transition between exciting/energetic activities and preparation for bedtime
- Never use bedtime as a punishment or a threat
- Do not initially put the residents to bed and then immediately go to your office - stay around for a while; keep your eyes and ears open to prevent all your good work being undone in seconds!

## Young people with limited reasoning, comprehension and low self esteem

Young people who have low intellectual functioning often have limited reasoning, reduced comprehension abilities and sometimes low self-esteem. Also, some young people you work with will have experienced rejection, abandonment and will have been told, either explicitly in words, or by the actions of their primary caregivers that they have little or no value to their family or society. These individuals require special attention and management.

- Acknowledge their presence, and provide them with your time and resources
- Take into account the young person's level of functioning in all interactions with him/her
- Use simple language for instructions and explanations
- Repeat explanations if necessary (perhaps using different language or phrases and demonstrate the behaviours or activity when verbal instructions seem insufficient)
- Don't pay 'lip service' (i.e. non-genuine) to their needs or wellbeing - acknowledge the young person's needs and worth by asking what their needs are
- Be firm and maintain clear limits for behaviour (in a non-authoritarian manner)
- Do not reinforce their low self-esteem by various verbal and non-verbal interactions i.e.: turning your back on them when they speak, agreeing with peers when they tease or put the young person down
- Don't promise phone calls or actions and do not follow through
- Encourage relaxation if distressed such as physical activity, breathing, quiet time etc.
- Be vigilant when the young person is alone or in isolated areas
- Don't accept their compliance and invisibility as 'everything is OK'
- Don't encourage and reinforce their silence by promoting compliant young people as 'good'
- Don't ignore them and pay attention to other young people who are noisier or 'favourites'
- Don't allow the young person to be the scapegoat of the unit/group/task
- Young people with an intellectual disability can be willing to please persons in authority - do not take advantage of this by give the young person all of the disliked jobs

## When a Young Person Continually Lies

- Recognise that this behaviour may be a survival skill that has allowed the young person to manage his or her life until now
- Acknowledge that the skill has had some value for the young person in the past, but within the current setting (whatever it may be), the skill is not needed
- Let the young person know that you know that he/she is lying but DO this in a gentle, constructive, non-judgemental manner
- Help the young person see the discrepancies in what he/she is saying
- Acknowledge the young person's struggle in letting go of old techniques and acknowledge his/her courage in attempting new ones
- Ask the young person not to say anything on the unit, in group, during interview, etc. unless it is the truth

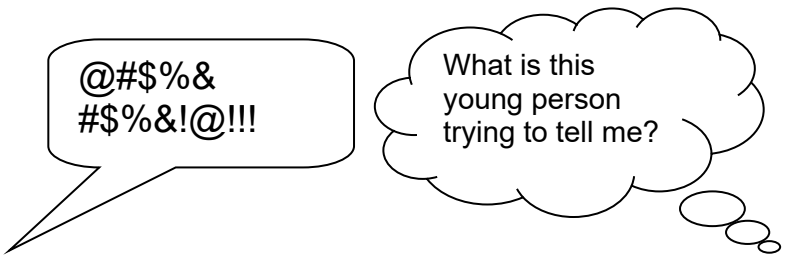
- Never 'set up' a young person to lie when you know something about them
- Be direct with the information and do not place the young person in a position that will encourage him/her to lie

## When a young person is verbally abusive

When an adolescent enters the Juvenile Justice system, remember that they behave as they do for various reasons, generally because that is what they have learned in their family or peer group.

Swearing may be a normal pattern of communication, it may be an attempt at bravado or just that the young person has not other way of explaining or expressing himself or herself. Our job as staff members is to contain unacceptable behaviour, and place limits by setting boundaries for acceptable (pro-social) behaviour.

- Swearing should not be encouraged by any staff
- Check that you are a positive role model and that you are not swearing of being abusive
- Speak in a soft non-threatening voice when requesting the behaviour to stop
- Maintain a calm approach
- Name the behaviour, and state clearly that swearing or abusive language is not appropriate in the setting
- Discuss the type of behaviour that is acceptable
- If you find this behaviour personally offensive, take responsibility for your own feelings and explain to the young person how it is affecting you (i.e.: "...when you speak like that, I feel...")
- Do not draw undue attention to the young person, as this will reinforce the negative (and unacceptable) behaviour
- Praise the attempts the young person makes to change his or her behaviour and conform to the rules
- Look for, and focus on, behaviour that you can praise (reinforce) rather than behaviour that requires modifying
- Be consistent when dealing with the young person - don't allow something one day, then enforce the rules the next



# 13. Crisis Intervention [30]

Specialist staff may be regularly called on to provide support and intervention to an offender with an intellectual disability due to inappropriate or difficult behaviour. This is of particular relevance to young people in custody. Consider the four functions of problem behaviour when dealing with a crisis situation involving a young person with intellectual disability.

| Functions of Problem Behaviour [31] |
|---|
| ***Socio-environmental control***<br><br>Aggression and self-injurious behaviour can be reinforced (e.g. by only removing a person with an intellectual disability from an unpleasant situation in response to acts of aggression or self-harm, can increase the probability that the person will react similarly in the future) |
| ***Communication***<br><br>Problem behaviours can often be a non-verbal means of communicating a variety of messages such as attention, discomfort and needs |
| ***Modulation of physical discomfort***<br><br>Medical conditions, including adverse reactions to medication, can cause physical discomfort which can lead to aggression and self-injurious behaviour |
| ***Modulation of emotional discomfort***<br><br>Problem behaviours can occur as a consequence of disorders such as major depression or bipolar disorder manic phase |

## Presentation of aggressive or self-injurious behaviour [32]

The most common categories of crisis presentations in individuals with intellectual disability are:

- New onset or escalation of aggression, self-injurious behaviour, or both
- Changes in mental status, such as:
  - Hyperactivity or irritability
  - Confusion or disorientation
  - Lethargy or withdrawal
  - Psychotic symptoms
  - Other changes in mood, energy, or sleep patterns
- Medication side effects, especially extrapyramidal symptoms
- Physical complaints or behavioural manifestations that might signify physical illness

Of these, the most frequent cause of acute crisis presentations is aggression or self-injurious behaviour. Most individuals with intellectual disability do not display this kind of behaviour. In those who do, it is not necessarily an indicator of psychiatric illness. Rather, when verbal expression is impaired, distress resulting from many possible causes may be expressed through maladaptive behaviour such as aggression and self-injurious behaviour. Such behaviour may be seen as an indication of various medical, psychiatric, interpersonal, and environmental circumstances. A thorough evaluation is required to determine the factors driving the behaviour.

## What needs to be done? [32]

When possible, intervention should be directed at the medical illness, psychiatric disorder, or other underlying cause of the maladaptive behaviour. The following table shows various factors that may incite aggression, with the appropriate treatment linked to the cause of the aggression.

It is essential to reduce distraction and over-stimulation when assessing or intervening with a young person in a crisis situation. Utilising a quiet, comfortable room away from loud noise, bright lights, heat etc. can be helpful. The goal is to increase the sense of safety and understand what precipitated the crisis situation. [33]

When approaching a young person with an intellectual disability and his or her caregivers (centre staff, family, or carers) in a crisis situation, following certain basic principles help facilitate a less stressful, more nurturing, and more accurate evaluation.

| Tips for Dealing With the Young Person in a Crisis Situation | |
|---|---|
| Secure the environment | Interview the young person in a safe, private, quiet place. Seeing, hearing, and being seen and heard by other clients and staff can be frightening, distracting, or over stimulating. Some individuals may deliberately attract attention by behaving disruptively when they have an audience. [3] |
| Act quickly | Conduct the assessment promptly. Having to wait may cause additional behavioural deterioration. [34] |
| Reassure | When possible, invite familiar staff, family, or both to keep the young person company and provide history. Individuals with intellectual disability benefit from predictable, reassuring stimuli. [33] |
| Calm everyone | Calm the young person and the caregivers. Attending to the needs and concerns of the caregivers and encouraging them to contribute to the solution can often help defuse the problem. |
| What happens next | Explain any immediate interventions simply and clearly. |
| Do no harm | Unless absolutely necessary; try to avoid measures such as seclusion and restraint that may increase the young person's distress. [29] |
| Reason for intervention | Determine the reason for the request for crisis intervention. This may seem obvious, but a hidden agenda may exist. [35] |
| Vanishing problem | Beware of the ‘vanishing’ problem. A previously agitated client, who calms down with the arrival of specialist staff, presents a diagnostic dilemma because it is difficult to evaluate a behaviour that is not in evidence. It is therefore necessary to evaluate the underlying problem, speak to the staff that have witnessed the behaviour, assess the likelihood of a recurrence, and intervene appropriately. [33] |
| Follow up | It is not necessary to resolve the problem completely immediately. You may draw on the experience and resources of the staff or caregivers to help formulate an appropriate interim plan to manage the situation. Determine the need for further assessment by a G.P or Psychiatrist either immediately by presentation to the Accident and Emergency at the local hospital, or via Justice Health and the Forensic Mental Health Network. |

# 14. Working with an Aboriginal and Torres Strait Islander young person

[36] [37] [38]

Respect for the Aboriginal and Torres Strait Islander young person's culture will assist in communication, assessment and delivery of interventions.

Information Sheet 5: Aboriginal & Torres Strait Islander Historical Context
Information Sheet 6: Aboriginal & Torres Strait Islander Culture and Language

- If you have concerns about a young persons' level of functioning - approach a Psychologist or Counsellor to talk about your concerns
- Attend training in cultural awareness and intellectual disabilities. Educating yourself will help in working with these young people
- Where a young person is identified with a disability, it is everyone's responsibility to provide a support role. HOWEVER, if the support is too noticeable, further discrimination from the peer group can result.
- A young person with an intellectual disability is at greater risk in a custodial environment due to being easily influenced, prone to misunderstanding others intentions and poor communication skills. A greater level of monitoring will be required to maintain safety.
- Indigenous young people learn through watching and participating. The modelling of appropriate behaviour is particularly important when the young person has an intellectual disability.
- When working closely with an Indigenous young person with an intellectual disability, it is important to develop strong relationships with the young person's local/regional services. This can lead to greater support for the young person and their family/carers. All Indigenous young people need to maintain close links with their family, and this is especially important when the young person has an intellectual disability. Facilitating these contacts will assist in behaviour management and help to reduce the trauma of coming into a foreign environment.
- Always utilise Indigenous support staff, as well as Psychologists and Counselling staff and community contacts to assist your work, particularly when the young person is in custody.

See the following sections for further information on Aboriginal and Torres Strait Islander young people with intellectual disabilities.

6 Aboriginal and Torres Strait Islander young people
7 Identification of intellectual disability in an Aboriginal and Torres Strait Islander young person

# 15. Working with a young person with a brain injury

There are many ways that a young person can sustain a brain injury. Some of these include; motor vehicle accidents, violence, and drug/alcohol abuse including sniffing solvents. [39]

Remember to utilise other staff members if you find yourself becoming frustrated - take up opportunities for supervision and debriefing.

| Strategies for Working with a young person with a brain injury | |
|---|---|
| Memory | Problems with memory can be the most common effect of a brain injury. This can be a problem remembering names, dates, appointments, what has been read in a book, and passing on messages. People can forget where they have put things and get lost around the streets. It is important to assist the young person in developing strategies to help compensate for the memory deficits.<br>▪ Use a diary or calendar where the days can be crossed off and important events recorded |

| Strategies for Working with a young person with a brain injury | |
|---|---|
| | ▪ Have routines clearly displayed in the unit or home<br>▪ Give clear, simple reminders of instructions verbally |
| Thinking and behaviour | People who have brain injury often find it difficult to recognise changes in their thinking and behaviour. If a problem situation arises and the individual cannot see what the issue is.<br>▪ Provide simple, clear feedback, trying to explain what the issue is<br>▪ Don't push the issue if the person continues to deny or rationalise the problem<br>▪ Having a preferred staff member or family member explain the issue can be helpful |
| Concentration | A person with a brain injury can often have problems with concentration, and complain of being bored, becoming easily distracted. You can assist in helping the young person to cope with concentration problems.<br>▪ If focus on a task is required, the environment needs to be as free of distractions as possible<br>▪ Set tasks in short stages, and allow a break in between<br>▪ Encourage the young person to try new tasks<br>▪ Be creative in making a task more interesting<br>▪ Be realistic with your expectations and build up to more complex tasks if the young person responds well |
| Slowed response times | A person with a brain injury can display slowed response times in answering questions, performing tasks, keeping up with a conversation and responding in an emergency. It is important to remind yourself that delayed responding may not be deliberate 'difficult behaviour'.<br>▪ Allow the young person time to respond to you<br>▪ Always check for understanding of your request or question<br>▪ Make only one request at a time<br>▪ Slow down a conversation so the young person can keep up |
| Planning ahead or solving problems | Another common effect of a brain injury is difficulty in planning ahead or solving problems. The young person may appear lazy or disinterested, but often they may not know where to start. Planning and problem solving are skills, which can be taught with ongoing interaction.<br>▪ Break down the problem into more manageable steps<br>▪ Clearly talk about each step, and consider the action required for each one<br>▪ Giving concrete options to the young person can help them plan what they need to do<br>▪ Write a list of the steps involved and tick off each one as it is completed - this helps with memory, initiative and planning<br>▪ Provide simple, clear feedback |
| Motivation | A person with a brain injury can have significant difficulty with motivation. If they fail in their previous attempts at tasks, the result can be frustration and embarrassment with peers and staff. Difficult behaviour can be an attempt to avoid being seen as incompetent. |

| Strategies for Working with a young person with a brain injury | |
|---|---|
| | ▪ Give encouragement and praise in successful completion of tasks<br>▪ Request support from other staff, family or carers to re-enforce the schedule that needs to be followed<br>▪ Be aware of the reactions and comments of peers, and intervene when necessary<br>▪ Schedule more demanding tasks when the young person is at their best (usually mornings) |
| Inappropriate behaviour | Many people who have had a brain injury sustain damage to the parts of the brain that involve thinking before you act or speak, frustration tolerance and controlling anger. This can lead to social embarrassment, inappropriate behaviour and angry outbursts, making their behaviour difficult to manage.<br>▪ Become aware of the triggers that seem to initiate frustration and anger<br>▪ Intervene early if you recognise the signs of an impending outburst<br>▪ Encourage the young person to let you know when they begin to feel irritated<br>▪ Work with specialist staff to design an appropriate emotional management plan<br>▪ Try not to take angry words personally<br>▪ Separate the person from the behaviour<br>▪ If a behaviour or comment is unacceptable, say so and why in a calm clear way<br>▪ Give consistent messages and consequences for behaviour<br>▪ Cue the young person to slow down and tell you what they are doing if they begin to act impulsively<br>▪ Encourage the use of relaxation skills |
| Social Skills | People with an intellectual disability or who have sustained a brain injury can often have significant deficits in social skills.<br>▪ You may need to model or directly teach social skills such as taking turns, appropriate language with peers, expression of frustration etc. Consult your specialist services staff for more information<br>▪ Be careful not to encourage inappropriate comments or behaviour. Laughter, even due to nervousness, simply reinforces the behaviour<br>▪ If a behaviour or comment is unacceptable, say so and why in a calm clear way<br>▪ Remember that inappropriate behaviours can be an attempt to gain recognition from peers, communicate a need, or simply not knowing what to do in that situation<br>▪ People with an intellectual disability or brain injury often have difficulties picking up on non-verbal communication (body language), ensure you also reinforce messages verbally.<br>▪ A person with a brain injury can have problems controlling their emotions, often crying or laughing at inappropriate times |

# 16. Working with a young person with Foetal Alcohol Syndrome

| Behaviours of young people with Foetal Alcohol Syndrome [40] [41] [42] | | |
|---|---|---|
| **Behaviour** | **Misinterpretation** | **Alternative Interpretation** |
| Non-compliance | ▪ Wilful misconduct<br>▪ Attention seeking<br>▪ Stubborn | ▪ Difficulty translating verbal directions into action<br>▪ Doesn't understand |
| Repeatedly making the same mistakes | ▪ Wilful misconduct<br>▪ Manipulative | ▪ Cannot link cause to effect<br>▪ Cannot see similarities<br>▪ Difficulty generalising |
| Often late | ▪ Lazy, slow<br>▪ Poor parenting<br>▪ Wilful misconduct | ▪ Cannot understand time<br>▪ Needs assistance organising |
| Can't sit still | ▪ Seeking attention<br>▪ Bothering others<br>▪ Wilful misconduct | ▪ Neurological need to move while learning<br>▪ Sensory overload |
| Poor social judgement | ▪ Poor parenting<br>▪ Wilful misconduct<br>▪ Abused child | ▪ Cannot interpret social cues from peers<br>▪ Does not know what to do |
| Over-active | ▪ Wilful misconduct<br>▪ Deviancy | ▪ Hyper or hypo-sensitive to touch<br>▪ AD/HD<br>▪ Does not understand about physical boundaries |
| Cannot work independently | ▪ Wilful misconduct<br>▪ Poor parenting | ▪ Chronic health problems<br>▪ Cannot translate verbal directions into action |

## Intervention Strategies

Many of the intervention strategies outlined within this document are also appropriate for a young person with Foetal Alcohol Syndrome (FAS). As intellectual disability is a common consequence of Foetal Alcohol Syndrome, similar strategies may be helpful. It is particularly important to take into consideration:

- Behaviours that result from the effects of Foetal Alcohol Syndrome can be challenging and frustrating for even the most dedicated and skilled staff member
- The results of intervention strategies can be particularly discouraging when they seem to be effective on one occasion and fail the next
- The misinterpretation of behaviour can result in a response that fosters more difficult behaviour
- Due to these difficulties primarily being due to brain dysfunction, it is not often a case of 'won't' but 'can't' [43]
- Utilise everyday situations as opportunities to model appropriate interpersonal skills

**Note**: Be mindful of the cultural background the young person is from. Seek advice from an appropriate agency (i.e. Transcultural Mental Health Centre, Migrant Resource Centre, or Aboriginal Agencies) for assistance determining how best to provide intervention to a Culturally and Linguistically Diverse (CALD) young person.

| Strategies for Working with a young person with Foetal Alcohol Syndrome[42] | |
|---|---|
| Be Concrete | The social-emotional understanding can be far below chronological age |
| Ensure Consistency | Difficulties with generalising can be minimised if everyone involved with the young person can agree on similar rules, language and standards of behaviour |
| Use Repetition | Short-term memory deficits require frequent repetition and cuing |
| Create Routine | Establishing stable routines will reduce anxiety and increase compliance |
| Ensure Simplicity | Young people with FAS are easily overstimulated and overwhelmed - keep all interventions simple |
| Be Specific | Problems with abstraction require all directions to be clear and specific |
| Use Flexibility | If one intervention is not working, be flexible and try something else |
| Ensure Supervision | Close supervision is required, as a young person with FAS can be very naive |
| Build on Success | When you find a successful intervention, use praise and share it with colleagues! |

# 17. Reporting and writing about people with a disability

## Portrayal of people with a disability

Historically, people with disabilities have been regarded as individuals to be pitied, feared or ignored. They have been portrayed as helpless victims, repulsive adversaries, heroic individuals overcoming tragedy, and charity cases who must depend on others for their well being and care. Media coverage frequently focused on heart-warming features and inspirational stories that reinforced stereotypes, patronized and underestimated individuals' capabilities.

Much has changed lately. New laws, disability activism and expanded coverage of disability issues have altered public awareness and knowledge, eliminating the worst stereotypes and misrepresentations. Still, old attitudes, experiences and stereotypes die hard.

People with disabilities continue to seek accurate portrayals that present a respectful, positive view of individuals as active participants of society, in regular social, work and home environments. Additionally, people with disabilities are focusing attention on tough issues that affect quality of life, such as accessible transportation, housing, affordable health care, employment opportunities and discrimination.

## Eliminating stereotypes - words matter!

Every individual regardless of sex, age, race or ability deserves to be treated with dignity and respect.

The disability community has developed preferred terminology - People First Language. The People First Language is an objective way of acknowledging, communicating and reporting about disabilities. It eliminates generalizations, assumptions and stereotypes by focusing on the person rather than the disability.

As the term implies, People First Language refers to the individual first and the disability second. It's the difference in saying the autistic and a child with autism. (See the other side.) While some people may not use preferred terminology, it's important you don't repeat negative terms that stereotype, devalue or discriminate.

Equally important, ask yourself if the disability is even relevant and needs to be mentioned when referring to individuals, in the same way racial identification is being eliminated from news stories when it is not significant.

Information Sheet 7: People First Language

### What Should You Say?

Be sensitive when choosing the words you use. Here are a few guidelines on appropriate language:

- Recognize that people with disabilities are ordinary people with common goals for a home, a job and a family.
- Use People First Language to tell what a person **has**, not what a person **is**.
- Emphasize abilities not limitations.
- Avoid negative words that imply tragedy (e.g. afflicted with, suffers, and unfortunate)
- Recognize that a disability is not a challenge to be overcome, and don't say people succeed in spite of a disability - ordinary things and accomplishments do not become extraordinary just because they are done by a person with a disability.
- Promote understanding, respect, dignity and positive outlooks.

## 18. Federal and State legislation

### Mental Health (Forensic Provisions) Act 1990 (NSW)

Section 32 (s32) of the Mental Health (Forensic Provisions) Act 1990 (MHFPA) provides magistrates with an alternative means of dealing with criminal charges where a defendant has an intellectual disability or mental disorder. The result of an order made under s32, the person is diverted from the criminal justice system into the 'human services' sector.

Previously, conditional orders made under s32 were difficult to enforce, with no ramification for non-compliance. Therefore magistrates were reluctant to utilise s32 in all but minor criminal matters where the accused was clearly disabled.

An amendment was made to Section 32 of the Mental Health (Forensic Provisions) Act 1990 which commenced on 14 February 2004. This amendment was made under the Crimes Legislation Amendment Act 2002. The effect of this amendment is that, for a period of up to 6 months, the person may be bought back to court if they breach the conditions and the charges may be dealt with de novo (from the beginning)

A readable summary of the application of s32/33 Mental Health (Forensic Provisions) Act 1990 for criminal proceedings in Local and Children's Courts can be found on the Intellectual Disability Rights Service (IDRS) website: www.idrs.org.au/education/s32-guide/IDRS_Section_32_Guide_online.pdf

Following are excerpts from the Act.

***Application***

**31.(1)** This Part applies to criminal proceedings in respect of summary offences or indictable offences triable summarily, being proceedings before a Magistrate, but does not apply to committal proceedings.

**(2)** Sections 32 and 33 apply to the condition of a defendant as at the time when a Magistrate considers whether to apply the relevant section to the defendant.

***Persons Suffering from Mental Illness or Condition***

**32.(1)** If, at the commencement or at any time during the course of the hearing of proceedings before a Magistrate, it appears to the Magistrate:

**(a)** that the defendant is developmentally disabled, is suffering from mental illness or is suffering from a mental condition for which treatment is available in a hospital, but is not a mentally ill person within the meaning of Chapter 3 of the Mental Health Act 1990; and

**(b)** that, on an outline of the facts alleged in the proceedings or such other evidence as the Magistrate may consider relevant, it would be more appropriate to deal with the defendant in accordance with the provisions of this Part than otherwise in accordance with law, the Magistrate may take the action set out in subsection (2) or (3).

**(2)** The Magistrate may do any one or more of the following:

**(a)** adjourn the proceedings;

**(b)** grant the defendant bail in accordance with the Bail Act 1978;

**(c)** make any other order that the Magistrate considers appropriate.

**(3)** The Magistrate may dismiss the charge and discharge the defendant:

**(a)** into the care of a responsible person, unconditionally or subject to conditions; or

**(b)** on the condition that the defendant attend on a person or at a place specified by the Magistrate for assessment of the defendant's mental condition or treatment or both; or

**(c)** unconditionally.

**(4)** A decision under this section to dismiss charges against a defendant does not constitute a finding that the charges against the defendant are proven or otherwise.

***Mentally Ill Persons***

**33.(1)** If, at the commencement or at any time during the course of the hearing of proceedings before a Magistrate, it appears to the Magistrate that the defendant is a mentally ill person within the meaning of Chapter 3 of the Mental Health Act 1990, the Magistrate (without derogating from any other order the Magistrate may make in relation to the defendant, whether by way of adjournment, the granting of bail in accordance with the Bail Act 1978 or otherwise):

**(a)** may order that the person be taken by a member of the Police Force to, and be detained in, a hospital for assessment; or

**(b)** may discharge the defendant, unconditionally or subject to conditions, into the care of a responsible person.

*25/94 repeals (1)(a) and (b) and inserts:

**(a)** may order that the defendant be taken by a police officer to, and detained in, a hospital for assessment; or

**(b)** may order that the defendant be taken by a police officer to, and detained in, a hospital for assessment and that, if the defendant is found on assessment at the hospital not to be a mentally ill person or mentally disordered person, the person be brought by a police officer back before the court; or

**(c)** may discharge the defendant, unconditionally or subject to conditions, into the care of a responsible person.

**(2)** If a defendant is dealt with at the commencement or at any time during the course of the hearing of proceedings before a Magistrate in accordance with this section, the charge which gave rise to the proceedings, on the expiration of the period of 6 months after the date on which the defendant is so dealt with, is to be taken to have been dismissed unless, within that period, the defendant is brought before a Magistrate to be further dealt with in relation to the charge.

**(3)** If a defendant is brought before a Magistrate to be further dealt with in relation to a charge as referred to in subsection (2), the Magistrate must, in dealing with the charge, take account of any period during which the defendant was in a hospital as a consequence of an order made under this section.

**(4)** The fact that charges are to be taken to have been dismissed under subsection (2) does not constitute a finding that the charges against the defendant are proven or otherwise.

**(5)** The regulations may prescribe the form of an order under this section.

## NSW Disability Services Act (1993)

NSW Disability Services Act (1993) was developed from the Commonwealth/State Disability agreement that stated all states and territories must pass laws enshrining similar principles and objectives to the Commonwealth Disability Services Act (1986).

This legislation outlines principles and applications of the principles for the provision of services to people with a disability in NSW.

Services funded by the NSW Government must conform to the standards as set out in the Act to receive funding.

## Commonwealth Disability Services Act (1986)

The Commonwealth Disability Services Act (1986) aims to ensure that people with disabilities have the same rights as other members of the community, and that people with disabilities receive services necessary to maximise their full potential.

The Act is based on principles and objectives defining service quality and outcomes. Commonwealth funded services must meet criteria defined in the Act in order to receive ongoing funding.

## The Commonwealth/State Disability Agreement (1991)

The Commonwealth and State Governments signed this agreement in 1991. The document outlined funding responsibilities for disability services for State and Commonwealth governments. It also directed States and Territories to develop their own legislation reflecting the principles and objectives of the Commonwealth Disability Services Act (1986). It was designed to ensure a more coordinated approach to the provision of disability services in Australia.

Under this agreement the Commonwealth was allocated responsibility for the funding of employment programs for people with disabilities, and the State and Territory Governments were responsible for accommodation services, respite care, information and non-vocational daytime activity. Joint responsibilities were for advocacy, research and development.

## Community Services (Complaints Reviews and Monitoring) Act (1993) No 2

The Community Services (Complaints Review and Monitoring) Act outlines an independent mechanism to investigate complaints concerning the provision of community services in NSW. This Act provided for the establishment of the Community Services Commission, which is an independent tribunal that monitors and investigates complaints about services provided by the Family and Community Services (FaCS).

The Community Services Commission is unique to NSW, and also provides a mechanism to ensure the rights of people with disabilities are upheld.

## Disability Discrimination Act (1992)

The Disability Discrimination Act (1992) prohibits discrimination on the basis of disability. The Act aims to ensure that people with disabilities have a right to equal treatment before the law, and promote community understanding of people with a disability.

# Consultation & Referral Process for a Young Person who is on Bail in the Community

**JUVENILE JUSTICE STAFF SUSPECT INTELLECTUAL DISABILITY / COGNITIVE IMPAIRMENT**
No court requested psychological report

**COURT REQUESTS PSYCHOLOGICAL REPORT**

Psychological assessment by private practitioner is arranged by the court

**SERVICES FOR YOUNG PERSON**
Legal representative may take further action based on findings of psychological assessment

**STEP 1: REFER TO PSYCHOLOGIST**
If no previous diagnosis of Cognitive Impairment / Intellectual Disability has been made, refer young person to a Psychologist via CIMS

**INTELLECTUAL DISABILITY / COGNTIVE IMPAIRMENT CONFIRMED**

If it has been determined that the young person does not have a cognitive impairment or intellectual disability then consider other special needs to ensure duty of care

**STEP 2: LEGAL OPTIONS?**
Caseworker and Psychologist liaise with the young person's legal representative so legal options can be considered

- Children's Court – S.32 MHFPA
- Higher Court – further action by Legal Aid

**STEP 3: CONTACT NDIS**
Contact the young person's carer and or gain consent from the young person to complete the NDIS Consent Forms available at the local NDIS Office and My Access Checker tool at ndis.gov.au or Email: enquiries@ndis,gov.au

# Consultation & Referral Process for a Young Person who is on Remand in Custody

**CENTRE OR COMMUNITY STAFF SUSPECT POSSIBLE INTELLECTUAL DISABILITY**
No court requested psychological assessment

**STEP 1: REFER TO CENTRE PSYCHOLOGIST**

Interviews young person and obtains all available history and records, an assessment of cognitive and adaptive functioning to be completed as required

**Cognitive Impairment / Intellectual Disability indicated**

**FULFIL DUTY OF CARE RESPONSIBILITY**

If it has been determined that the young person does not have an intellectual disability then consider other special needs to ensure duty of care

**STEP 2: LEGAL OPTIONS?**
Caseworker and the Psychologist liaise with the young person's legal representative so legal options can be considered

- Children's Court – S.32 MHFPA
- Higher Court – further action by Legal Aid

**STEP 3: CONTACT NDIS**
Contact the young person's carer and or gain consent from the young person to complete the NDIS – Consent Forms available at the local NDIS Office and
**My Access** Checker **tool at ndis.gov.au**
or **Email: enquiries@ndis.gov.au**

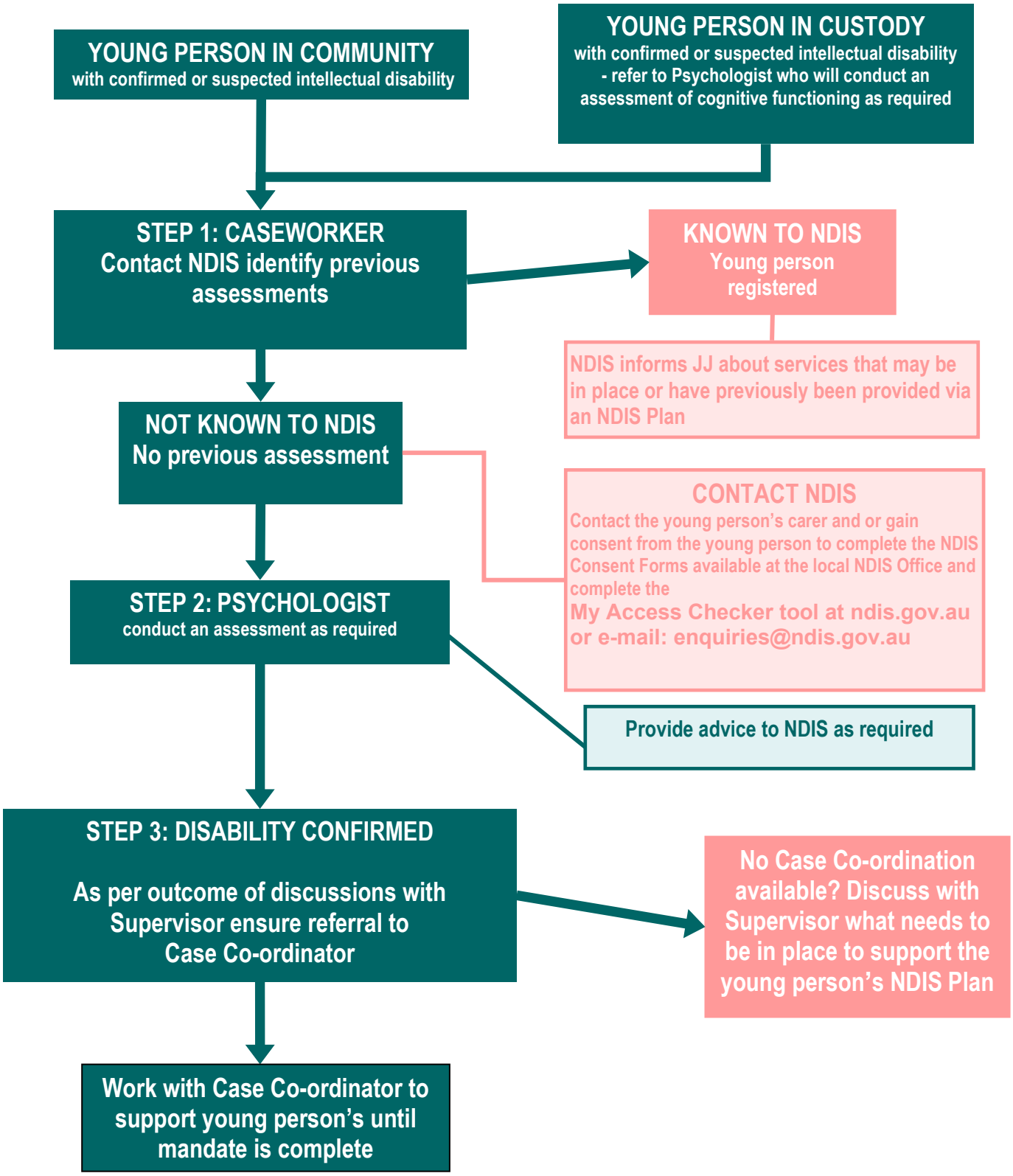
**COURT REQUESTS PSYCHOLOGICAL REPORT**

**STEP 1: REFER TO PSYCHOLOGIST**
Manager at client's JJCS office contacts the Psychologist to complete a Confidential Psychological Report (CPR)

**PSYCHOLOGICAL REPORT COMPLETED**
Report completed on CIMS and provided to the court

If evidence of Cognitive Impairment / Intellectual Disability, Psychologist to liaise with JJ Caseworker and contact Centre-based Psychologist

# Consultation & Referral Process for a Young Person who is on a Custodial or Community Order



# Effects of Substance Abuse

A significant number of young people with an intellectual disability present with a dual diagnosis of substance abuse disorder. Accidents associated with drug and alcohol use are the leading cause of head injury and orthopaedic impairment among adolescents.

It is understandable how a direct physical trauma to the brain can cause damage, however damage caused by drug and alcohol abuse is less obvious.

The process by which this occurs can include:

- Alcohol and drugs can have a toxic effect on the central nervous system
- Alcohol results in changes to metabolism, heart functioning and blood supply
- Alcohol interferes with the absorption of Vitamin B1 (important to brain functioning)
- Abuse of alcohol and drugs is commonly associated with poor nutrition
- Alcohol can cause dehydration, leading to wastage of brain cells
- Overdose can lead to oxygen not getting to the brain (such as with heroin or ketamine) causing damage
- Alcohol and drug abuse can lead to falls, accidents, fights etc which can lead to brain injury

See the following information sheets for further information.

Information Sheet 2: Alcohol Related Brain Injury

# Alcohol Related Brain Injury (ARBI)

Alcohol is a particularly damaging substance for the brain. Excessive and prolonged abuse of alcohol can cause specific injuries to the brain resulting in loss of functioning. Whilst some young people with an alcohol abuse problem may not have developed the following disorders, they are at significant risk.

| Disorders Associated with ARBI | |
|---|---|
| Cerebellar Atrophy | Alcohol induced wastage of the cerebellum causes balance and coordination problems, generally affecting the lower limbs causing a wide based gait (Ataxia). |
| Peripheral Neuropathy | A sensory disturbance that affects the hands, feet and legs. Generally the person cannot feel their lower limbs. |
| Hepatic Encephalopathy | A disorder seen in people with liver disease (which can be caused by excessive prolonged alcohol consumption). It can cause changes in mood and personality, impairment in consciousness accompanied by confusion, delirium and hallucinations. |
| Long Term Alcohol Exposure | Effects executive functioning and associated behaviours including:<br>▪ socially inappropriate behaviour<br>▪ difficulties problem solving<br>▪ inability to control sexual impulses<br>▪ difficulty planning and/or applying consequences from past actions<br>▪ Problems with abstract concepts (eg time and money)<br>▪ Information processing deficits<br>▪ Difficulty storing and retrieving information<br>▪ Needs frequent cues and supervision<br>▪ Difficulty with verbal self-regulation (self talk)<br>▪ Fine motor skills<br>▪ Exaggerated emotions and problems with emotional regulation<br>▪ Problems with self-motivation |
| Wernicke's Encephalopathy | Severe thiamine (Vitamin B1) deficiency resulting in an acute neurological reaction such as problems with vision, ataxia and confusion. Thiamine supplementation may reduce the effects. |
| Korsakoff's Amnesic Syndrome | Severe impairment of short-term memory, causing an almost complete inability to acquire new information. |

A neuropsychological assessment may be warranted if indicators of neurological impairment are observed. This assessment may assist in determining areas of dysfunction and aid in developing appropriate intervention strategies. Discuss with your supervisor.

See the following information sheets on alcohol related brain injury.

Information Sheet 1: Effects of Substance Abuse

# Syndromes Associated with Intellectual Disability

While the cause of intellectual disability is unknown in 30-50 % of cases, there are a number of syndromes which are associated with cognitive impairment in some individuals.

**Down Syndrome**

Resulting from an extra copy of chromosome 21, and affecting approximately one in every 860 babies born worldwide, Down syndrome is associated with developmental delay, particularly in speech. Down syndrome is one of the most common causes of intellectual disability, although the cognitive impairment is usually mild to moderate.

**Foetal Alcohol Syndrome**

Caused by excessive alcohol consumption by a mother during pregnancy, foetal alcohol syndrome (FAS) is characterised by dysfunction of the central nervous system, growth retardation and facial abnormalities. Alcohol is a "teratogen" or substance toxic to the brain of a foetus that may lead to birth defects. Effects are dose related and damage can occur to many areas of the developing brain and central nervous system, resulting in higher than average rates of intellectual disability, behaviour problems, ADHD, seizures and ASD. A less severe diagnosis of foetal alcohol effects (FAE) or foetal alcohol spectrum disorder (FASD) may be given.

**Fragile X Syndrome**

Fragile X Syndrome (FXS) is a genetic condition known to be a cause of intellectual disability. The intellectual disability may be mild to profound. Though FXS occurs in both genders, the abnormality of the FMR-1 gene is located on the X chromosome and males are generally more severely affected. FXS is also the most common single gene cause of autism spectrum disorder worldwide. It is estimated that 5 % of individuals with a diagnosis of autism spectrum disorder also have FXS.

**22q11.2 Deletion Syndrome**

A genetic syndrome caused by the deletion of a small piece of chromosome 22 with several presentations including DiGeorge syndrome (DGS), velo-cardio-facial syndrome, Shprintzen syndrome, conotruncal anomaly face syndrome and Strong syndrome. Features vary widely, even among members of the same family, and affect many parts of the body. Signs and symptoms may include birth defects such as congenital heart disease, defects in the palate, recurrent infections due to problems with the immune system (particularly in children) and learning difficulties.

Information Sheet 4

# Common Co-morbid Mental Disorders

Co-occurring mental and physical conditions (e.g. cerebral palsy or epilepsy) are frequent in individuals with an intellectual disability. The most common co-morbid mental and neurodevelopmental disorders are autism spectrum disorder, attention deficit/hyperactivity disorder, anxiety disorders, depressive and bipolar disorders, stereotypic movement disorder (with or without self-injurious behaviour), impulse control disorders and major neurocognitive disorder. Assessment based on self-report is obviously difficult in nonverbal individuals and the observations of knowledgeable informants are therefore essential.

**Autism Spectrum Disorder**

The majority of children and young people who are diagnosed with autism spectrum disorder (ASD) also have an intellectual disability. DSM-5 states that a diagnosis of ASD should specify whether or not it is accompanied by language or intellectual impairment. Young people with an intellectual disability alone do not have significant impairments in reciprocal social interaction, and can engage in social communication, verbal or nonverbal (such as gestures and eye contact) appropriate to their developmental level.

**Attention Deficit / Hyperactivity Disorder**

The diagnostic criteria for attention deficit/hyperactivity disorder (ADHD) are based on observable behaviour as reported by multiple informants and thus can be applied to nonverbal children. ADHD should be differentiated from situation-specific inattentiveness (such as at school if the academic expectations are too high), and where there may be adverse effects associated with prescribed medication.

**Anxiety Disorders**

Verbal persons with mild intellectual disability can report on subjective feelings of anxiety. In nonverbal persons, symptoms such as avoidance behaviours and agitation might suggest the diagnosis. Anxiety problems frequently emerge early in life in children with an intellectual disability, and seems to remain stable over time. These emotional problems can cause significant distress and interfere with the development of adaptive functioning skills, resulting in problems with school and social success. [44] The tendency toward anxiety and social avoidance is also part of the behavioural phenotype of Fragile X Syndrome.

**Depressive Disorders**

Depressive disorders are quite common in persons with intellectual disability. [45] In verbal persons with a mild intellectual disability, the complaints are simple and concrete. History obtained from caregivers and other evidence is necessary in assessing mood changes. Depressive disorder may also manifest as aggressive behaviour. Environmental events, such as an abrupt move to a new setting or change in care provider, may trigger a depressive episode. Adverse side effects of prescribed drugs should be considered, e.g. depression as a result of taking beta-blockers or agitation/akathisia associated with neuroleptic medication.

**Tic Disorders and Stereotypic Movement Disorder**

In Tourette's disorder, movements or vocalisations are less complex and appear involuntary, as opposed to the self-stimulatory stereotypes seen in persons with severe intellectual disability. For the latter, the diagnosis of stereotypic movement disorder may be used if other mental disorders are excluded. The specifier "with self-injurious behaviour" is added if bodily damage results. Self-injurious behaviour is common in certain syndromes associated with intellectual disability, particularly Lesch-Nyhan syndrome.

**Disruptive, Impulse-Control and Conduct Disorders**

These disorders involve the inability to regulate emotions and behaviours. While poor impulse control is common amongst individuals with an intellectual disability, a diagnosis should only be given where the behaviours are significantly greater than those observed in individuals of comparable age and severity of intellectual disability. In assessing non-compliance, i.e., not following commands of caregivers, one should consider the child's ability to understand social rules and the presence of sufficient verbal skills necessary to communicate opposition.

**Post-traumatic Stress Disorder**

Post-traumatic stress disorder should be routinely considered in persons with an intellectual disability as they are more vulnerable to abuse than people without an intellectual disability (I have a reference for this).

**Obsessive-compulsive Disorder**

The diagnosis of obsessive-compulsive disorder (OCD) may be difficult in nonverbal persons who cannot report on obsessional thoughts underlying their compulsions. Some repetitive behaviours (e.g. hoarding objects, flicking lights on and off, and obsessive cleaning and/or rearranging) have been suggested as indicative of OCD in persons with an intellectual disability.

**Eating Disorders**

Anorexia and bulimia nervosa are relatively rare in individuals with an intellectual disability, particularly moderate to severe intellectual disability, but intellectual disability is a predisposing factor for other eating disorders such as pica and rumination. Pica (the ingestion of non-nutritive substances) and rumination (the regurgitation and re-chewing of food) occur with greater frequency as the severity of cognitive impairment increases. When such behaviours are a focus of clinical attention, these diagnoses should be considered.

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1 Nunn R & Tonge B (2004). Anxiety in young people with intellectual disability. *Current Research Monash University*, VIC Australia.

2 Hollins S C (1999) Depression in people with intellectual disabilities. *Learning about intellectual disabilities and health.* www.intellectualdisability.info

# Aboriginal and Torres Strait Islander Historical Context

Aboriginal and Torres Strait Islanders have successfully occupied this country for over 30,000 years. A little over 200 years ago, European occupation began bringing with it unimaginable abuse, genocide and disease to the original inhabitants. The effects of this invasion remain with the Indigenous people to this day through intergenerational trauma, dispossession of land, degradation of cultural practices and language' and a host of social and health issues. There is also an enormous strength of culture and spirit within Indigenous communities, in part responsible for the survival of many cultural practices that still exist today.

With respect to intellectual disability in Aboriginal and Torres Strait Islander communities, these issues must be viewed in context of the disadvantages experienced as part of everyday life. Indigenous people in Australia experience higher levels of disadvantage than any other group. Such disadvantages are:

- Life expectancy for an Indigenous person is around 20 years less than the rest of the population, bringing with it significant grief and loss issues, [1]
- Indigenous infant mortality rates are between 2.3 and 3.5 times higher than overall Australian rates [2]
- 85% of Indigenous children suffer ongoing hearing loss significant enough to interfere with education [2]
- There is approximately 40% unemployment (compared to 8% in the general population) [3]
- Indigenous students have one of the lowest retention rates to year 12 of any cultural group [3]
- Medically, there are significantly higher rates of asthma, kidney disease, diabetes, and substance abuse related health issues [1]

Respect for the Indigenous young person's culture will assist in communication, assessment and delivery of interventions.

Information Sheet 6: Aboriginal & Torres Strait Islander Culture and Language

[1] Bostock L (2004) Surviving the System, Aborigines and Disabilities. Paper delivered at International Disability Day Seminar, Marrickville, NSW.

[2] Centre for Remote Health (2003). Facts and Figures. Working with Indigenous peoples with disabilities. WIRED www.wired.org.au

[3] Sotori M (2004). Criminal justice and Indigenous people with cognitive disabilities 2 – a scoping paper. For Aboriginal and Torres Strait Islander Services, Australian Government.

# Aboriginal and Torres Strait Islander Culture and Language

There are two Indigenous groups in Australia – The Australian Aboriginals and the Torres Strait Islanders. Within these two major cultures there are at least several hundred different cultures with their own customs, traditions and languages. [4]

Many Indigenous people use the follow names to identify themselves, depending on the area of Australia they come from:

| | |
|---|---|
| New South Wales | Koori |
| Victoria | Koorie |
| Northern Territory (Armhem Land) | Yolngu |
| Tasmaia | Palawa |
| Western Aistralia (North and South) | Nyoogar |
| North NSW and Queensland (Eastern) | Murri |
| South Australia | Nungah |

For the majority of indigenous people, a form of Indigenous English (or Kriol) is commonly spoken, with variations evident depending on the area the person is from.

For many years Indigenous English ahs been seen as a deficient form of standard English, however it is now recognised through educational bodies that Indigenous English is a valid, important form of communication, which does not need to 'be corrected'. [5]

- Indigenous English has a structure of rules and forms that are often more consistent than Australian English
- Indigenous English has similarities that are consistent throughout the entire nation
- The form of Indigenous English will vary depending on the community the young person comes from

With Indigenous people from more remote communities, English may be their second or even third language. An interpreter may be necessary for communication in these cases if the young person is not fluent in English.

Respect for the Indigenous young person's culture will assist in communication, assessment and delivery of interventions.

Information Sheet 5: Aboriginal & Torres Strait Islander Historical Context

[4] Message Stick (2003) Cultural Protocol. FAQ - answers to the questions ABC Indigenous units are asked. ABC Online. www.abc.net.au

[5] Glynn R (2003) Working with Indigenous peoples with disability. Communication Guidelines. WIRED www.wired.org.au

# People First Language

| People First Language to Use | Instead of Labels that Stereotype and Devalue |
|---|---|
| people/individuals **with disabilities**<br>an adult who has a disability<br>a child with a disability<br>a person | the handicapped<br>the disabled<br>the disabled |
| people/individuals **without disabilities**<br>typical kids | normal people/healthy individuals<br>atypical kids |
| people with **mental retardation**<br>he/she has a cognitive impairment<br>a person who has Down syndrome | the mentally retarded; retarded people<br>he/she is retarded; the retarded<br>he/she's a Downs kid; a Mongoloid; a Mongol |
| a person who has **autism spectrum disorder** | the autistic |
| people with a **mental illness**<br>a person who has an emotional disability<br>with a psychiatric illness/disability | the mentally ill; the emotionally disturbed<br>is insane; crazy; demented; psycho<br>a maniac; lunatic |
| a person who has a **learning disability** | he/she is learning disabled |
| a person who is **deaf**<br>he/she has a hearing impairment/loss<br>a man/woman who is hard of hearing | the deaf |
| a person who is deaf and **cannot speak**<br>who has a speech disorder<br>uses a communication device | is deaf and dumb<br>mute<br>uses synthetic speech |
| a person who is **blind**<br>a person who has a visual impairment<br>man/woman who has low vision | the blind |
| a person who has **epilepsy** | an epileptic |
| people with a **seizure disorder** | a victim of epilepsy |
| a person who uses a **wheelchair**<br>people who have a mobility impairment<br>a person who walks with crutches | a person who is wheelchair bound<br>a person who is confined to a wheelchair<br>a cripple |
| a person who has **quadriplegia**<br>people with paraplegia | a quadriplegic<br>the paraplegic |
| he/she is of small or **short stature** | a dwarf or midget |
| he/she has a **congenital disability** | he/she has a birth defect |
| **accessible** buses, bathrooms, etc.<br>reserved parking for people with disabilities | handicapped buses, bathrooms, hotel rooms, etc.<br>handicapped parking |

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