

A GUIDE TO ASSESSING PARENTING CAPACITY WITH PARENTS WITH INTELLECTUAL DISABILITY

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The authors of this report would like to acknowledge the traditional custodians of the lands on which this resource was produced. We pay our respects to their Elders past, present and future.











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STATEMENT OF PURPOSE

The resource aims to increase disability awareness among professionals working in care and protection, and to improve their knowledge and skills to engage with parents with intellectual disability. In particular, the resource will assist clinical assessors and experts, judicial officers, Statutory Authorities, caseworkers from government and non-government organisations (NGOs), Independent Legal Representatives, Legal Aid and private solicitors.

It aims to provide guidance to:

- Make an Assessment Order for judicial officers, legal representatives, and caseworkers
- Allocate a parenting assessment for specialist bodies such as the New South Wales (NSW) Children's Court Clinic to determine Authorised Clinicians selection and resources allocation
- Complete a parenting assessment for Authorised Clinicians and private assessors
- Write an Expert Report for Authorised Clinicians and private assessors
- Provide background information for Statutory Authority (casework and legal) teams to support comprehensive assessment
- Source suitable services for managers/caseworkers and NGOs with delegated case management during care matters
- Represent a parent with intellectual disability for public and private solicitors to ensure parents understand their rights and can give informed instructions.

ABOUT THE STUDY

The Toward Access and Equity study was conducted over a 12 month period between June 2021 and June 2022. Data collection and analysis was completed between September 2021 and May 2022.

Study aims:

- Address barriers to a fair assessment of parenting capacity of parents with intellectual disability,
- 2. Develop a disability-informed approach to assessing parenting capacity with parents with intellectual disability, and
- 3. Increase disability awareness and skills for professionals working in child protection and the Children's Court.

Study methods:

- 1. Rapid evidence review of evidence-based tools and measures used to assess parenting skills and capacity of parents with intellectual disability.
- 2. Desk-based review of 20 Assessment Orders and Expert Reports (conducted on site at the NSW Children's Court Clinic).
- 3. Anonymous online survey of 65 professionals who do parenting assessments to understand beliefs and knowledge about parenting with intellectual disability.
- 4. Focus groups with seven professionals and eight parents with intellectual disability about views of the barriers and enablers to good practice.

Main findings:

- Professionals viewed assessments involving parents with intellectual disability as more complex.
- The assessment process and Expert Reports were longer than usual.
- There was inconsistency in how professionals responded to the presence of intellectual disability in their assessments.
- Differences included when and what cognitive instruments were used, and what types of adaptations were adopted.
- Some clinicians conducted assessments over several days and liaised with other professionals.

Practice recommendations from professionals who took part in the study*:

- Regular and disability-specific training to engage with parents with intellectual disability.
- Provision of additional resources and time to undertake complex assessments.
- Greater support for parents with intellectual disability by the statutory authority prior to making an order.
- Collaboration between all services working with parents with intellectual disability to ensure accuracy of Expert Reports.

^{*} Read key messages from parents who took part in the study about how professionals can improve the assessment experience on pages 21–29.

SNAPSHOT OF RESEARCH ON PARENTS WITH INTELLECTUAL DISABILITY

Estimated population size (1%) is widely believed to

UNDER-REPORT

actual prevalence

Most parents with intellectual disability (85%) are in the

MILD-BORDERLINE RANGE

for cognitive functioning

Professionals hold

NEGATIVE AND PESSIMISTIC VIEWS

of their parenting capacity



PARENTING
WITH INTELLECTUAL
DISABILITY

They 'FLY BELOW THE RADAR'

and unmet support needs are exacerbated to the point of crisis

They were found to be 10% OF THE CARE AND PROTECTION MATTERS

Sources: Llewellyn & Hindmarsh, 2015 IASSID Special Interest Experiences of

STIGMA AND DISCRIMINATION

make them reluctant to disclose their disability to professionals

REFLECTIVE ACTIVITY

Research Group, 2008

What do you know about parents with intellectual disability?

Draw a line down the middle of a piece of paper. On one side write 'Parenting' and on the other write 'Intellectual disability'.

List what you associate with each of these words. Check both lists and draw a line wherever there is crossover.

How many lines do you see?
What does this say about your
knowledge and views of parents
with intellectual disability?

Parenting

Intellectual disability

HOW CAN NEGATIVE VIEWS OF DISABILITY AFFECT ASSESSMENT PRACTICE?



Ableism

The term 'ableism' refers to negative and limiting stereotypes about disability that emphasise individual deficits and hold people to a normative standard against which they are likely to fall short.

Ableism justifies discrimination, oppression, and exclusion and can operate consciously or unconsciously. Standardised instruments, such as psychometric or cognitive measures, can reinforce ableism if they are not modified and tested for use with disabled people.



Ableism in Action

Unconscious bias can occur in the absence of sound evidence and can impact on the professional judgment by those who assess parenting capacity. If their Expert Reports sway court decisions then the rights of parents to fair and equal treatment before the law has been undermined.

Reliable research conducted over four decades shows that IQ is not a reliable proxy for parenting competency. Despite this, many professionals who come into contact with these parents due to child protection concerns continue to attribute parenting problems to intellectual disability (attribution bias) and to hold pessimistic views about the ability of a parent with intellectual disability to understand and implement the changes needed to keep their child safe (unconscious bias).

You can read more about parenting and its challenges for people labelled with intellectual disability in a position paper prepared by the IASSIDD Special Interest research Group on Parents and Parenting with Intellectual Disabilities (2008). Parent labelled with intellectual disability: Position of the IASSIDD SIRG on Parents and Parenting with Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities, 21 (4), 296–307. http://whqlibdoc.who.int/publications/2001/9241545429.pdf

An international evidence review was undertaken to identify existing parenting capacity assessment tools or instruments that had been evaluated for use with parents with intellectual disability. The review confirmed that this evidence is in its infancy. The Skills Assessment for Parents with Intellectual Disability (SAPID) represents the most reliable evidence-based tool available. The tool consists of fourteen observational checklists across five domains: safety, planning, home management, child cleanliness, parent-child interaction. An evaluation showed that the tool was reliable (Zeitlin et al, 2021).

WHAT IS INTELLECTUAL DISABILITY?

- Intellectual functioning refers to general cognitive ability, such as learning, information processing and problem solving.
- Intellectual disability is defined as a condition characterised by significant limitations in both intellectual functioning and adaptive behaviour that originates before the age of 22. (AAIDD n.d.).
- The developmental phase is now seen to extend from birth to 22 years. This recognises that early learning and socialisation opportunities or restrictions create ripple effects into early adulthood.
- Adaptive behaviours refer to skills and behaviour learnt over time to assist with independent
 everyday living. This includes conceptual skills such as language, literacy and numeracy; social
 skills such as interpersonal communication and following rules; and practical skills such as self-care,
 domestic and occupational skills.
- IQ testing is the standard way to measure a person's cognitive ability. An IQ score gives an indication of how far above or below their peers an individual's cognitive abilities sit. An IQ score 70 or below is a diagnostic marker of intellectual disability but a score up to 80 may demonstrate limitations that significantly impact on their cognitive functioning. This is referred to as the borderline range.
- Many people with **mild to borderline intellectual disability** may never have been formally diagnosed. It is common for them to describe themselves as having been a 'slow learner at school' than as being intellectually disabled (IASSID, 2008).
- The International Classification of Disability and Health Framework (WHO, 2002) recognises that disability is caused by the interplay of impairment and environmental adaptation. This means that IQ is only one feature of a person's disability alongside environmental barriers that restrict their social participation, which include interpersonal and structural discrimination.

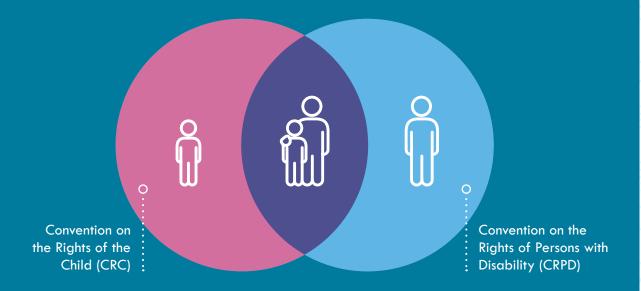
GUARDIAN AD LITEM

In most cases, parents with intellectual disability will be able to give instruction if communication is adjusted to suit them (e.g., amount of information exchanged is manageable and plain or easy English is used) and the parent has time and support of someone who is familiar with their communication style or a disability advocate.

Section 101 of the Act enables the Children's Court to appoint a Guardian ad Litem (GAL) for the parent of a child or young person if it is of the opinion that the parent is incapable of giving proper instructions to his/her legal representative due to intellectual disability or mental illness.

Appointing a GAL for a parent with intellectual disability should be a last resort and only done after consultation with a disability advocate and/or professional with expertise in communicating with persons with intellectual disability (e.g., psychologist, speech therapist, occupational therapist, or social worker). For more information about GAL visit https://www.gal.justice.nsw.gov.au/Pages/Gal_what_is_gal.aspx.

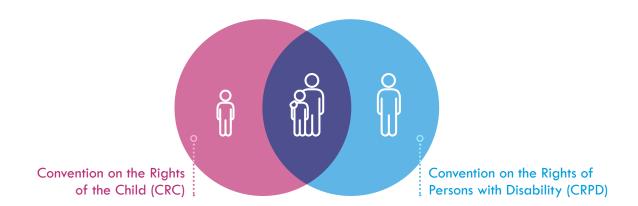
WHAT ARE THE RIGHTS OF FAMILIES WHERE A PARENT HAS INTELLECTUAL DISABILITY?



The Convention on the Rights of the Child ([CRC] United Nations, 1989) is a key guiding framework for the work of all professionals involved in child protection.

The CRC upholds the family as "the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children" and states that the family as a unit "should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community." (Preamble)

Access and equity before the law is a fundamental principle of civil society and achieving equity for people with disabilities is enshrined in the UNCRPD. Australia is a signatory to the UNCRPD, which carries an obligation to take steps to remove barriers to equity and access.



Article 2 of the CRC

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States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, **disability**, birth or other status.

The rights of the children to grow up in a family where they and/or their parents have disability is also enshrined in the Convention on the Rights of Persons with Disability ([UNCRPD] United Nations, 2006) the guiding framework for the rights of people with disability.

Workers may be less familiar with the UNCRPD and how these rights must be upheld in the context of care and protection decision making.

Article 13 of the CRPD: Access to justice

 States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

People with intellectual disability have the right to intimate relationships and parenthood but their decision to become parents is often met with scepticism and negativity from family, friends and workers. When they have a child, interpersonal and structural forms of discrimination, oppression and exclusion prevent them enjoying the same rights and freedoms to raise their children as other parents. If concerns about parenting arise, they encounter child protection workers and statutory systems that see their disability as an insurmountable risk to the safety and wellbeing of their child.

Article 23 of the CRPD: Respect for home and the family

- 1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.
- 4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

Parents with intellectual disability have a right to receive information they can understand. The responsibility lies with governments to make sure the information available is accessible. The professionals who engage with parents with intellectual disability such as caseworkers, Children's Courts, lawyers, and assessors should take active steps to find out from the parent how to make information accessible and to then provide it in a format that they can understand.

Article 21: Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others ... including by: Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost.

Parents with intellectual disability should be able to expect that the workers they engage with, who are responsible for administering justice, to have received training so they have the skills to communicate effectively with a person with intellectual disability and that their practices and decisions are free from bias.

Article 13: Access to justice

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

THE LEGAL CONTEXT FOR ASSESSING PARENTING CAPACITY IN NEW SOUTH WALES

The Children and Young Persons (Care and Protection) Act 1998 No 157 (hereafter referred to as 'the Act') outlines the circumstances for making a parent capacity order and who is to undertake the assessment.

54 Assessment of person's capacity for parental responsibility

- 1. The Children's Court may, for the purposes of an Assessment Order, appoint a person to assess the capacity of a person with parental responsibility, or who is seeking parental responsibility, for a child or young person to carry out that responsibility.
- 2. Such an assessment may be carried out only with the consent of the person whose capacity is to be assessed.

58 Provision of assessment reports and other information

- If the Children's Court makes an Assessment Order, it is to appoint the Children's Court Clinic to prepare and submit the assessment report concerning the child or young person to it, unless the Children's Court Clinic informs the Children's Court that –
 - a) it is unable to prepare the assessment report, or
 - b) it is of the opinion that it is more appropriate for the assessment report to be prepared by another person.
- 2. If the Children's Court Clinic informs the Children's Court that it is unable to prepare the assessment report or that it is of the opinion that it is more appropriate for the assessment report to be prepared by another person, the Children's Court is to appoint a person whose appointment is, so far as possible, to be agreed to by the child or young person being assessed, the parents or other persons who have parental responsibility for the child or young person, and the Secretary.
- 3. The Children's Court may, of its own motion, order
 - a) the Children's Court Clinic, or
 - b) a person appointed under subsection (2), to provide the Court with such other information as may be within the expertise of the Children's Court Clinic or the appointed person (as the case requires) to provide.
- 4. The Children's Court may order the Children's Court Clinic to provide any such information regardless of whether an Assessment Order has been made in relation to the child or young person concerned.
- 5. Any information provided to the Children's Court pursuant to an order under subsection (3) is taken to be a report to the Children's Court rather than evidence tendered by a party.

91E Making of parent capacity orders

- 1. The Children's Court may make a parent capacity order in relation to a parent or primary caregiver of a child or young person (including a parent or primary caregiver found to have breached a prohibition order under section 90A) if it is satisfied that
 - a) there is an identified deficiency in the parenting capacity of the parent or primary caregiver that has the potential to place the child or young person at risk of significant harm, and it is reasonable and practicable to require the parent or primary caregiver to comply with the order, and
 - b) the parent or primary caregiver is unlikely to attend or participate in the program, service or course or engage in the therapy or treatment required by the order unless the order is made.
- 2. A parent capacity order may be made whether or not a care application or care order has been made and at any stage in care proceedings.

THE PROBLEM WITH PARENTING CAPACITY ASSESSMENTS

A lack of evidencebased practice guidance for assessment of parenting capacity

A lack of clarity about when to include cognitive measures for the Children's Court

A lack of knowledge about intellectual disability among relevant professionals

A lack of minimum standards and training for professionals who conduct assessments There is no agreed, evidence-based practice standards or guidelines on how to assess parenting capacity. The standard for 'good enough' parenting is both imprecise and based on a set of unacknowledged, culturally based beliefs and values that set up many families to fail. Ableism shapes these beliefs and values when the unacknowledged standard is an able-bodied parent and when cognitive impairment is viewed as causing irreparable damage to learning capacity and caregiving performance.

There is no current guidance for judicial officers or assessors on when, how, and what role cognitive testing plays in assessment of parenting capacity or on how to screen for intellectual disability prior to a care application. Standardised instruments are used by suitably qualified professionals to measure individual intelligence (IQ) against a population norm. Cognitive functioning is assessed for clinical treatment and diagnostic purposes using instruments such as the Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV) and the Stanford-Binet Intelligence Scales, Fifth Edition (SB5). Although these are informative tools to measure IQ and cognitive ability, they are not validated to assess parenting capacity, nor adapted for use with parents with intellectual disability or cognitive impairment.

Although the NSW Children's Court Clinic provides training for its Authorised Clinicians on how to adapt their practices to accommodate diverse learning needs, there is no requirement that Authorised Clinicians must conduct assessments in a standardised manner. The Clinic Director may allocate assessments to Authorised Clinicians with relevant expertise to assess parents with intellectual disability. However, there is no oversight of the standard of assessments that are conducted by private assessors or assessments that are referred outside of the Children's Court Clinic context.

There is no mandatory requirement that assessment of parents with a diagnosed or suspected intellectual disability is done by, or in consultation with, disability specialists or assessors with demonstrated skills and experience in working with people with intellectual disability.

To our knowledge, there is no mandatory national accreditation scheme that ensures assessors or report writers who are privately sourced by the statutory authority, such as the Department of Communities and Justice in NSW, are appropriately qualified, experienced, and held accountable for the accuracy of their reports.

Section 58 of the Act stipulates that if the Children's Court of New South Wales makes an Assessment Order, it is to appoint the Children's Court Clinic to prepare and submit the assessment report. It is assumed that parenting capacity assessments conducted by the NSW Children's Court Clinic will be undertaken by a person with appropriate qualification, experience, and training.

THE ECOLOGICAL MODEL OF PARENTING ASSESSMENT

Professionals who conduct parenting capacity assessments operate within a statutory child protection system that determines how they work with other professionals and how they view parents with intellectual disability involved in care matters. Their assessment sits within a complex web of interactions that includes how these parents and their children encounter them and other professionals and how their engagement is influenced by multiple factors related to their life history and current circumstances.

Parents with intellectual disability face environmental vulnerabilities that often co-occur and compound each other, placing them at higher risk of contact with the child protection system than other parents. Among these are factors such as:



Growing up with the social stigma and persecution faced by all people with intellectual disability.



The burden of low expectations from teachers and other adults at school thus having fewer post-school training and education opportunities.



Having their decision to become a parent treated as a cause for despair rather than joy by family members and professionals.



Unemployment, housing insecurity and financial hardship.



Having **fewer people** to call on in times of need.



Social isolation, exclusion and even victimisation within the community.



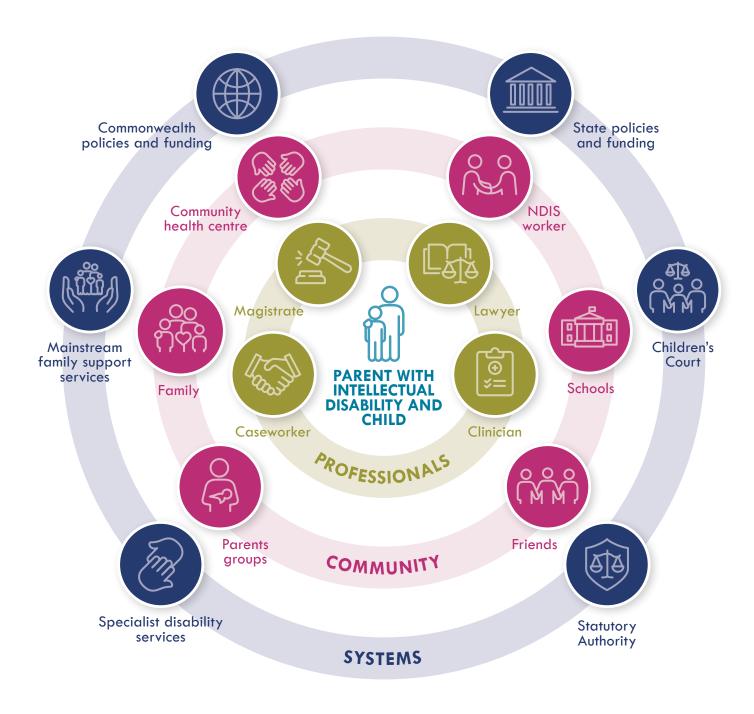
Higher rates of domestic and family violence than for non-disabled mothers, especially if they have a history of childhood adversity themselves.



Living with untreated mental health issues such as depression and anxiety.



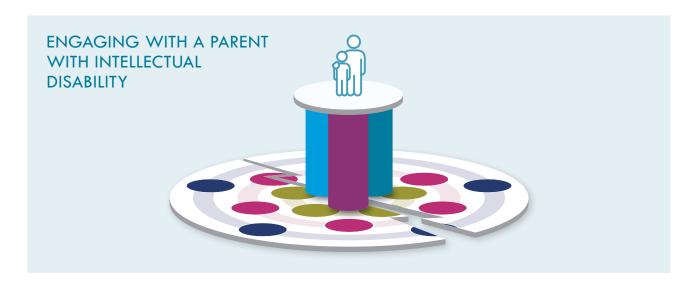
Well-founded fears of child removal, thus reducing trust in professionals.



TRAVELLING THE CHILD PROTECTION BUMPY ROAD

The Bumpy Road is a website with resources about navigating child protection that was created for and by parents with intellectual disability.

https://www.bumpyroad.org.au/



THERE ARE THREE KEY ASPECTS TO THE ENGAGEMENT APPROACH:

RELEVANCE

Both the parent and professional need to **see the relevance** in the engagement process.

- What is being discussed or requested needs to make sense for there to be 'buy in'.
- Don't assume what you are discussing or requesting the parent to do makes sense or holds the same significance as it does for you. Check for understanding. Ask "What does this mean for you? What do you understand as the purpose of this assessment?"
- Professionals working with parents with intellectual disability need to be critically reflective, particularly about assumptions which may impact on one's investment in the professional relationship with the parent/family.



Both the parent and professional need to **feel safe** in the engagement.

- Parents are more likely to feel safe when they are in familiar settings, when they know what is expected of them, when they have a trusted person with them, when they do not feel rushed and they feel people are being respectful and honest.
- Professionals are more likely to feel safe if they feel competent and comfortable working with a parent with intellectual disability.

AVAILABILITY

Both the parent and professional need to **be** available to engage.

- Availability will be influenced by competing demands; particularly time-related demands.
 Engaging with persons with intellectual disability requires additional time.
- For persons with intellectual disability, their availability may be affected by logistical and financial restraints (e.g. being able to travel to a place), competing demands for their attention, as well as cognitive, sensory and emotional overload.

The Understanding and Planning Support (UPS) is a process to engage parents with intellectual disability in a discussion about parenting and goal setting. You can find information about this process here: https://fams.asn.au/wp-content/uploads/2019/08/The-UPS-User-Guide.pdf

PARENTING ASSESSMENT THROUGH A DISABILITY-INFORMED LENS



Parenting Capacity Assessment is the evaluation of a parent or caregiver to meet their parental responsibilities. During the making of parenting capacity orders, the Act is focused on:

- a) the parents' abilities to meet the needs of the child and whether the child is at risk of significant harm, and
- b) the parents' ability to engage in services, courses, therapy, and treatment.



Parental responsibility, in relation to a child or young person, means all the duties, powers, responsibilities and authority which, by law, parents have in relation to their children.

Parental responsibility involves making and actioning decisions in relation to a child. Pursuant to Section 70 of the Act, the Children's Court may make an order allocating all aspects of parenting or more specific aspects of parental responsibility for a period specified in the order. While accountability for parental responsibility is held by a designated person or persons (commonly the birth parents), other parties may provide input in the making of decisions and carrying out these decisions, such as:

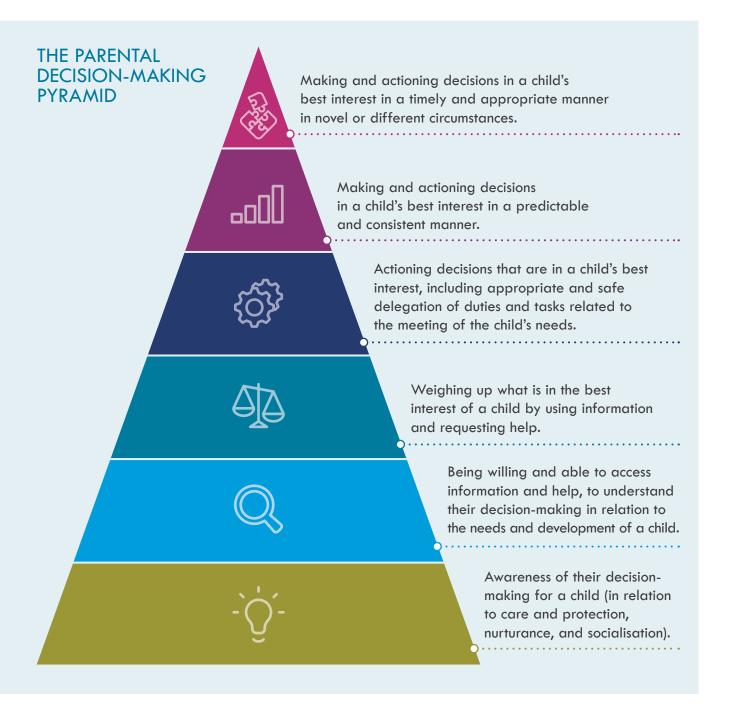
- a) one parent to the exclusion of the other, or to both parents jointly
- b) solely to the Minister, or
- c) to one or both parents and to the Minister jointly, or
- d) to one or both parents and to another person or persons jointly, or
- e) to the Minister and another suitable person or persons jointly, or
- f) to a suitable person or persons jointly.

PRACTICE GAP

Professionals who make parenting capacity orders or complete assessments need evidence-based practice guidance. To be disability-informed, they need access to reliable and current evidence, and instruments that have been designed and tested with parents with intellectual disability. Unfortunately, an international evidence review confirmed that no such tool currently exists. One related tool has been tested in different contexts and offers a contribution to building disability-informed practice.

The Hayes Ability Screening Index (HASI)

These are screening instruments used to identify intellectual disability and the need for in-depth assessment and accommodations. These tools were developed to overcome a potential barrier to procedural fairness for people with intellectual disability in law enforcement and criminal law. They have been tested in police, criminal justice, psychiatric and drug and alcohol contexts in Australia and internationally. The HASI and HASI-NV are widely used in health care settings in the UK, where there is emphasis upon GPs recognising which patients have intellectual disability. They have high inter-rater reliability and can be scored by clinicians and non-clinicians with little training (Young et al 2015). To our knowledge, HASI has not yet been used in the care jurisdiction.



PROMPT QUESTIONS

- What is the parent's awareness of their child's needs?
- What is their willingness and ability to gather the information and help they need, to weigh up what is in the best interest of the child?
- How could parental decision-making be supported in the best interest of the child?
 - Informal (including shared parental responsibility with a family member).
 - Formal (including adapted/targeted parenting skills training offered longer term, and both residential and home-based options as needed).
- ? How might this support be phased out, modified and/or sustained where necessary, over the child's developmental trajectory?
- Are there potential factors or barriers that might be encountered in implementing these supports (such as disengagement from agencies, parents, or families)?
- **?** Could these barriers be overcome or minimised by:
 - Building therapeutic alliance with caseworkers and mental health professionals?
 - Engagement with disability support services?
 - Engagement with child focused services?
 - Relationship building through community participation?
- If it is deemed not realistic and feasible to support parental decision-making,
 - How should family connection be supported?
 - How would the child like to have contact with their family (where a child has a say)?
 - If there are concerns about the child's safety or parent engagement, how could risk be minimised?



THE PARENTAL
DECISION-MAKING
PYRAMID

WHAT ARE THE PRINCIPLES OF DISABILITY-INFORMED PRACTICE?

The first principle is that good practice is inclusive and accessible for all.

Professionals who are disability-informed respond as if any parent they engage with may have a disability, and then set out to understand the parent's preferred mode of communication and adapt their practice based on this. Lessons from the extensive field of trauma-informed practice encourages practice development to be seen as a process and a continuum (Wall, Higgins & Hunter, 2016). This can be applied to developing disability-informed practice.



Disability aware

Take steps to learn more about disability, disability rights and policy frameworks to address societal barriers and stigma; take up training opportunities and seek out information from reputable sources about parenting with disability.



Disability responsive

Incorporate a person-centred approach into your practice by understanding that every person with intellectual disability is different. Take time to learn how the person you are working with views their disability, strengths and limitations, and support system resources and tailor your response based on this information.



Disability sensitive

Recognise the need to identify intellectual disability among clients and use a suitable screening tool (see below); share information and resources about disability with colleagues; have information about disability rights, advocacy and services available in the community (e.g., PWDA, IDRS, NDIS).



Disability-informed

Lead organisational and system change to challenge deficit-based practice and advocate for system-wide reforms that help call out discrimination in processes and practices. Find ways to collaborate with people with intellectual disability and their supporters to create inclusion and equality.

APPLYING DISABILITY-INFORMED PRACTICE TO PARENTING ASSESSMENT

A case study is used to assist professionals to apply the three stages of disability-informed assessment to practice. It is a composite case study which means the details are not based on a specific case. This case study has been developed to draw attention to common features of cases for which a request for a parenting capacity assessment is made.



Introducing Allyra, Brock and Jason

Allyra and Brock, both aged 26, are the parents of 5-year-old Jason. Jason started school earlier this year and his kindergarten teacher has noticed he often seems inattentive and withdrawn. The teacher made several attempts to discuss these issues with Jason's parents at school pick up early in the year, but felt they dismissed her concerns. Over the year Jason has had frequent and unexplained absences from class and arrived at school without any food and wearing dirty clothing. The teacher has become increasingly concerned about his wellbeing and Jason's parents have been uncontactable. She made a mandatory report about a child at risk of neglect which led to a substantiated ROSH report.

Allyra and Brock have been together since high school and although their relationship is rocky, they always get back together. Allyra has no contact with her birth parents but is still in touch with her foster carer and recently reconnected with extended family who live in regional NSW. Brock is a truck driver but has been off work for a year due to a back injury and is in chronic pain. Brock's birth parents live nearby and assist in the care of Jason. Both parents use cannabis and alcohol recreationally and police have been called out a few times due to noise complaints, but neither have criminal records. There are also concerns about the hygiene and tidiness of their home. The family engaged with Brighter Futures when Jason was younger and completed 1-2-3 Magic and Circle of Security at a local service.

REFLECTIVE ACTIVITY

ttow can you increase your understanding of intellectual disability?

How can you improve your communication with parents with intellectual disability?

How can being disability-responsive help you to identify strengths in parenting?

How can it help you understand limitations of parenting capacity?

What disability-informed practices have you already incorporated into your practice?
What more can you do to be person-centred rather than diagnosis focused?

How can family group conferencing models be better utilised to support parents?
How can you involve family and support people to help you engage with parents?

THE THREE STAGES OF THE PARENTING CAPACITY ASSESSMENT

Different strategies may be required at different stages of the assessment processes by legal and non-legal professionals. Legal professionals may include judicial officers, the child's Independent Legal Representative or the legal representatives for the parent (referred to as 'lawyers') or the Department. Non-legal professionals may include caseworkers, casework managers, Authorised Clinicians or private assessors (collectively referred to as assessors).









ADVICE FROM PARENTS WHO TOOK PART IN THE STUDY

To: Professionals within the Children's Court Message: How to prepare us for the assessment

Don't prejudge our capacity before you meet us.

Give us a chance to be prepared for what will happen - a pamphlet or a phone call to tell us what the questions are going to be about.

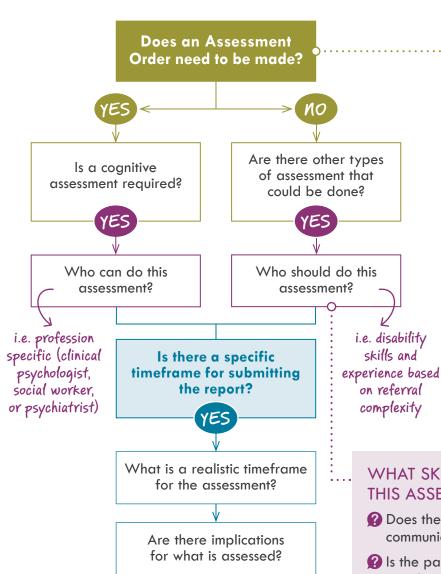
Make sure we know our rights: tell us what will happen, how long it will take and that a support person can come.

Arrange a disability advocate or support person to attend.

Tell us what you are going to do before you start.

Introduce yourself, say what you are doing and how you are doing it.

Explain what 'capacity' means in plain English.



WHAT TO ASK ABOUT PRE-APPLICATION CASEWORK?

- Is there a confirmed diagnosis of intellectual disability?
 - If so, how was this assessed?
 - Has the assessment been supplied by the Department of Communities and Justice (DCJ)?
- Have any other prior formal assessments been done?
 - Have these been made available to the Court?
- ② Does the parent have a formal or informal support person?
- Has the parent been offered a Family Group Conference (FGC)?
 - If there was an FGC, can you see a copy of the family plan?

WHAT TO ASK IN THE ASSESSMENT ORDER

- What is known about the parent's learning needs?
- How does intellectual disability affect parenting or decision-making?
- Obes one or both parents have additional learning needs?
- ? How much time will it take to do a disability-informed assessment?
- What does the court need to know to make decisions about supports and resources the parents may need to parent the child/children?

WHAT SKILLS ARE NEEDED TO DO THIS ASSESSMENT?

- ② Does the parent have special communication needs?
- Is the parent from an Aboriginal or culturally diverse background?
- Assessors are mental health professionals, including social workers, psychologists (registered, forensic, and clinical), and psychiatrists. All Authorised Clinicians have received training on conducting parenting capacity assessments, however not all Authorised Clinicians or private assessors have received specialised training in conducting assessments with parents with intellectual disability.
- Professional backgrounds and training may also affect the types of assessments that they are able to conduct. For example, psychiatrists specialise in complex mental health and psychiatric presentations, such as drug-induced psychosis, schizophrenia.
 Psychiatrists and psychologists conduct psychometric testing but social workers do not.

ACCEPTING THE ASSESSMENT

Information gathering

Written DCJ (Caseworker notes)
Current case management ('response to issues')
Police records and other documents
Contact the parent and a

nominated support person

SUGGESTIONS FOR INITIATING COMMUNICATION WITH PARENTS

This is your first chance to start building rapport:

- Check if the parent has any specific communication needs.
- Tell the parent what information you will be asking from them.
- Some clinicians provide a short page of questions to think about (i.e. what led them to current proceedings, what is their focus in therapy if relevant, what is important to them and their child).
- This process may take several phone calls or text messages if the parent experiences difficulties with communication.

Ask for any copies of other assessments:

- May have been previously assessed for NDIS.
- Casework may include adaptive functioning assessment.
- May be included in previous medical records.
- May have reports from schooling or education.
- May have attended previous child protection assessment.

Discuss with parent where parenting capacity assessment occurs:

- Where is safe? Suggest a familiar, neutral location.
- Where is comfortable? Suggest a location that is quiet.
- Where is accessible? Suggest somewhere the parent can get to easily and give instructions if needed.

Who is going to be present?

- Check if the parent would like to have someone with them.
- Ask if they have a safe and supportive family member who can bring them.
- If not, provide contact details for a disability advocate.
- Check if they want to have the person in the room or nearby for support.
- Contact the support person and explain their role and boundaries.

PARENT ENGAGEMENT

It takes good communication skills to engage any parent in an assessment of their parenting capacity given the sensitivity of this task. In the case of a parent with intellectual disability, professionals will need to apply all these skills and develop them to a higher level.

The first thing to remember is that no two people with disability are the same. While individuals may have similar impairment, how this disables them is influenced by the interplay of multiple factors including gender, age, culture, roles and responsibilities, resources, wellbeing, temperament, life experiences and opportunities.

Parents with intellectual disability:

- Need to understand the relevance of what is asked of them in order to engage.
- Need to feel safe to engage in what is being asked of them.
- Need to be resourced so they can be available to engage in what is being asked of them.
- Should have choice and control over matters involving them.

EXPLORING PRE-ASSESSMENT THROUGH A CASE STUDY



Returning to Allyra, Brock and Jason

The Department of Communities and Justice is currently providing case management and have referred the parents to a community-based drug and alcohol service where they can receive counselling and support. Case notes state that Allyra appears slow to understand information and does not often remember details of conversations with caseworkers. Jason has been temporarily placed in the care of his paternal grandparents.

You are the assessor who receives a referral from the Children's Court Clinic to complete a parenting capacity assessment. The Assessment Order from the Children's Court rates this as a low-level referral and you have a month to conduct an assessment and submit a report. The magistrate has requested the parenting capacity assessment include an assessment of the extent of the parents' recreational substance use, and a cognitive assessment of Allyra and whether her cognitive functioning affects her parenting of Jason.

PRACTICE PROMPTS

- What would you consider before accepting this referral?
- Process How could you and the parent's lawyer make initial contact with Allyra and Brock?
- What information would you or the parent's lawyer request from the Statutory Authority?
- What issues will the assessment focus on?
- Could the lawyer or caseworker meet with the parent before their assessment to explain what the process would entail?
- Where would you conduct the assessment?
- Would you require additional time to conduct the assessment?
- How would you make Allyra and Brock aware that they could invite a support person to attend the assessment?
- Would you and their lawyer confirm their assessment appointment by phone, text or email?
- What instruments would you use to screen or assess cognitive capacity?
- Plas the Statutory Authority offered the parents a family group conference?
- If Aboriginal Placement Principles applied to this family, how would you, their lawyer and caseworker approach case planning and assessment to ensure the child's cultural needs are met?

OTHER TIPS

When there are questions about parental cognitive functioning, there should be an expectation that a suitably experienced caseworker or in-house psychologist from the Statutory Authority conducts preliminary screening of cognitive functioning or a summary of their interactions with the parents for the court and this is available to the parent's lawyer and assessor.



ADVICE FROM PARENTS WHO TOOK PART IN THE STUDY

To: Professionals involved in our care matters Message: How to engage us during the assessment

Make sure the assessment is not too long and give us regular breaks.

Don't use our contact visits for your assessment.

Ask us about how we learn and what our difficulties are.

Don't ask so many questions. Don't make us write down our answers.

Don't make us feel watched and judged.

Explain why you are asking questions about our history.

Give us a bit of time and don't write us off.

Check in with us about how we are feeling.

Check we understand what you mean and if not, use different words.

Listen to what we say is important to us being good parents.

Focus on what support we need, not only on the problems.

TIPS FOR COMMUNICATING WITH A PARENT WITH INTELLECTUAL DISABILITY:

- Ask about their reading ability.
- Simplify explanations and repeat information.
- Give the parent opportunities to ask questions.
- Give them enough time to reply to questions before moving on.
- Check that the parent has understood before moving on.
- Break tasks down into manageable components.
- Offer the parent regular breaks.
- Offer them extra time if they need it.

TIPS FOR MAKING INFORMATION ACCESSIBLE

- Making information accessible is about using different tools rather than reliance on written information.
- This might mean giving information in verbal, video, or pictorial formats. When you do provide written information, it means providing it in an easy read (pictorial) format or keeping your language simple and clear.
- Think about what a person with a reading age of around Year 5 could be expected to understand.
- Find out about the parent's strengths and skills.

More information at:

https://www.3dn.unsw.edu.au/sites/default/files/documents/3DN_AccessibleInformation_Toolkit_ERv1.pdf

https://cid.org.au/resource/inclusivecommunication-tips/

REFLECTIVE ACTIVITY

Adapting your communication style

People with intellectual disability often have difficulties including verbal and written communication and comprehension.

What adjustments do you currently make for different learning styles? How do you know what you should do to adapt to different learning styles?

What adaptive functioning tools help you learn about a parent's strengths?

What ways could you find out more about a particular parent's preferred style?

EXPLORING ASSESSMENT THROUGH A CASE STUDY



Returning to Allyra, Brock and Jason

Allyra and Brock are punctual to their first appointment and do not appear to be under the influence of substances. You observe that Brock fills out the client information forms for Allyra and himself. You notice that Allyra tends to remain quiet during initial discussions and Brock does most of the talking.

You conduct individual interviews with Allyra and Brock and notice that Allyra requires you to repeat questions and simplify them. She has difficulties with dates and appears to be a poor historian. Allyra indicated that she attended mainstream school but reported that she had difficulties with learning.

You observe Allyra and Brock with Jason. Jason engages with his parents and appears familiar and affectionate with both. Allyra and Brock are attentive to Jason and their interactions with him are warm. It is clear that Allyra and Brock love and care for Jason, though individual interviews suggest that both parents experience difficulties implementing a daily routine in the home, attending to washing and hygiene needs, getting Jason to school, and ensuring that Jason has packed lunches.

Jason reports in his brief interview with you that his father is often 'loud and yells at mum' and that his mother sometimes 'forgets' to wash his clothes for school and 'forgets to pack snacks'. Jason is living with an aunty and says that he goes to school every day but does not like 'all the house rules' and having to go to bed before 8pm.

Brock blames the problems that led to the ROSH on Allyra, saying that she is responsible for providing care to Jason and cleaning their home, as he has been suffering from a back injury. Brock discloses that he has been drinking excessively (up to 6–8 standard drinks on some nights) and smoking cannabis almost every day to manage pain and frustration.

Allyra, when spoken to in the absence of Brock, reports that she has been feeling isolated, anxious about their financial situation, and depressed. She denied physical violence in their relationship but describes Brock as being coercive and controlling. She previously smoked 1–2 joints on weekends, but reported that her cannabis use and alcohol consumption has increased in the last year when Brock hurt his back and was unable to work.

Allyra appears tired by the end of her individual interview and observation with Jason. You had originally planned to conduct a cognitive assessment on the same day.

EXPLORING ASSESSMENT THROUGH A CASE STUDY

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PRACTICE PROMPTS

- ? How would you modify their assessment to ensure that Allyra and Brock understand the purpose of the assessment and provide consent individually to participate in interviews and observations with Jason?
- How would you and the lawyer build rapport with Allyra?
- Would you conduct screeners for cognitive functioning at the start of the day or an interview first?
- Can you conduct cognitive testing on another day or would you offer Allyra a rest and then resume assessment?
- (2) Is it feasible for Allyra to attend cognitive testing on a second day?
- What are the benefits and limitations of conducting the cognitive testing on a second day?
- ② Does Allyra need or want a support person to attend the appointment with her?

TAKE HOME MESSAGES

It is good practice to check in more regularly with a parent with intellectual disability during the assessment. It may be more exhausting for them than other parents. You can observe closely how the parent appears to be coping and also ask them for feedback.

You can offer them more regular breaks or suggest holding the assessment over multiple appointments. It is important to remind them they can have a support person be there. You can offer to contact PWDA or another disability advocacy service if they do not have someone they trust who can attend.



Returning to Allyra, Brock and Jason

You organised a second assessment day to conduct cognitive testing. Allyra brought her maternal aunt along as her support person. Allyra scores 22.1 on the Montreal Cognitive Assessment (MoCA), indicative of mild cognitive impairment. Her score of 70 on the Full-Scale IQ Score (FSIQ) of the WASI-II suggests that she meets criteria for borderline intellectual disability. Her cognitive screening results makes her eligible her for the Disability Support Pension, which she does not yet receive. Her responses on the Beck Depression Inventory (BDI-II) reached clinical significance for depression. According to the Adaptive Behaviour Assessment Scale-Third Edition (ABAS-III) scored by her caseworker, Allyra demonstrates a moderate level of general adaptive functioning and independence. She requires reminders and some support to complete daily tasks like self-care, chores (laundry and washing), and finances. Her self-hygiene like brushing her teeth and showering may fluctuate, particularly when she experiences low moods. She states that she does not know how to cook and relies on Brock to make meals. Allyra recognises that she needs support but feels mistrustful of possible providers or support services. However, she indicates her willingness to engage with a drug and alcohol counsellor and domestic violence therapist.



ADVICE FROM PARENTS WHO TOOK PART IN THE STUDY

To: Professionals involved in our care matters
Message: How to make sure we understand the report

Don't just send us a copy of the report, make a time to talk to us about what it says.

We need support people around us when we have this conversation.

Make the report accessible - plain English or a recording!

What is in the report should not be a surprise to us!

The report needs to be accurate about what we said.

Give us a chance to read the report before it is finished.

Follow up with the people we suggested you talk to before you finish your report.

Have a review process to follow if we don't agree with the report.

After the assessment has been completed:

- Check the parent understands what happens next.
- Give the parent and their support person a chance to ask follow-up questions.
- Make sure any information you give them and the key message are in an accessible format.
- Be clear about timeframes.
- Offer them suggestions for additional services that the appointed case manager can follow up.

As you begin to prepare the report keep in mind:

- The report goes to the parent and should be in disability-inclusive language.
- Some assessors and caseworkers may summarise the report so that the parent understands the key messages and recommendations of the report. The parent may find it helpful if the caseworker or legal representative explains the recommendations of the report.

EXPLORING POST-ASSESSMENT THROUGH A CASE STUDY



Returning to Allyra, Brock and Jason

You complete an assessment of Allyra and seek collaborative sources of information regarding her and Brock's parenting capacity, nature of their relationship, their willingness to engage with services.

You follow up with a phone call to Brock and Allyra separately to clarify information and enquire about their thoughts and reflections about the assessment process. You provide a summary of their discussions, observation of their interactions with Jason. You are concerned about both parents' relationship and ongoing substance misuse and its impact on their ability to provide care for Jason, such as ensuring that he has regular meals, the home is kept tidy, that Jason attends school in clean clothes and brings food with him, that he goes to bed at a reasonable hour. Both parents acknowledge their substance use, although Allyra still does not appear to understand why the Department is involved. She states that she has never deliberately hurt Jason, though agrees that she finds it hard to get Jason to brush his teeth, have a shower, and go to bed on some days. Brock also emphasises that he has never physically hurt Allyra or Jason. You recommend that if Jason is to be restored to the care of his parents, the parents would need to address their substance use and engage in professional support for their relationship issues, mental health, and parenting skills.

PRACTICE PROMPTS

- ② Does Allyra understand what happens next or when her report will be submitted to court?
- (2) How do you ensure that the lawyer or caseworker contacts the parent following the assessment to check on their feelings about how the assessment went and if they were heard?
- Whose responsibility is it to make sure this happens?
- ? How did you make sure Allyra is able to ask follow-up questions or provide feedback on the assessment process?
- How can you check if Allyra's lawyer or caseworker have encouraged her to re-engage with services?
- How would you follow up with the parent's caseworker to make relevant referrals
 or engagement with services prior to release of your report?
- ? How can you make sure caseworkers maintain contact with you regarding recommendations in the report?

TIPS

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Some clinicians provide pen and paper to the parent to make notes on their discussions or to type written notes on their phone, i.e. to follow up with their caseworker about accessing a drug and alcohol counsellor.

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