

# **Toward Access and Equity: Improving Clinical Assessment of Parenting Capacity for the Children's Court of NSW: Final Report**

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## **1. Executive Summary**

The Toward Access and Equity study examines barriers to fair and equitable assessment of parenting by people with intellectual disability and provides guidance on accommodations that can be adopted to improve assessment processes used in the Children’s Court of NSW.

The study was funded by an Access to Justice Innovation Grant from the Department of Communities and Justice (2021/2). It was a partnership with the NSW Children’s Court Clinic, Intellectual Disability Rights Service, and the WASH House. The study draws on the professional experience and wisdom of an Expert Advisory Group which included the research team, partner organisations, Wiradjuri elder and foster carer, Aunty Glendra Stubbs, and Children’s Court Magistrate, Tracy Sheedy.

### **1. Context**

The NSW Children and Young Persons (Care and Protection) Act 1998 provides for the making of parenting capacity assessment orders (Section 70). This assessment is to evaluate a parent (or caregiver’s) ability to meet their parental responsibilities and ability to engage in services, courses, therapy, and treatment alongside evaluation of the needs and risk of significant harm to the child. Professionals who undertake or interpret parenting capacity assessments need guidance based on current evidence and best practice models to provide an accurate account of parenting strengths and limitations. This ensure equal access to justice before the Children’s Court irrespective of parental cognitive ability which is consistent with our state obligations under the Convention on the Rights of the Persons with Disabilities [CRPD] (Articles 13 and 23, United Nations, 2006).

### **1. Aims**

Study aims are:

1. To address barriers to a fair assessment of parenting capacity of parents with intellectual disability
2. To develop a disability-informed approach to assessing parenting capacity with parents with intellectual disability
3. To increase disability awareness and skills for professionals working in child protection and Children’s Court

## **1. Research Questions**

The research was guided by the following questions:

1. What influences the clinical assessment of parenting capacity with parents with intellectual disability?
2. What do clinical and private assessors view as important for parents with intellectual disability to show they have adequate capacity?
3. What do parents with intellectual disability view as barriers to fair and equitable assessment of their parenting capacity?

## **1. Design**

A mixed method approach was used to identify existing evidence on good practice for assessing the parenting capacity of parents with intellectual disability and to surface professional and system factors that hamper good assessment practice. Methods included a rapid evidence review of evidence-based assessment tools; a survey of professional views and beliefs; focus groups with clinicians and parents with intellectual disability, and a desk-based review of a matched sample of assessment orders and expert reports.

## **2. Results**

Current evidence-based guidance on effective instruments and approaches to assess the skills and competency of parents with intellectual disability is very limited. Only two studies were identified as meeting a rating of supported evidence, and both had limitations. That the international evidence is nascent represents a significant barrier to good practice.

Survey and focus groups with professionals indicate a high degree of uncertainty about how to effectively assess parenting capacity of parents with intellectual disability and the use of psychometric testing, including how much bearing should be placed on the results. They were concerned that inadequate resources were allocated to do these assessments, which were longer and more complex. Lack of practice consistency or understanding of what adaptations may be needed to take account of disability is a serious barrier to fair and equitable assessment. Parents reported that the assessment process was confusing and unsafe. A necessary adjustment identified by parents was to have a support person with them during the assessment and to be assessed in a familiar environment. In contrast, professionals were

ambivalent about whether a support person should be involved and, on balance, preferred to do assessments in a neutral location, typically their office or the Children's Court Clinic.

Over half of the assessment orders reviewed explicitly requested cognitive capacity assessments be done to determine whether parents' cognitive deficits met criteria for intellectual disability and the extent to which a parents' ability to meet children's safety and wellbeing needs was impaired. Five assessment orders considered parental intellectual disability as the primary risk factor for child protection involvement. It was noted that the terms '*cognitive impairment*' and '*intellectual disability*' were used interchangeably in assessment orders. Analysis of expert reports showed that clinicians were hesitant about recommending restoration of children to parents with intellectual disability as they were concerned about parents' ability to consistently ensure the safety of their children and adapt to children's developing needs. Clinicians were more likely to recommend that children be placed in kinship care and advocated for children to reside within their family and community where possible.

#### **4. Recommendations**

The following recommendations are offered to improve the consistency and quality of assessments involving parents with intellectual disability.

1. There is an urgent need for the child protection workforce to receive training to develop knowledge and skills to work with parents with intellectual disability. This should be done in partnership with the Department of Communities and Justice, Children's Court Clinic and involve key child protection and disability advocacy and industry bodies to ensure it is fit for purpose.
2. The disability-practice resource developed through this project is a starting point for assisting a range of professionals to reflect and adapt their practice to meet the learning, communication, and support needs of parents with intellectual disability.

3. Funding allocation for assessments need to be reviewed so that resources match the need for a comprehensive and tailored engagement where one or both parents have intellectual disability
4. Parents with intellectual disability should be explicitly advised of their right to have a support person present and professionals should engage this person in the assessment planning and process. Where a parent cannot identify a support person within their informal networks, the Children's Court should require that a disability advocate be offered to them and that the Funded Service Provider managing their case arrange this on their behalf.
5. Further research should be undertaken to clarify the role of psychometric testing in assessment of parenting capacity and provide guidance to the court on when this should be requested in an assessment order and other processes that are more suitable when psychometric testing is deemed unnecessary.

## 6. Background

Parents with intellectual disability have been described as a 'hidden group' (Tymchuk, 2001). The majority fall in the low-borderline intellectual range and, as a result, may not have a formal diagnosis or have received learning support or disability services during their early life (IASSID Special Interest Research Group on Parenting with Intellectual Disability [SIRG], 2008). Goffman's (1963) seminal work on stigma helps to explain why so many people with mild intellectual disability choose to 'pass' as non-disabled rather than disclose their disability status. However, this 'passing' can become much harder when they have or are expecting a child due to increased scrutiny by maternal and child health and other professionals on their capacity to provide 'good enough' caregiving. Six decades of research in the field of parenting with intellectual disability makes it clear that intelligence is not a reliable proxy for parenting competency (IASSID SIRG, 2008). Evaluations of adapted parenting training interventions establish that parents with intellectual disability can learn parenting skills when they receive training and support that is matched to their needs (Wade et al., 2008). However, low trust in professionals can make parents reluctant to seek help and mean that by the time they receive support they are already in crisis (Booth et al., 2006; Tarleton et al., 2006).

It is not easy to disentangle experiences and impacts of discrimination and social exclusion over the lifecourse from the challenges that arise in the context of parenting for this group. Social disadvantage is a common feature of the lives of people with intellectual disability (Emerson & Brigham, 2014). Co-occurring environmental stressors that are associated with parenting difficulties in the general population are common among parents with intellectual disability (Collings et al., 2019; McConnell et al., 2011). With this in mind, it is not surprising that research consistently shows parents with intellectual disability are far more likely to be involved in child protection matters and have children removed than other parents (Llewellyn & Hindmarsh, 2015). It is estimated that around 3 in 5 parents with intellectual disability will have their children removed from their care (IASSID SIRG, 2008). This disproportionality is reflected in local data, too. Despite their small size in population terms, a study undertaken in New South Wales found that 1 in 10 parents appearing in care matters before the Children's Courts had intellectual disability (Llewellyn, McConnell & Ferronato, 2003).

Parenting capacity assessments hold substantial weight in care proceedings and influence judicial decisions about the best interests of children (Budd, 2005; Curtis, 2009).

Inconsistencies exist in how parenting is assessed when a parent has intellectual and/or psychosocial disabilities (Callow et al 2017; Spencer 2001). Parenting capacity assessments with parents with intellectual disability usually involve psychometric testing using instruments that are not designed for this purpose and whose use is predicated on the belief that IQ score is predictive of capability. Assessments are often completed by professionals who lack disability training, who may hold negative views of parenting by people with disability and have had no or little frontline experience designing and implementing support plans for parents with intellectual disability (Aunos & Pacheco, 2020; Lightfoot et al., 2010). Discriminatory attitudes have also been identified among other professionals involved in child protection decision-making including caseworkers, judges, and lawyers (McConnell & Llewellyn, 2000; Sigurjónsdóttir & Rice, 2017).

## **Methods**

Mixed methods were used to identify the influence of professional and systemic factors on assessment practice. A rapid evidence review was undertaken to identify evidence-based measures and tools to assess parenting by people with intellectual disability, particularly in the context of child protection. An anonymous survey was used to surface professional beliefs and knowledge of parenting with disability. Focus groups were used to elicit the perspectives of parents with intellectual disability and the clinicians who undertake assessments. A review of a matched sample of assessment orders and expert reports was undertaken to examine how parental disability is identified in the order, the assessment process and recommendations to the court. Ethics approval was sought and granted for this project from the University of Sydney HREC (2021/590) and Sydney Children's Health Network HREC (2021/ETH11311).

### **1. Rapid Evidence Review**

A rapid evidence review was used to document evidence-based assessment instruments and approaches for assessing parenting by parents with intellectual disability. The review was restricted to studies that were published in peer-reviewed journals between 2001-2021 and were in English. A comprehensive database search and review of studies that met inclusion criteria was undertaken in December 2021-February 2022 (See Appendix 1 for database search and extraction process).



## **2. Survey**

Professionals who conduct child protection assessments, such as psychiatrists, clinical and forensic psychologists and clinical social workers, were recruited to complete an anonymous survey between August 2021-March 2022. The survey was hosted on a secure server at the University of Sydney using the Qualtrics platform. The survey could be completed via a computer or mobile phone and took approximately 20 minutes to complete. Information about the study was available and consent was deemed to be given upon submission of the survey. Information about the survey and a link to register were distributed by the Children's Court Clinic, Legal Aid Commission, and Department of Communities and Justice. The questions were designed to elicit views and beliefs about disability and skills and confidence to assess the parenting of people with intellectual disability [see Appendix 3 for survey questions].

## **3. Focus groups**

Focus groups were held in October and November 2021 with professionals who conduct parenting capacity assessments and parents with intellectual disability who have had such an assessment. Focus groups were approximately 1.5 hours duration and were conducted on Zoom due to COVID-19 lockdowns and social distancing restrictions. A semi-structured interview guide was used to elicit views and experiences of barriers and enablers of fair assessment of parenting capacity by people with intellectual disability.

Two focus groups were held with each participant group. Professional participants were recruited by the Children's Court Clinic, Legal Aid Commission, and Department of Communities and Justice and provided with written information about the study. Those who consented to take part were contacted by a research team member and a suitable time was arranged when at least three people were available. Parent participants were recruited by two organisations working with parents with intellectual disability involved in care proceedings - the WASH House and Intellectual Disability Rights Service. In recognition that this was a sensitive and emotional topic eligibility was restricted to parents who did not have open care matters and had not had a parenting capacity assessment within the last twelve months. A disability support worker from the WASH House was engaged to support parent

participation. She recruited participants and assisted them to give informed consent, download the Zoom application to their mobile device, and join the focus group. The worker also attended both focus groups to observe how each parent appeared to be coping, assist them to speak up and suggest we take a break if a parent was becoming distressed. The worker followed up with each parent after the focus group to check how they were feeling and make sure that they had someone to talk to if they felt worried about their personal safety. She also made sure they knew how to contact the Lifeline and Beyond Blue 24-hour hotlines.

#### **4. Assessment Orders and Expert Reports**

A desk-based review of twenty matched assessment orders and expert reports undertaken in 2019-2021 by authorised clinicians of the Children's Court Clinic was undertaken. Staff at the Children's Court Clinic conducted an electronic record search to identify assessment orders and expert reports of eligible parents using keywords such as 'intellectual impairment', 'cognitive impairment', 'cognitive disability', and 'intellectual disability'. The assessment orders and expert reports were reviewed by two independent coders. Thematic analysis was undertaken to identify commonalities and differences across the sample.

## Results

### 1. Rapid Evidence Review

The rapid evidence review returned 711 articles, of which 335 remained after duplicates were removed. Abstract and title screening resulted in 13 studies being retained for full-text review by two members of the research team. Of these, four met inclusion criteria [see Appendix 1 for details]. Two relevant rating scales were used to assess the evidence level of these studies [see Appendix 2 for details]. Only two studies met the criteria for evidence set by the Californian Evidence-Base Clearinghouse (CEBC, 2022)<sup>1</sup> rating scale (Azar et al. 2012, Lindberg et al. 2017). The Their Futures Matter (TFM) rating scale adopts a more pragmatic approach in order to identify promising models. Given the limited number of studies that met inclusion criteria, using the TFM rating scale enabled two further studies to be included in the review (Aunos & Pacheco, 2021, Zetlin et al, 2021). The studies are described below.

#### Supported evidence

In the United States, Azar et al. (2012) tested the validity of the Social Information Processing (SIP) used to measure psychological and physical indicators of neglect. A cross-sectional comparison design was used with a matched sample of 73 participants recruited from Child Protective Service agencies. The sample included 43 mothers who had a child protection record of neglect, and a comparison group of 30 mothers with no such record. All mothers were from low socioeconomic status backgrounds, and data about their age, education, marital status, income, and the number, age and gender of their children were collected. Mothers with low IQ were oversampled in both groups. Participants were assessed and the SIP model used to compare outcomes. SIP includes assessment techniques such as questionnaires, problem-solving tests, cognitive vignettes, and observational rating scales. Results showed that mothers with history of child neglect had more difficulties across the SIP domains and confirm model validity. SIP problems were associated with direct measures of neglect (e.g., cognitive stimulation provided children, home hygiene, beliefs regarding causes of child injuries). SIP problems appear linked to neglectful parenting in a sample of mothers with low IQ. The study supports a social learning approach to understand the origins of a person's SIP difficulties and enhancing social cognitive capacities may be more effective for

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<sup>1</sup> California Evidence Based Clearing House (CEBC). (2022). *Program Registry: Rating Scales*. Retrieved 24 February 2022. <https://www.cebc4cw.org/registry/ratings/>

to building parenting skills than behavioural learning approaches alone. Targeting hostile attributions (re-attribution training) and challenging inappropriate expectations (cognitive restructuring) may be useful along with work on attentional skills, rule shifting, and updating

In the United States, Zeitlin et al (2021) evaluated the psychometric properties of the Skills Assessment for Parents with Intellectual Disability (SAPID), an assessment tool to assess parents with intellectual disability with child welfare involvement. SAPID is an observational tool, consisting of fourteen observational checklists across five domains: safety, planning, home management, child cleanliness, and parent-child interaction. A sample of 133 participants was drawn from a prevention program for parents with intellectual disability. A range of sociodemographic data on parents and children were collected. Results show that the tool accurately assesses parenting skills of parents with intellectual disability and that program completion was significantly associated with a moderate to large observable change. The absence of a comparison group is a limitation, but the tool was applied at four time points and two methods were used to assess validity of the tool, strengthening reliability. The potential limitations of checklist-only format are not explored.

### **Promising Evidence**

In Canada, Aunos & Pacheco (2021) conducted a case file review to examine and compare parenting capacity assessment reports by child welfare agencies and specialist disability services. A total of 13 parenting capacity assessment reports conducted on 8 families with parent(s) with intellectual disability were included. Significant differences were identified between reports by service type. Child Welfare services typically concluded that the parent lacked the capacity to raise their children and framed them in negative terms. All except one report concluded that parental incompetence was a permanent state, and several did not evaluate the parents' learning capacity. Reports by specialist disability services identified that with appropriate support, parenting capacity was adequate and took a strengths-based view. Child welfare service reports did acknowledge environmental and systemic issues. Across all CW and ID service reports, 34% of variables and 60% of recommendations fall into this category. Small sample size limits the reliability and requires replication in a larger study.

In Sweden, Lindberg et al. (2017) examined the quality of maternal sensitivity among mothers with mild intellectual disability. Mild intellectual disability was defined as a having

an IQ between 55-70 and significant limitations in adaptive functioning. Although the context was not child protection and the study did not test a specific assessment tool, it was relevant to parenting assessment as it outlines an evidence-based approach to measuring maternal sensitivity. A matched comparison design was used with a sample of 48 mothers, 23 with a mild intellectual disability and a comparison group of 25 mothers without a diagnosis of intellectual disability. All mothers were living with a child aged 5-8 years at least 50% of the time. Mother and child demographic data was collected along with area level disadvantage ratings. A semi-structured interview was conducted at the participant's home and followed by a laboratory visit which included observations during four different play situations; IQ tests; interviews; and a child attachment task. The study found that mothers with intellectual disability were significantly lower in sensitivity than the comparison group. Low sensitivity was associated with history of maltreatment and low social support and predictive of disorganized child attachment. In the comparison group, high maternal sensitivity was related to partner presence and social support, and predictive of child intelligence. The statistical power of this study is limited by the small sample size and the use of descriptive statistics.

## **Summary**

There is a dearth of evidence-based tools and instruments specifically designed for assessing the skills and competency of parents with intellectual disability. Two studies demonstrated efficacy in predicting neglect (Azar et al 2012) and assessing parenting skills (Zetlin et al 2021) among this parent group. Both studies were conducted in the United States and both tools, the SIP and SAPID, had notable limitations, due to design and small sample. Neither are classified as well-supported evidence. This review shows that the international evidence base in assessment of parenting capacity by parents with intellectual disability remains nascent and represents a significant barrier to advancing good practice.

## 2. Survey analysis

### Sample

A total of 65 professionals commenced and 37 completed the anonymous online survey. The majority had at least 8 years' experience in conducting parenting assessments and came from either a social work (N=21) or psychology (N=12) background, with the remainder from 'other' profession (N=4). No respondents stated they had a received training in the assessment of parents with intellectual disability. The sample were comprised mostly of private assessors or authorised clinicians (N=26) with the remainder being in-house assessors for the Department of Communities and Justice (N=11).

### Responses

#### Question 1

The survey was broken into three sections. The first question asked respondents to rank 13 factors by order of importance when assessing a parent with intellectual disability. For reporting purposes, important/very important and not important/low importance are combined. See Table 1 for results.

**Table 1: Factors important for capacity assessment**

Factors	Important	Not Important	Neutral	20%+ Neutral
Assessment Order specifies ID	33		4	
Assessor has background information about the removal.	36		1	
Assessor has information about parent cognitive functioning	35		2	
Assessor communicates with family /support person about parenting capacity.	36		1	
Parent observed with their child/children.	36		1	
Assessment takes place in their home with a support person.	29		8	22%
IQ tests must be used to make a diagnosis of ID	23		14	38%
Adaptive functioning assessment to determine impairment level.	29		8	
Adaptive functioning assessment as evidence of impacts of impairment on parenting capacity	33		4	
Adaptive functioning assessed using standardised tools, and in home and community settings.	30		7	20%
Views of child on parent ID sought if able to express their views.	35		2	
Parents would benefit from parenting programs to develop skills	23	2	14	38%
Parents would benefit from 1:1 support with parenting skills	34		3	

Overall, respondents rated every factor as important or very important. The only factor rated as not important, by two out of the 37 respondents, was parents' participation in parenting programs.

A notable finding was the high level of 'neutral' responses. Over a third of respondents were unable to decide on the importance of psychometric (IQ) tests or whether parents would benefit from attending parenting program. Around 1 in 5 respondents were uncertain about assessments being conducted in the home with a support person and a similar number were unsure about them being held in the home or community setting. This is likely to reflect a preference for assessment to occur in a professional setting, possibly to facilitate parent-child observations and because clinicians wanted to have materials used in assessment readily available.

## Question 2.

In the second section of the survey, respondents were asked to rate the relative importance of 10 factors about parenting capacity. See table 2 for results.

**Table 2: Relative importance of parenting factors**

Factor	No 1	No 2	No 3	% top 5
Ability to meet the child's emotional safety and wellbeing needs	6	11	2	65
Ability to meet the child's physical safety and wellbeing needs	9	4	2	52
Ability to adapt to the child's developmental needs	1	1	8	52
Insight into child protection involvement	6	1	2	48
Ability to demonstrate sustained change to parenting skills	0	1	4	39
Receptiveness and willingness to accept feedback	1	5	2	42
Appropriate support services or family support in place	0	0	1	39
Responsive and cooperative with services	1	2	2	29
Has addressed domestic violence concerns if relevant (e.g., attending programs, left relationship, moved house)	1	3	3	52
Has addressed substance abuse concerns if relevant (e.g., remains abstinent, attending urinalysis)	3	1	3	48

The factor ranked number one most frequently was the parents' ability to keep their child physically safe (9) followed by meeting the child's emotional/ wellbeing needs or insight into child protection involvement (6 for both). Almost two thirds (65%) of people ranked ability to meet child's emotional/ wellbeing needs in the top five most important factors. The factor least likely to be in respondents top five was parents' cooperation with services at only 29%.

### Question 3

The third question asked respondents to score their level of agreement with statements about beliefs and experience of assessing parents with intellectual disability. Table 3 presents the results.

**Table 3: Beliefs about assessment with parents with intellectual disability**

Beliefs	Agree	Disagree	Neutral	%Neutral
IQ score < 70 is sufficient to diagnose ID	10	10	12	37.5
Parents with ID experience >parental stress than other parents	15	5	12	37.5
Parents with ID experience >difficulties with child behaviour	17	3	12	37.5
Parents with ID experience are able to provide 'good enough' care	27	0	5	15.5
Parents with ID experience > difficulties accessing support	21	1	10	31.25
Parents with ID > likely to have children removed	19	6	7	22
Parents with ID > likely to have other issues e.g., Domestic violence, Substance misuse, mental health issues	9	9	14	43.75

Two patterns emerged from the data. The first pattern was that respondents were split down the middle on whether a confirmed diagnosis of intellectual disability was important (10, 10) and whether parents with intellectual disability were more likely to have other issues (e.g., domestic and family violence, substance misuse) (9, 9). The second pattern was the high rates of 'neutral' responses, with over 1 in 3 respondents opting for this response to most questions. This was particularly stark in relation to the questions about stress and child behaviour problems (37.5%) and co-occurring risk factors (43%) for parents with intellectual disability compared to other parents. This finding indicates that most respondents lacked confidence in their knowledge about parents with intellectual disability.

The only area that elicited a high degree of consistency was the statement 'Parents with intellectual disability are able to provide 'good enough' care and parenting'. No respondent disagreed and the statement elicited the fewest neutral responses (15.5%). While over half of respondents (59%) agreed that parents with intellectual disability are more likely to have their children removed than other parents, this still left 2 in 5 people who were either unsure or disagreed. This may reflect a professional belief that this parent group are not treated



differently in care matters or that other parent groups at greater risk than them. Irrespective of the reasons, this represents a critical gap in knowledge for this workforce.

### **Summary**

The results indicate a high degree of uncertainty amongst professionals in relation to assessment of parenting by people with intellectual disability. This may indicate a low level of confidence to assess these parents. It is noted that the majority of professionals agree that parents with intellectual disability can provide 'good enough' care. Overall results suggest hesitancy among professionals about whether the level of support needed for parents with intellectual disability to achieve a satisfactory standard of parenting competency is likely to be available. Increasing the understanding of professionals about intellectual disability and how it may (and may not) impact on parenting capacity and providing professionals access to research about parenting support and training for this group would assist in building their confidence.

### **3. Analysis of matched assessment orders and expert reports**

Twenty assessment orders were independently coded by two members of the research team. These and the corresponding twenty expert reports, written by authorised clinicians contracted by the Children’s Court Clinic, were then coded and analysed by one of the two researchers. As indicated above, the research team attained ethics approvals from the University of Sydney and Sydney Children’s Health Network HRECs, including a waiver of consent from parents to examine their assessment orders and reports. The dual coders also attained site approval to attend the Children’s Court Clinic at Parramatta to extract data from hard copy files. The administrative team from the Children’s Court Clinic stored assessment orders and expert reports in a locked cabinet. No assessment orders or reports were removed from the Children’s Court Clinic. The coders saved extracted data on a password protected Excel spreadsheet. All data extracted from assessment orders and expert reports were deidentified, unique identifiers created for individuals and the files stored on the secure server of the University of Sydney (see Appendix 4 for list of data extraction fields).

Of the 20 matched assessment orders and expert reports, 18 were assessments for initial care proceedings and two were assessments for S90 (restoration) applications. A total of 14 (70%) assessment orders involved Aboriginal parents. The majority (60%) were from regional courts, with eight orders from metropolitan courts such as Parramatta, Surry Hills, and Broadmeadows.

#### **Assessment Orders**

Nine assessment orders sought assessment by an authorised clinicians with specified expertise in conducting cognitive assessments and advising the court on how parental cognitive impairment and comorbid presentations may affect parenting capacity. Examples of these requests include:

*“Psychiatrist or Clinical Psychologist with knowledge and experience in relation to mental health, cognitive capacity and parenting capacity”.*

*“Clinician with expertise in cognitive assessments”.*

*“Clinician with qualification to assess the parent’s cognitive capacity, intellectual capacity, and mental health as these factors are considered integral to the assessment of their parenting capacity”.*

## Reasons for referral

Thematic analysis of assessment orders indicate that cognitive capacity assessments were requested to inform the court about the child’s needs and the parents’ abilities to meet these needs, particularly if parents met diagnostic criteria for intellectual disability. Assessment orders also required authorised clinicians to make recommendations about suitable support services for parents to provide care to children.

Of the 20 assessment orders, 12 orders explicitly requested cognitive capacity assessments and referred to concerns about parental intellectual disability and cognitive impairment (see Table 4). There are distinct differences between intellectual disability and cognitive impairment. Cognitive impairment may not affect or be indicated by the person's IQ score, while those with intellectual disability will consistently score below 70 to 75 on a standardized IQ test. Borderline intellectual disability refers to those who test above 70 but below 80 on a standardized IQ test and have limitations to adaptive functioning. The purpose of requesting cognitive capacity assessments is threefold: to determine whether parents’ cognitive difficulties or deficits meet criteria for intellectual disability; how cognitive impairment or intellectual disability affects the parents’ ability to meet children’s needs; and what services are needed to support parents and children to ensure that the child’s safety and wellbeing needs are met.

In five of the eight assessment orders that did not explicitly request cognitive capacity assessments, authorised clinicians assessed that one or both parents showed evidence of cognitive impairment and cognitive difficulties, but did not meet criteria for intellectual disability. The processes involved in assessing parents with intellectual disability and cognitive impairment are outlined in greater detail in the next section (see Expert Reports).

**Table 4: Case numbers of Orders requesting cognitive capacity assessments**

<b>Referral from Assessment Orders</b>	<b>Case No</b>	<b>Sample No</b>
Sought cognitive assessment and made reference to cognitive impairment	1, 3, 4, 5, 6, 8, 9, 11, 16, 18, 19, 20	12

Did not seek explicitly seek assessment of cognitive disability, cognitive impairment or intellectual disability	2, 7, 10, 12, 13, 14, 15, 17	8
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The reasons for requesting cognitive capacity assessments were varied. Five of the assessment orders (cases 1, 2, 4, 6, 7, 8, 9, 11, 15, 19) considered parental intellectual disability as the primary risk factor for child protection involvement. In these cases, the parent or parents had a history of cognitive deficits that were documented but the parent may not have been formally assessed or diagnosed with intellectual disability. In other cases (cases 5, 9) parental intellectual disability has been established in previous assessments. In these reports parents were described as having presentations such as *'memory cognition, and information processing issues'*, *'difficulties multitasking'*, or *'does not appear to understand protective concerns'*. Cognitive capacity assessment was sought by the court to clarify whether the parent's presentation met standardised criteria for intellectual disability. It was noted that the assessment orders associated cognitive deficits, cognitive impairment, or a diagnosis of intellectual disability with an increased risk of parental abuse or neglect. For example, case 8 sought an assessment of the *'mother's cognitive capacity and its impact on her parenting capacity and social functioning, including her ability to understand her children's needs and to acquire and retain skills to care for them appropriately'*.

More than half of the assessment orders outlined concerns regarding cognitive impairment and comorbid presentations, including mental health diagnoses (such as Post Traumatic Stress Disorder and Major Depressive Disorder), substance use, and domestic violence. The terms of assessment often requested clarification about the parents' *'cognitive capacity and whether the [parents'] mental health will impact on [their] parenting abilities'*. In one of the assessment orders (case 3), the authorised clinician was asked to *'comment on the mother's cognitive functioning and whether this explains why she returns to the domestic violent relationship with the father'*.

Misinterpretations and misunderstanding about the terms *'cognitive impairment'* and *'intellectual disability'* were apparent in the assessment orders. It was noted that the terms *'cognitive impairment'* and *'intellectual disability'* were used interchangeably in assessment orders, such that judicial officers, legal professionals, and caseworkers assumed that these

terms were identical. Thematic analysis indicated that poor literacy skills and low level of education were often misinterpreted as indicating intellectual disability, such as in case 4, ‘...assess the father’s cognitive abilities given his limited literacy’. It was also noted that caseworkers requested cognitive capacity assessments for parents who did not appear to be making improvements in parenting capacity despite engagement with support services. The terms of assessment in orders would request that the authorised clinician comment on the impact of cognitive impairment or intellectual disability on parenting capacity and ability of the parent to meet the needs of the child. These findings are consistent with empirical research that show that intellectual disability is inaccurately perceived as troublesome and a risk factor for child maltreatment (Aunos & Pacheco, 2021).

### **Expert reports**

Data from the sample of expert reports were analysed to highlight assessment processes that may limit a fair assessment of the parents’ cognitive ability and parenting capacity and to identify examples of best practice when assessing parents with intellectual disability. Table 5 outlines the professional backgrounds of authorised clinicians who conducted the assessments.

Four assessments were conducted by social workers and 11 assessments were conducted by clinical, forensic, and registered psychologists. Review of assessment reports also showed that the Children’s Court Clinic Director jointly allocated assessments to authorised clinicians to maximise their expertise and knowledge in complex matters, such as those involving parents with cognitive impairment, comorbid presentations, intergenerational trauma, as well as children with complex needs. Two assessments (cases 7 and 14) were jointly conducted by a psychiatrist and a social worker. Three assessments (cases 10, 13, 17) were jointly conducted by a clinical psychologist and social worker. Joint assessments involving two authorised clinicians is a relatively new practice within the Children’s Court Clinic, as assessments with each family are typically conducted by one authorised clinician.

**Table 5: professional backgrounds of authorised clinicians**

<b>Profession</b>	<b>Cases</b>
Social worker	1,6,8,12

Clinical psychologist/forensic psychologist/psychologist	2,3,4,5, 9,11, 15, 16, 18, 19, 20
Psychiatrist and social worker	7,14
Clinical psychologist and social worker	10, 13,17

### **Assessment processes**

This study reviewed the processes involved in assessments to examine whether these processes are disability-informed, whether supports were offered to parents to attend their appointments, whether consent was sought from parents to participate in interviews and psychometric testing, and whether these processes facilitated a fair assessment process for parents. Although not the primary focus of this study, the impact of COVID-19 restrictions and the pandemic on parents with intellectual disability and assessments were also examined.

Consent was sought from all parents who attended interviews and observations as part of the parenting capacity assessment. The reports indicated that clinicians explained their role to the parents, described what the assessment entailed, who would read the report, and how the report would assist with decision-making about their child’s placement.

There was a lack of consistency regarding where the assessment of parents with intellectual disability took place. Although some authorised clinicians assessed parents at their own home or that of their child’s kinship carer, the majority of assessments were conducted either at the Children’s Court Clinic assessment room or the clinician’s office. The reports indicated that some parents had difficulties using public transport to get to the Children’s Court Clinic or clinician’s office. In one case (case 3), a NIL report was filed, as the clinician indicated that the parents had rescheduled the appointment three times and were unable to attend their assessment due to a concurrent house inspection. On the basis that the father and mother had not complied with urinalysis, the clinician held the view that the parents were unlikely to be cooperative or willing to attend and did not make further efforts to engage the parents for assessment. Due to COVID-19 related restrictions, six assessments were conducted via telehealth. It was noted that parents with cognitive limitations, poor computer skills, and low literacy found assessments via telehealth a challenge. Reports indicated that parents had

difficulties accessing the video link and, in some cases, parents had no access to a reliable phone, computer or internet connection.

It was unclear if parents were given the opportunity to bring a support person to their assessment. In two cases (cases 19, 20) where the children were placed with foster carers, the parents attended their assessment with a NDIS support worker who assisted them with travel arrangements. In cases where children were placed with kinship carers, maternal and paternal family members were able to attend the assessments as support persons. Support people were generally able to corroborate or provide additional information about the parents' daily and adaptive functioning, which assisted authorised clinicians in making recommendations for support services needed by the parents.

Expert reports indicated that assessments of parents with intellectual disability required more than one day, with most clinicians spending at least three to four days. Clinicians indicated that additional time was required to explain processes, to seek consent, conduct interviews, observations, home visits and assess cognitive capacity. The complexity of assessments where one or both parents had intellectual disability was also reflected in significantly longer reports. Compared to a typical expert report of approximately 30-40 pages, reports involving parents with intellectual disability are typically 80-120 pages - or three times as long. Despite the increased labour required to conduct assessments and write reports, no extra time was offered to clinicians to file their report (approximately six weeks from when the Assessment Order was made).

### **Assessing intellectual disability**

Descriptions of the parents' presentation at interview and assessment were included in each report, such as whether parents attended on time, their appearance, behaviours, perception, cognition, affect, insight, and understanding of the purpose of the assessment. To achieve this, clinicians conducted the Mental State Examination, a structured tool that allows the clinician to observe and assess a parent's current mental state. Observations of the parent's emotional state and the extent to which it was congruent with verbal conversations between clinician and parent were documented. Clinicians also made a quick assessment of the parent's memory, whether they were '*reliable historians*' or had difficulties with short or long-term memory, to inform cognitive assessment.

Parental engagement in the assessment process was also described in reports, including level of cooperation and receptivity to feedback. Willingness to cooperate and engage with professionals appeared to be important in clinical decision-making, such that poor level of engagement was perceived to be a risk factor to a child. It was noted in several reports (such as cases 5, 6, 8, and 9) that mothers with intellectual disability were described as ‘*younger than her stated age*’ or as speaking in a ‘*child-like manner*’. Some mothers (such as cases 2 and 9) were described as ‘*nervous*’ about the assessment process. It was also noted that the clinicians in these cases ensured parents could take breaks and observed that parents were able to engage in self-soothing and relaxation skills such as ‘*deep breathing and box breathing*’ (case 2).

Clinicians interviewed and observed parents and, if deemed necessary, conducted psychometric testing over several days to minimise testing fatigue. Some clinicians also conducted additional assessment of the parent’s personality traits, mental health, and emotional functioning. These assessment tools may inform the clinician about the parent’s cognitive abilities, verbal skills or processing skills. However, clinicians indicated in their reports that these tools did not directly assess the impact of cognitive abilities on parenting capacity. The limitations of the use of cognitive assessment tools on parents of Aboriginal, Torres Strait Islander, and Culturally and Linguistically Diverse (CALD) backgrounds were also acknowledged by some clinicians. Assessment tools that were relevant to assessment of cognitive capacity are outlined in Table 6.

**Table 6: Assessment tools used to assess cognitive capacity**

<b>Assessment tools</b>	<b>Description</b>
Mental Status Examination (MSE)	Utilised by all clinicians to assess the parent’s current mental state, identify any difficulties with memory or comprehension, preliminary assessment of general cognitive functioning.
Adaptive Behaviour Assessment System- Third Edition (ABAS-3)	Frequently utilised by clinicians to assess parent’s adaptive functioning, such as conceptual, social, and practical life skills. Clinicians often sought assistance from support



	workers or caseworkers or family members to establish the parent's independent living and adaptive life skills.
Vineland Adaptive Behaviour Scales, Third Edition (Vineland-3)	Less frequently used by clinicians. An individually administered measure of adaptive behaviour that is widely used to assess adaptive skills across the domains of communication, daily living skills, and socialisation
Montreal Cognitive Assessment (MoCA)	Utilised by social workers and psychologists to assess mild cognitive difficulties
Wechsler Adult Intelligence Scale IV (WAIS 4 <sup>th</sup> edition)	Utilised by trained psychologist to measure intelligence and cognitive ability including verbal comprehension, working memory, perceptual organisation, and processing speed. Helpful in establishing severity of intellectual disability for the purpose of diagnosis or application for NDIS funding, though not helpful in establishing how cognitive functioning affects parenting capacity.
Wechsler Abbreviated Scale of Intelligence II (WASI 2 <sup>nd</sup> edition)	A brief measure to assessed cognitive ability that is utilised by trained psychologist.

### **Recommendations based on assessment of parental intellectual disability**

The analysis of the sample of 20 expert reports found that cognitive difficulties varied between all parents. Parents' abilities and their children's needs were assessed individually. Recommendations for each family also varied, such that supports for each family were tailored to the family's unique needs.

Some clinicians perceived intellectual disability as a risk factor for child maltreatment and neglect. This was particularly the case if parents presented with comorbid mental health issues, substance use concerns, and historical or current domestic violence (such as in cases 1, 2, 7, 8, 10, 15, 17, 18, 20). Clinicians outlined concerns that parents would not be emotionally attuned to the physical and emotional needs of children. Clinicians were concerned that parents with intellectual disability would experience difficulties adapting and making decisions. However, clinicians also offered suggestions and recommendations that supported parents, so that parents can remain involved in caregiving and maintain relationships with their children.

In some cases (such as cases 4 and 15), clinicians recommended that the children were placed in the care of the other parent, who did not have a diagnosis of intellectual disability or cognitive impairment. Where feasible and safe for children to remain with kinship carers (such as in cases 7, 10, 19), clinicians recommended that children continue to reside with family. In cases involving Aboriginal and Torres Strait Islander children (such as cases 2, 5, 6, 7, 11, 16), clinicians recommended that children were placed with kin in keeping with the Aboriginal Child Placement Principle, and that Aboriginal community-based services were involved in the care and support of the family. Clinicians advocated for parents to be involved in caregiving activities, such as preparing school lunches and attending parent-teacher meetings, so that parents played an active role in their children's lives. Parents' active engagement with children under the guidance of kinship carers could also assist parents in parental skill building through culturally appropriate role modelling.

Clinicians recommended the following scaffolding supports for parents with intellectual disability and cognitive impairment:

- a. *Facilitating parents' development of adaptive functioning skills:* Expert reports indicated that parents with intellectual disability rarely received early intervention support or services to facilitate skill development in daily and adaptive functioning skills. Recommendations included assisting parents with developing daily schedules. Some examples included parents are groomed and meeting hygiene needs, able to prepare food for themselves and their children, purchase groceries, develop basic financial skills, and go to bed at a reasonable time. Recommendations also included assisting parents develop help seeking behaviours and establishing a support network.
- b. *Community of support:* Clinicians identified parental stress, social isolation, mental health concerns, substance use, and domestic violence as potential stressors and risk factors for parents with intellectual disability. All clinicians recommended that DCJ caseworkers assist parents in engaging in a community and network of support to ameliorate these risk factors. It was recommended that parents with mild intellectual disability engage with an individual support worker who conducts home visits but also assists parents with problem solving and attending to daily chores or tasks. Clinicians also recommended that parents engage with psychologists or mental health professionals with expertise in working with cognitive impairment to assist parents develop healthy coping strategies and help seeking behaviours. Given the complex

needs of parents with intellectual disability, clinicians emphasized the importance of collaboration between support services and the necessity for a multiagency approach to provide holistic support for parents. As demonstrated in case 12, the clinician stated, *'The specialisation is that the services also needs to be able to work with a young parent, of Aboriginal culture, who also has some mental health difficulties, conflicted family relationships and needs to be supported to learn in ways appropriate to her cognitive capacities.'*

- c. *Improve home environment:* Clinicians emphasized the importance of home-based interventions and support where possible. Clinicians suggested that parenting capacity is enhanced when parents are more likely to develop skills in familiar, home-based environments and when these skills are practice based. For example, having support workers modelling how parents could ensure that their home is safe for themselves and children, or implementing routines in their home so that parents learn to attend to personal hygiene and cleanliness in their homes. These skills are further enhanced when interventions are supported and reinforced by family-based support.
- d. *Tailored parenting programs and interventions:* Clinicians were aware that many parenting programs may not be suitable for parents with communication difficulties and cognitive limitations. Clinicians acknowledged the limitations to appropriate programs and interventions for parents with intellectual disability and recommended tailored interventions to suit the current level of parental functioning based on assessment results. For example, clinicians recommended support workers or, preferably, a family member attend parenting programs such as Mums and Kids Matter or Triple P Parenting (aimed at parents without cognitive difficulties) with parents with intellectual disability. Clinicians indicated that support workers or family members could facilitate parents' learning by repeating information, practicing new skills, role playing, utilising positive behaviour interventions, using visual or audio prompts to assist parents in recall and recognition of new skills.
- e. *Improve support worker-client relationship:* Clinicians highlighted the importance of a trusting relationship between parents and caseworker and support workers. Reports indicated that some parents with intellectual disability perceived caseworkers and support workers were focused only on what they could not do (deficit-based practice) and this made them disengage with these services. When parents with intellectual disability had positive relationships with their caseworkers and support workers, they

were more likely to demonstrate ongoing engagement with services, which enhanced opportunities for them to build their parenting skills.

- f. *Engagement with culturally appropriate and culturally sensitive services:* Clinicians emphasized the importance of engaging with culturally sensitive and responsive support services, where relevant. Examples of services included AbSec's Aboriginal Statewide Foster Care Support Service, Cultural Journeyz (OOHC support in the Newcastle area), and Transcultural Mental Health teams.

### **Summary**

Analysis of assessment orders indicated that legal and child protection professionals perceive parental intellectual disability as a risk factor to child maltreatment. The reasons for referral for cognitive capacity assessments are often associated with the view that parents demonstrating cognitive difficulties may not understand the reasons for child protective concerns, may demonstrate limited insight, and may not be able to provide 'good enough' care to their children. The terms of assessments often requests that the clinician determine the level of cognitive functioning of the parent, and whether this level of functioning places the child at risk or harm.

Consistent with survey results, clinicians indicated that parents with intellectual disability can provide 'good enough' care, though also emphasised the need for collaborative, multiagency approaches in order for parents with intellectual disability to achieve a satisfactory standard of parenting competency. Analysis of expert reports showed that clinicians were hesitant about recommending restoration of children to parents with intellectual disability as they were concerned about parents' ability to consistently ensure the safety of their children and adapt to children's developing needs. This was compounded by comorbid presentations such as parental history of mental health issues, trauma backgrounds, substance misuse, and domestic violence. Clinicians were more likely to recommend that children be placed in kinship care and advocated for children to reside within their family and community where possible. Clinicians were supportive of kinship placements where parents with intellectual disability could assist in the care of children and remain involved in their children's lives without sole responsibility for children's day to day care and decision-making.

## **5. Thematic analysis**

Four online focus groups were held in October and November 2021. Two focus groups were with professional participants and two were with parents with intellectual disability. Each focus group was audio-recorded and transcribed. Data was independently coded by two researchers and thematically analysed using an established process (Braun & Clarke, 2022). Open coding was used to proliferate initial codes, which were reviewed to remove duplicates and regroup under new code names. Categories were created to organise codes what pertained to system, parent and practice barriers or strengths. Inconsistencies were resolved through discussion. Three themes emerged from these focus groups: (1) same but different; (2) to test or not to test; and (3) doing better.

### **Parent participants**

The focus groups with the parents explored their experience of undergoing a parent capacity assessment as part of the care proceeding process. Some of the parents had undertaken several parenting capacity assessments with one couple having undertaken six such assessments. Three key themes emerged from parents' experience of the assessment process: 1) Confusion with the process; 2) Feeling unsafe; and 3) barriers to demonstrating capacity. Overall parents these factors impacted on their ability to fully engage in the process and appropriately demonstrate their parenting capacity.

#### **A) Confusion with the process**

All the parents reported being asked to undertake a parenting capacity assessment but having little understanding of what such an assessment involved or what they would be asked and why. Moreover, they were unaware of how what they said or did would be reported, as reflected in this parent's comments

*They don't tell you, they just tell you you've got an appointment with this assessor, like assessment person, to go and have a chat with the whole day with your kids and everything, and then you go on the day and then you're a bit nervous and that. I've asked a couple of times to go out for a smoke and they said yeah, but then they put in the report that I was going out every five minutes or something for the report to have a smoke.*

For many adults with intellectual disability (especially in the mild to borderline range), their time at school was painful; and for some, significantly impacted on their self-esteem as adults. Many felt they were not understood or appropriately supported in the school system and ashamed and even angry about their school performance. Not surprisingly, several parents were sensitive about clinicians asking question about their academic performance at school. As one parent reported.

*I went to my lawyer and said, 'I'm not doing it because it's got nothing to do with kids. It's just got everything to do with what I learnt at school, what's that got to do with it?'*

Several other parents questioned and were perplexed about why they were being asked about their schooling to relation to their ability to parent. This is reflected in the following comments.

*I don't know what history and geography and science had to do with raising your kid, but they asked me a bunch of questions about what you learned at school, and that had nothing to do with raising my daughter. So, I really don't understand why those questions were asked or why those assessments have to be based on what you learned from school.*

*I went to my lawyer and said, 'I'm not doing it because it's got nothing to do with kids. It's just got everything to do with what I learnt at school, what's that got to do with it?'*

For another parent, not only did they not understand the relevance of the assessor's line of questioning, but they perceived their performance at school was used against them in the assessment.

*[It]was a big thing for them, they were like, "well how are you going to parent this child and bring them up and know their times tables, and stuff like that. I said, well when it gets to that, they'll be going to school.*

### **A) Feeling unsafe**

All the parents spoke about feeling unsafe being subjected to a parenting capacity assessment. All reported feeling scared. As one parent explained:

*Just the name of it is scary. Parent Capacity Assessment, that's just scary in itself how it's named. You don't know – they're going to test me on my parenting and they're going to criticise me, they're going to - if I'm doing something wrong, they're going to criticise. There's not one parenting style the same. You're parenting your child how you believe your child needs to be parented, because all children are different.*

One parent who reported having undertaken six assessments said the process never got easier and that it depended on the individual court clinician.

*I was petrified. In fact, I've had six parenting capacity assessments done from the courts, and I've had some come back really good. But it all depends on the court clinicians really.*

Several parents spoke about finding it hard to trust people they do not know and that this impacted on their ability to participate in the assessment process. As the following parents said

*I have an intellectual disability, and when people say, "we're here to support you," it takes a long time to actually trust somebody. You've got to actually know the person, to actually trust them.*

*For parents who in the process of having their child removed felt betrayed by professionals, being able to trust the assessment process was significant issue*

*Because if it's just you and that person in the room it's your word against theirs, and because they're working for the court it's automatically what they say is the truth and what you're saying isn't the truth.*

For this reason, many parents spoke about wanting to have a support person present during the assessment. Whether they had a support person present during the assessment depended on the availability of someone (e.g., such as an advocate) they could trust as well as the openness of the clinician to having a support person sit in on the assessment. The following excerpt exemplifies the level of distrust this parent had going into the assessment.

*[T]he assessors they don't care if you've got a disability or not, they assess you on what you're capable of knowledge. That's all they care about is your knowledge, they don't care about anything about you. I had to like to have a support person in the room with me with the assessor with Community Services the first time they were called DOCS and they were like, 'You can't have a support person' and I'm like, "Well if I don't get a support person in the next three hours I'm walking out' and I pretty much walked out because I'm just like, 'I'm not dealing with this.*

Parents spoke about being allowed to have a support person present depended on the assessor. As this parent put it:

*Not the first one. She said outright no. 'No, you're not allowed to have a support person', but the second time we actually had someone who specialises in special needs. This assessor said, 'You're allowed a support person' [the assessor] highly encouraged a support person. Yeah, [the assessor] encouraged and said if we want a support person [they had] no problems with it and that.*

There was consensus in both the focus group that parents with intellectual disability be offered a support person during their parenting capacity assessment as a matter of course.

### **C) Barriers to demonstrating capacity**

Parents also identified several barriers that impacted on their capacity to be emotionally and cognitively available during the assessment process and to demonstrate to the best of their ability their parenting capacity.

Several parents spoke about where the assessment took place and were of the view that they would have been able to demonstrate their parenting knowledge and skills if they were in a more conducive environment. All parents agreed that assessments should be conducted in places in neutral places and where the parent and their children felt comfortable. As the following parents commented:

*I think it should happen in a neutral place, not in a daunting FACS place. In a coffee shop, in a park, in a library, I don't know – not in a DOCS office. You already feel overwhelmed. If*



*your baby, your life got taken away from you as it is, and you're already so low about your self-esteem, you just don't want to be around that kind of area, because you've got so much hurt and so much anger towards them already.*

*Yeah, [my assessment with my child took place] in a very clinical room, nothing fun, nothing – all you've got is a few toys in the corner, a little kitchen thing, and that's about it.*

Some parents spoke about the fact that the assessors did not make adjust their communication style, making it hard for them to understand what was being asked. As these parents noted:

*We had an assessor when we first done it and she was going backwards and forwards in the questions. She'll go to one question, then she'll go to another question, 'We'll go back to this question, we'll go to that question, we'll go to this one' and she just was all over the place.*

*[The assessor] was using big words where you don't know. That was another hard part, she was using really big words and that, and that's when we done this assessment and we said the last assessment was using really big words.*

Parents also commented on the length of the assessment sessions, recalling finding the process stressful and tiring.

*They do the whole testing one day, and I had to talk in one time, play with my kids in another and then during that whole day I had to go in there and do a test, like my knowledge test, they spoke to my kids and everything like that too. But yeah, I was just so emotional for the whole day.*

Parents thought it would be better to be assessed for shorter period over an extended timeframe, in a more natural settings so as not to be so overwhelmed and to be able to demonstrate what they know and what they can do. As these parents noted:

*Well, the first one came to the house, we had the interview, then we went to [suburb] to be with the kids and show how we can look after them and parent them for two hours; you can't really show two hours. That was over two days, and then when we done this next assessor, he*

*done it over two days too. If they break it up it would be better. Four days for [us] to talk to the assessor, and we started like nine o'clock in the morning.*

## **Summary**

The themes highlight the importance of effectively engaging parents in the assessment process. The issues parents identified align with the Three Pillars of Engagement model (see the disability-informed practice guide, p.14).

For parents with intellectual disability to engage the assessment process, what is being asked needs to be of relevance to the parent. It cannot be assumed parents understand the rationale for why they are being asked particular questions (e.g., about their schooling) or asked to perform certain tests that seem to the parent to having nothing to do with caring for their child. Clinicians need to provide clear explanation of the assessment process and parents needs to feel safe. The parents who participated in focus groups regarded it as valuable, and indeed their right, to have a support person present during the assessment process.

Moreover, barriers that compromise the parent being able to be emotionally, physically, and cognitively available to the assessment need to be addressed by the clinician. In relation to where an assessment takes place, priority should be given to choosing a location that is conducive for the parent rather than convenient for the clinician. Additional time needs to be given to conduct an assessment on a parent with intellectual disability. Regular breaks are a reasonable and necessary accommodation and should factored into the assessment process.

## **Professional participants**

The professional participants who participated in focus groups were clinicians who do parenting capacity assessments in care proceedings either as a Children's Court authorised clinician or in a privately contracted capacity. They all had experience in assessing parents with intellectual disability and considered themselves to have (and to be seen to have) expertise doing such assessments. Three themes emerged from these focus groups: (1) same but different; (2) to test or not to test; and (3) doing better.

### **A) Same but different**

All clinicians who took part said that they apply the same schema to assess parenting capacity when assessing parents with intellectual disability as they use with any other parents. However, there was no uniform schema used across clinicians and the theoretical framework that was applied to assess parenting depended on the individual clinician's discipline (e.g., social work or psychology) and what was prioritised as important for parenting. Some clinicians referred to a framework, developed by the Children's Court Clinic, which focuses on the functional components of parenting:

*I sometimes think about a framework that .... a previous clinic director developed, I think broadly you're looking at practical parenting, you're looking at the capacity to change your parenting, adjusting to children's ages and stages, you're looking at safety, you're looking at nurturing care, you're looking at connection to the community including being able to maintain a child at school or educationally.*

Other clinicians described schemas central to developmental psychology and based on attachment theory.

*I use as a part of my schema for assessing parenting capacity is the attachment theories of Patricia Crittenden, and in particular the adult attachment styles of the parents and anybody else that's involved. One of the aspects of that is looking at whether the person sees things from the point of view of themselves as compared with the point of view of other people, whether they're able to perceive the child as a real person if you like, in their own right, separate from themselves.... It's always a red flag for me if, [the parent says] 'DOCS did this, my ex-partner did this, my mother-in-law did this, and that's why the children were removed.' Unless it actually looks at, 'Well what part did I play in that and what can I change?', that's for me a concern.*

*I also... get involved into their experience of parenting and what parenting is to them...So getting into their background...what parenting is, what's their consideration of normal, what's their experience, and drawing out what we need to work with, what's the supports, what do they use, what's positive, or can they recognise these things that are culturally appropriate are actually putting the child in danger...*

The variability in clinical approaches to assessment and the constructs of parenting capacity used by clinicians may explain the inconsistencies that were highlighted by parent in their focus groups.

Most clinicians stated they adjust their approach when assessing parents with intellectual disability, despite simultaneously claiming to use the same schema for assessing parenting capacity irrespective of whether parents had intellectual disability or not. The main adjustment cited was in relation to communication style, noting the need to simplify their language and check for understanding. Only a few clinicians could give specific examples of how they go about this, as one explained,

*The thing that I would do differently would be at the beginning when I'm explaining things, to get them to repeat back to me some of the things that I've said to ensure that they understand what the assessment is about. And also to say, 'Look, I know that you've got some difficulties with learning, so please ask me if I say anything that doesn't make sense to you or if you don't understand', that kind of thing, and if I notice that they don't appear to understand or they're just agreeing with everything I say then I would repeat that at other times. So that would be my biggest thing, I think.*

Though acknowledging the importance of adjusting communication when assessing parents with intellectual disability, the following clinician commented that this is not something 'special or specific' to parents with intellectual disability:

*I take [Clinician] point about changing language and being sensitive to use some words and terms and so on, but I pretty much do that with everybody in Children's Court jurisdiction because, without being pejorative, it's not going to be a legally sophisticated population, it's completely different – 90% of it completely different to say a Family Court population where you could have lawyers as parents, or police officers as parents, or extremely high level executives as parents, so they bring a high intellect and a verbal sophistication to that jurisdiction. That's exceptionally rarely the case in the Children's Court.*

Another clinician reported they try from the outset to make parents feel comfortable to speak up when they do not understand. This places the onus on the parent to manage the communication exchange, as highlighted below.

*Right at the beginning I think they need to understand that we're not going to judge them, that we're there to try and explain it simply, and I would try and explain it simply, but sometimes we use words that we don't realise aren't simple. So just making people aware that it's quite comfortable for them to do that.*

The ethics of telling parents they are not being judged is questionable in the context of child protection. Parents having their parenting capacity assessed *are* being judged. To be told otherwise, may explain why some parents in the focus groups felt that when they asked for things to be explained it was used against them. This was particularly the case when such 'help seeking' was recorded by the clinician in their report, as an example of the parent's limitations.

## **2. To test not or not to test**

According to clinicians in these focus groups, it is commonplace for the Children's Court or those ordering a parenting capacity assessment (e.g., DCJ or Legal Aid) to request psychometric testing on parents with intellectual disability as part of a parent capacity assessment. The consensus was that intellectual or neuropsychological assessments should be seen as having a distinct purpose and undertaken separately and not as part of a parenting capacity assessment. Several participants regarded these assessments as needing to be viewed as distinct so that adequate resources were allocated, rather than because doing them was best practice. As explained below, not all authorised clinicians are qualified to undertake certain psychometric tests, meaning that allocation can become difficult when these are requested by the assessment order.

*There are many social workers who don't – and most of us don't do testing or they might do screening, but they don't necessarily do testing. Apart from anything else a clinician is not going to want to do it either for three reasons (1) they don't do them, (2) they're a psychologist and they don't do testing and they don't believe in doing testing, or (3) they're a psychologist who will do it but they say – most of the – well, some of the psychologists will say every time there's a test involved it's like two and a half grand. So that makes a difference.*

Most participants agreed that psychometric testing, such as IQ Adaptive Behaviour Analysis Scales and neuropsychological assessments had a place in terms of providing additional information to assist in the assessment of parenting. However, were ambivalent about how it contributed. Some social worker participants noted that, while they were not trained to conduct psychometric testing, they sometimes used Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) to verify their suspicion a parent may have a cognitive impairment. As one clinician who was a social work said:

*I want to make sure people aren't disadvantaged by the fact that they're seeing me and not a psychologist.*

This clinician went on to explained that she sometimes undertook assessments in tandem with a psychologist who undertook an intellectual assessment requested as part of the court request and she did the parenting capacity assessment. As she commented:

*I think used correctly they can be quite helpful... as part of your battery of assessment the other parts are looking at the attachment, looking at functionality, looking at the history, looking at their relationship with the child, all those things, they're all part of that assessment. It's a much more complex thing.*

Some clinicians, however, shared concerns that there was a danger that test results can be extrapolated to make findings about the parenting capacity of parents with intellectual disability, which exceed the purpose and scope of such tests. As one clinician commented:

*I just want to return briefly to the bit about the neuropsych assessments because I think it's important in the sense that I too have read some shockers, some really dreadful ones... the tests are there to test something, to sample something, and what we're actually looking at is sampling real life. Sometimes the distance between what a test tests and what life throws at people are just worlds apart. That then introduces a critical factor called ecological validity, and the more we head down the path of neuropsych the more we're getting into very specific areas of cortical function which may be quite telling on a neuropsych battery, but in terms of its relationship to functioning in the real world we're heading into really fraught territory. We're moving further and further away from then an assessment of parenting capacity and*

*getting stuck if you like in the emperor's new clothes where we're starting to describe all sorts of things that are indescribable.*

These findings highlight the lack of clarity and understanding by those requesting and performing assessments about the rationale for conducting cognitive screening and psychometric testing in matters involving parents with intellectual disability. In addition, there was no consensus on how test result can and should be used to inform reporting on parenting capacity.

### **3. Doing better**

All clinicians conceded that they could be doing better when it comes to how they assess parents with intellectual disability. They were committed to ongoing improvement in their assessment practices with these parents and some had concrete ideas about how this could be achieved. However, they cited systemic and practice barriers as impeding them doing so.

Clinician agreed that it took longer to assess the parenting capacity of parents with intellectual disability. Time pressures were identified as the primary reason that they would decline a referral for a parenting capacity assessment on a parent with intellectual disability.

*I'm going to say timeframe and timeframe pressures is quite important because quite often they say, 'We need a full parenting capacity assessment, and we need it back in 10 days' and I'm like, 'Yeah, not going to happen.'*

As one clinician saw it, educating the court about the time required to undertake such assessment was critical:

*The other thing is obviously providing them with the tools to then push back with court saying, 'This is the structure we're going to need, and this is why we need extra time,'*

Fair remuneration for their work was a related issue to time pressure.

*I'd certainly say that finances, as in level of remuneration when it was a fixed price, certainly was a significant factor because I would know whether a parent with intellectual deficits or*

*challenges, that invariably there'd be additional hours of psychometric testing going on, and when it was on a sort of flat category-based funding that certainly made the return a lot more challenging.*

Clinician identified the importance of being given the scope in their assessment to gather collateral information by speaking with a parent's formal and informal support networks, as noted by the following clinicians:

*[It's]very valuable information that you get from speaking with someone like that because they have the day-to-day – see everything over a long period. We only have this cross-sectional view, and they have this longitudinal view of whether people have responded to things they've been taught, or whether they've learned from those things or not. It's not a matter of what you've been taught, it's a matter of what you've taken away from that. So, they're very helpful with that I think.*

*Like [another clinician] said, I think it's very important to speak to them and not get their written response because they tell you what they think is important, and sometimes it's, 'You said this, now can you tell me a little bit more?', and you've got particular questions about that which - you need to have that conversation rather than their interpretation of whatever picture they want to paint.*

Clinicians however reported that there was often confront restriction on who they could speak to as part of the assessment. Sometimes these restrictions came from DCJ or lawyers.

Clinician reported they often confronted service “gatekeeping’ in relation to access information.

*Well, I've got to say that I've rung a number of services where the worker who's working with the parent says, 'I'll have to check with my boss or my supervisor whether I'm allowed to speak to you', and then they say, 'Well maybe we'll send you an email' or something, and they actually, in a sense, won't speak to me, basically.*

Some clinicians spoke about the importance of being able to conduct assessments under more conducive conditions. One clinician spoke about the value of conducting at least part of the assessment in the family home.



*I work differently, I go and have at least one interview in their home, and I find particularly those who do have an intellectual disability, viewing the home, the photographs, the layout, it prompts me to ask some questions which they may not necessarily bring up when you're talking about supports, and they've got photographs of people everywhere and I can say, 'Who are they?', 'That's my cousin, she's here all the time', 'Great.' And I can change the language and I can prompt some things, and they can really describe the relationships and the support that they actually provide, and sometimes that gives me more information to then go looking somewhere else than I do if the conversations I have which are not in their home.*

*So sometimes their environment gives me the cues to pick up on to ask things, but also how it's structured. If I go into a home and it's actually really well laid-out, how does that happen? It sometimes can give me a bit different picture than what's written in words.*

While agreeing that doing a home visit may be beneficial, other clinicians stated that factors such as COVID restrictions, time restraints and safety issues as barriers to doing home visit. For the following clinician doing a home visit was more an accommodation they would make only if the parent did not have the capacity to travel.

*[G]enerally people I see are functioning in the community. I will sometimes do home visits, particularly for the first visit if I'm not sure people will actually be able to find their way. But bear in mind that if you're at Paramatta Court you've already got to the clinic, and I do most of my office visits at the clinic, so all I have to do is say, 'Did you get to the Court okay? Well we're on the ground floor.' So that reduces the number of people who are likely to have difficulty. But I do sometimes do home visits – there's a safety assessment involved in doing that in terms of who I would do that with, which wouldn't be everybody. But if I think there's doubt about whether they have the capacity to get there, I'll check that.*

Clinicians had ideas about how their assessment practices of parents with intellectual disability could be improved. The following clinician noted it would be good, if as part of the assessment process, clinicians were provided the time and resources to undertake

*Prolonged observation in the caring environment so you're able to see that parent actually function as a carer and have good quality observations associated with that.*

A few clinicians thought contact visit could be used more effectively to inform assessment of a parent's capacity. As one clinician noted:

*This element to me is the critical one of greater clinician involved contact processes, and I think that would be so informative to the court.*

A few clinicians thought it would be beneficial for their assessments of parents with intellectual capacity to include a therapeutic/educational intervention component. One clinician provided an example of how she used coaching during contact as part of an assessment. She noted this provided important evidence to demonstrate to the court the parent's capacity to learn.

*I spoke to the mother before the visit and prepared her with activities and talked about what she might be going to do on that day, and then I sat through the contact visit, and then I spent some time with her afterwards asking how she thought it went and giving her some feedback around that, I took notes so that the next time we came back I was able to give her some feedback and suggest things that she might like to try on the next occasion.*

## **Summary**

Themes from professional focus groups highlight that clinicians frame and approach assessing parenting capacity in a variety of ways. Clinician expressed that they used the same approach with parents with intellectual disability as they would with any other parent but adjust to accommodate a parent's communication style. While the parents spoke about the value of having a support person with them in the assessment, clinicians did not identify this as a consideration.

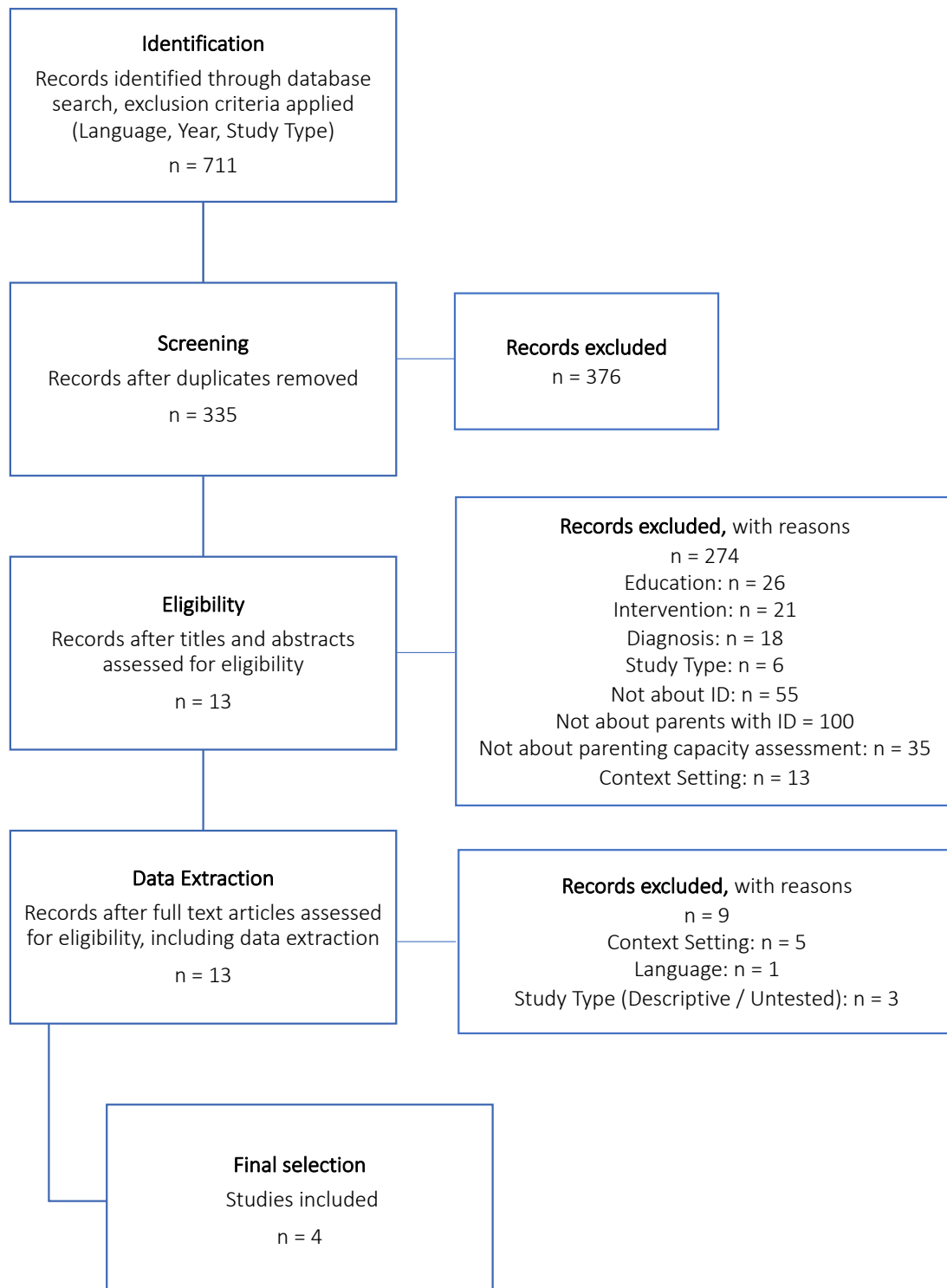
Clinician were ambivalent about the necessity, role, and value of psychometric testing to inform an assessment of parenting capacity. Their views varied depending on disciplinary qualification, with psychologists more positively disposed toward psychometric testing than social workers. There was consensus that psychometric testing should not be used as the basis of a finding on parenting capacity assessment but less agreement or clarity as to the extent to which they should influence an assessment outcome.

Finally, all clinicians conceded the process by which they assess the capacity of persons with intellectual disability to parent could be better. They cited systemic and practice barriers as the key obstacles to improving the quality of their assessment practices. They saw the value of having more time to observe parents with intellectual disability parenting their children firsthand and offering them therapeutic intervention and educational support as part of the assessment process to support evidence of a parent's capacity to learn new skills.

## **Conclusion**

## Appendix 1: Evidence review data extraction

### Database search and extraction process



## Appendix 2: Evidence rating of included studies

Status	Evidence Rating	Studies
<b>Included</b>	<b>Well-supported</b> by evidence <ul style="list-style-type: none"> <li>• Empirical evidence</li> <li>• High range reliability</li> <li>• Large range sample size</li> <li>• Demonstrates positive effect / outcome</li> </ul>	N/A - None met criteria
	<b>Supported</b> by evidence <ul style="list-style-type: none"> <li>• Empirical evidence</li> <li>• Medium range reliability</li> <li>• Medium range sample size</li> <li>• Demonstrates positive effect / outcome</li> </ul>	Azar et al. (2012) Zeitlin et al. (2021)
	<b>Promising</b> evidence <ul style="list-style-type: none"> <li>• Empirical evidence</li> <li>• Low range reliability</li> <li>• Small range sample size</li> <li>• Demonstrates positive effect / outcome</li> </ul>	Lindberg et al. (2017) Aunos & Pacheco (2021)
	<b>Evidence fails to demonstrate effect</b> <ul style="list-style-type: none"> <li>• Empirical evidence</li> <li>• Low – High reliability</li> <li>• Small – Large sample size</li> <li>• Does not demonstrate positive effect / outcome</li> </ul>	N/A - None met criteria

## Appendix 3: Survey Questions

1. Please indicate the extent to which you agree with the following statements

Factors	Not Important	Low Importance	Neutral	Important	Very Important
The Assessment Order specifies a parent(s) has a history of cognitive impairment and/or intellectual disability.	1	2	3	4	5
The assessor is provided background information about the removal of the child.	1	2	3	4	5
The assessor is provided additional information from caseworker or relevant health professionals about the parent(s)' cognitive functioning and its impact on parenting capacity	1	2	3	4	5
The assessor communicates with other family members or the parents' support person to establish their parenting capacity.	1	2	3	4	5
The parent(s) with intellectual disability is observed with their child/children as part of the assessment.	1	2	3	4	5
An assessment with the parent(s) with intellectual disability takes place in their home with a support person present.	1	2	3	4	5
A comprehensive battery of IQ tests (including the <i>Wechsler Adult Intelligence Scale</i> ) must be used to make a diagnosis of intellectual disability.	1	2	3	4	5
The assessment of parents' adaptive functioning is important to determine the severity of their intellectual impairment.	1	2	3	4	5
The assessment of a parents' adaptive functioning important to determine the extent to which these impacts on their parenting capacity	1	2	3	4	5
The assessment of a parents' adaptive functioning uses standardised tools (e.g., ABAS-3) and includes home and community environment.	1	2	3	4	5
The views of the child be sought on how their parent(s)' intellectual disability impacts on them if they are deemed capable of expressing their views.	1	2	3	4	5
Parents with intellectual disability would benefit from attending parenting programs to assist them developing parenting skills and address child protective concerns.	1	2	3	4	5
Parents with intellectual disability would benefit from one-on-one support to improve parenting skills and address child protective concerns.	1	2	3	4	5

2. Please rank these factors in order of importance (1 = *least important*, 10= *most important*) of factors that authorised clinicians and private assessors consider during assessment of parents with intellectual disability.

Factor	Rank
Ability to meet the child's emotional safety and wellbeing needs	
Ability to meet the child's physical safety and wellbeing needs	
Ability to adapt to the child's developmental needs	
Insight and understanding of child protective services involvement	
Ability to demonstrate sustained change to parenting skills	
Receptiveness and willingness to accept feedback	
Appropriate support services or family support in place	
Responsive and cooperative with services	
Has addressed domestic violence concerns if relevant (e.g., attending programs, left relationship, moved house)	
Has addressed substance abuse concerns if relevant (e.g., remains abstinent, attending urinalysis)	

3. Please indicate the extent to which you agree with the following statements.

<b>Beliefs</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly agree</b>
A score of less than 70 on IQ testing is sufficient to diagnose a parent with intellectual disability.	1	2	3	4	5
Parents with intellectual disability are more likely to experience parental stress than parents without intellectual disability.	1	2	3	4	5
Parents with intellectual disability are more likely to experience difficulties managing children's behaviours compared to parents without intellectual disability.	1	2	3	4	5
Parents with intellectual disability are able to provide 'good enough' care and parenting.	1	2	3	4	5
Parents with intellectual disability experience greater difficulties accessing support services.	1	2	3	4	5
Parents with intellectual disability are more likely to have their children removed compared to parents without intellectual disability.	1	2	3	4	5
Parents with intellectual disability are more likely to have issues such as domestic violence, substance misuse and mental illness compared to parents without intellectual disability.	1	2	3	4	5

## **Appendix 4: Data extraction for review of Assessment Orders**

### **Data fields that were extracted from assessment orders**

Date of order

Date of report to be filed

Court (location)

Is parent's ID mentioned in any capacity? (Y/N)

Why assessment is required

Data fields extracted from expert reports

Did the applicant request a clinician with specific expertise in ID?

Relevant demographics of the parents:

Aboriginality /cultural background of child

Documents filed by DCJ

Any previous reports/assessments

### **Data fields that were extracted from expert reports**

Date of report

Length of report not including CV

Assessor/Clinician professional background

Synopsis (child protection history)

Is ID the main concern in parenting capacity

Details of children:

- Number of children assessed
- Children's ages
- Children's gender
- Children's cultural background

Details of natural parents :

- Ages
- Psychosocial history
- Cultural background

Significant others

Support for parents after removal of children

Details of parents' disabilities

Assessment process:

- Communication with parent
- Support persons for parents
- Consent
- Role of clinician explained
- Assessment process- comment on any adjustments to ax to accommodate parents' disability
- Location of assessment
- Interview process
- How was ID/cognitive impairment assessed
- Impact of COVID-19 on assessment process

Recommendations made:

- Recommended services- do these services adequately support parents/ are they suitable for parents' level of functioning
- Supporting information provided (facts, family details, protection history)



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