Supporting the Woman, Supporting the Mother: Final Report

August 2022

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Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled People's Organisation
FAMS	
IAC	Independent Advisory Council
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
NSW	New South Wales
PWDA	People with Disability Australia
QLD	Queensland
TEI	Targeted Early Intervention
WASH House	Women's Activities and Self Help House

1. Executive Summary

This project was funded by a grant from the Department of Social Services through the National Disability Research Partnership Scheme, administered by the University of Melbourne.

1.1 Research aim

The research examines the interface between the National Disability Insurance Scheme (NDIS) and family support services targeted to families experiencing vulnerabilities in New South Wales (NSW), known as Targeted Early Intervention (TEI) with the aim of gaining a better understanding of how service gaps are impacting on the capacity of mothers with intellectual disability to care for their children. The project addresses a gap in knowledge on the extent to which the current service system recognises the indivisibility of disability from other aspects of a person's life, including their caregiving role and responsibilities. As women are typically the primary caregivers of children, the primary research focus is on mothers; however, these findings have broad relevance for all parents with intellectual disability.

1.2 Research questions

Two research questions guided the project:

1. How does the NDIS identify and address the support needs of women with intellectual disability who have childrearing responsibilities?
2. What are the enablers and barriers to service integration between the NDIS and TEI services for mothers with intellectual disability in NSW?

1.3 Research methodology

The project used a co-design methodology with an Expert Reference Group convened to guide the project. The Reference Group included the four investigators from the University of Sydney, six co-researchers with lived experience and five professional stakeholders. These

were representatives of two national Disabled Person's Organisations (DPO), the NSW industry body for TEI services, and a Non-Government Organisation (NGO) with an extensive track record in working with mothers with intellectual disability.

The Expert Reference Group met six times between September 2021 and May 2022 to discuss the project aims, reflect on findings that emerged from the data, and design resources that translated these findings into plain-English messages for parents and practice-ready messages for workers. The experts were involved in co-production of resources designed to increase service system awareness of: a) the difficulties that parents with intellectual disability face navigating a disjointed and inaccessible service landscape and b) ideas for improving the delivery of integrated, accessible and tailored support. These resources included tip sheets and video interviews [visit https://rccf-parenting-disability.sydney.edu.au/].

1.4 Data sources

The research team completed the following activities:

1. a desk-based review of publicly available information on the NDIS and TEI to provide a snapshot of available services targeted to support both parenting and disability-related needs;

2. a rapid review of the international evidence on service integration for parents with intellectual disability; and

3. a synthesis of qualitative data drawn from prior interviews with parents about support needs and gaps related to parenting with disability.

1.5 Key findings

The desk review of publically available documents showed that neither the NDIA nor the TEI program appear to have current capacity to monitor service usage and access by clients with both disability and parenting-related needs. The NDIA does not record the parental status of Scheme participants. The TEI program does not have reporting capability to identify clients receiving services who have children in their care and receive (or are eligible for) supports through the NDIS. This suggests that mothers with intellectual disability and their children in NSW are currently not receiving services that are targeted toward their specific needs.

The rapid evidence review found that research on service integration provides five recommendations for positive practice including: i) early identification and provision of services; ii) collaboration between services; iii) adopting a person-centred/family-centred approach; iv) provision of specialist services to support parents and; v) the provision of long-term consistent supports. Further discussion is provided about current systemic barriers within Australian services supporting parents with intellectual disabilty. Finally, recommendations on how to improve support of parents with intellectual disabilty within the current service approach are made based on the rapid review.

The synthesis of previously collected qualitative data from a small sample (n =7) of parents with intellectual disability identified the following three key contributors to child protection involvement and subsequent child removal: i) lack of competency-enhancing familial support; ii) lack of support with core adaptive living skills and; iii) difficulties accessing and engaging with mainstream support services. Each of these three contributors is discussed further to identify ways these risks could be potentially mitigated through the provision of support through the NDIS.

According to the NDIS funding guidelines, parents with intellectual disability should be able to access support to enable their independent living in the community. As adults with intellectual disability, becoming a parent should not mean they have to return to, or rely on, their family for support to maintain their independent living.

1.6. Key Recommendations

- Commitment by all levels of government to improving data collection, monitoring and reporting capability such that the prevalence, needs and outcomes of parents with intellectual disability and their children can be accurately ascertained and results used to plan and target services to improve outcomes.

- Commitment by State and Territory Governments to ensure families headed by parents with intellectual disability can access the early intervention services they need not only when they become parents but over the longer-term in recognition that they will need longer to develop parenting skills and a support scaffold to adapt their learning to children's changing needs.

- Commitment by the Commonwealth Government to initiate and lead a review of the NDIS to investigate barriers to disability and state-funded mainstream service integration for family living with disability and to urgently review reporting capability and data transparency.

- Commitment by the NDIA to adopt a family-centred approach to working with families headed by parents with intellectual disability, including those who are caregivers of children with disability, which recognises that parenting is an occupation that takes place within a family unit and cannot be isolated from other aspects of a person's disability and disability-related goals.

- Commitment by State and Territory Governments to design and test service models to achieve inter-agency collaboration across different sectors supporting families with parents with intellectual disabilty (e.g., SUF groups in Sweden) to assist with coordination and cohesion of support. This includes formal mechanisms for regular communication, clear role delineation and provision of suitable and holistic supports by different service providers working with a family with complex needs.

- State-based health services and early childhood clinics to trial a screening tool to identify parental intellectual disabilty during prenatal health checks and to provide health professionals with training in the use of the screening tool (e.g. screening tool developed and tested by McConnell et al 2021 in Canada).

- State and Territory Governments to formally recognise parents with intellectual disability and their children as a vulnerable group requiring priority attention and to commit to funding specialised parenting programs that assist them to develop parenting skills through

mainstream family support and early intervention program areas and to create a specialist disability service team with State and Territory statutory authorities.

- State and Commonwealth Governments to commit resources to Disabled Person's Organisations for free and nationally available independent advocates for parents with intelletctual disability who are involved in care and protection matters.

2. Introduction

2.1 Study context

This study was conducted in NSW. Although disability support is funded through the NDIS, family support is a State Government responsibility and, naturally, both types of services are delivered by state-based services through mainstream community programs funded by State and Territory Governments. In practical terms, the focus was on the service systems in NSW. Nonetheless, problems arising with the integration of human services that are designed, funded and delivered at different levels of government will transcend borders and are likely to be replicated, albeit with localised features, across the country. Disability is an experience that transcends state and territory borders and the provision of supports to realise the rights of people with disability is an issue of national relevance.

2.2 Background to project

2.2.1 Evidence about parents and parenting with intellectual disability

The right of people with disability, including intellectual disability, to receive assistance with childrearing is enshrined in the Convention on the Rights of Persons with Disability (CRPD), to which Australia is a signatory (United Nations, 2006 Article 23.2). In practice, given heteronormative parenting discourses, mothers are most likely to be the primary caregivers of their children and therefore wear the blame for any parenting issues (Malacrida, 2009). Women with disability are are at risk of social exclusion based on most socio-demographic markers, such as socioeconomic disadvantage, social isolation, discrimination, inadequate access to services, health care and housing, violence, and fewer education and employment opportunities (Dyson, Frawley & Robinson 2017; WWIDA Position Paper 2019).

Contrary to widespread and ableist assumptions about their parenting incapacity, women with intellectual disability can and do parent successfully when they receive timely and appropriately-delivered supports, combined with informal assistance from family, friends and/or allies (Collings, Grace & Llewellyn, 2017; Collings, Strnadova, Loblisk & Danker,

2020; Tarleton & Turney, 2020). There is compelling evidence on the most effective and appropriate ways to deliver parenting skills training adapted to their needs (e.g., Wade, Llewellyn & Matthews, 2008). Key research messages are that parents do well when they are given genuine chances to practice new skills in their own home, have training matched to individual needs, and receive support from workers who understand them and offer help with things they consider a priority (Tarleton & Turney 2020).

2.2.2 Evidence about child protection intervention

In Australia and internationally, statutory child protection is framed around amelioration of child safety risks. A risk lens means that services are primarily mobilised to identify parenting deficits and determine if and how these can be addressed. In this context, impairment itself can be mobilised by statutory workers as a risk factor rather than as a characteristic that, just like any other, presents a family with a unqiue mix of resources, strengths and difficulties. Research shows that child welfare practitioners are often pessimistic about the likelihood of keeping children in the care of parents with intellectual disability (Lewis, Stenfert-Kroese & O'Brien 2015; Proctor & Azar 2012). Parents with intellectual disability perceive when workers judge their parenting and this undermines the trust and openness needed to deal with the challenges they face (Collings, Spencer, Dew & Dowse, 2018). Australian and international child protection and court processes have been found to discriminate against parents with intellectual disability (DeZelar & Lightfoot 2018; McConnell & Llewellyn 2000; 2002; Sigurjónsdóttir & Rice, 2017). The chances of permanent removal are established to be the most likely outcome of involvement in statutory proceedings for mothers with intellectual disability and their children (Feldman & Aunos, 2020; Llewellyn & Hindmarsh, 2015).

2.2.3 Policy focus on parents with intellectual disability in Australia

Despite extensive evidence on effective support for parenting skills having been generated here in Australia, the research has rarely been used to drive national or state policy. An exception to this was for a brief period in the first decade of the new millennium when the Australian Government funded Healthy Start[1]. This national program aimed to build services systems

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[1] Information about Healthy Start available at https://www.parentingrc.org.au/programs/healthy-start/

capacity by training practitioners in the use of evidence-based practices to address the support needs of parents with intellectual disability (McConnell, Matthews, Llewellyn, Mildon & Hindmarsh, 2008). Investigators Collings, Spencer, Hindmarsh and Wedgwood previously worked together on Healthy Start. An evaluation of Healthy Start showed it had delivered improvements in professional knowledge, competency and collaboration around working with parents with intellectual disability (McConnell et al. 2008). For the most part however, Australian mothers with intellectual disability have not received the support they need to raise their children. This places their caregiving under considerable pressure and can bring them to the attention of statutory child protection services.

The NSW State Government introduced the Targeted Earlier Intervention (TEI) Program in July 2020, replacing five historically separated program areas. A key aim of the new program is to act early to prevent an escalation in the risk of child abuse and neglect. TEI programs can work as a soft entry point to the service system for children and families. TEI has four priority groups for early intervention: Aboriginal families; children from birth to 5 years; children and young people at risk of school/family/community disengagement; and vulnerable young parents. Funded by the Department of Communities and Justice (DCJ), TEI delivers voluntary flexible support to address child and family vulnerabilities. During 2020 and 2021, 118,024 clients were referred to TEI services. The two most common reasons for external referrals were mental health, wellbeing and self-care (18%) and family functioning (17%).

A hallmark of the pre-NDIS era was a service system that was siloed and fragmented (Productivity Commisson, 2011). When disability services were funded by the States, mothers with intellectual disability often failed to meet the strict eligibility requirements based on formal diagnosis. The majority of parents with intellectual disability are likely to fall in the borderline to low intellectual range and, as a consequence, may never have been formally diagnosed or received disability services (IASSID Special Interest Research Group [SIRG], 2008). This can render them invisible to service systems and mean their needs remain unmet until they are in crisis. Although they are eligible for mainstream and parenting programs, these are universal and not designed to suit additional learning needs associated with disability. Eligibility for more intensive support through State initiatives funded under the Targeted Early Intervention (TEI)

program, such as Brighter Futures[2] in NSW, is primarily through a report made about a child being at risk of harm. Mothers with intellectual disability may actively avoid such services due to a heightened (and legitimate) fear that they are seen as incapable of keeping their child safe. This avoidance can exacerbate unmet needs and mean they are in crisis by the time they receive the attention they need.

2.2.4 New service system gaps in the NDIS era

For mothers with intellectual disability, the promise of the NDIS was of no longer having to be seen as 'at risk' in order to get support with parenting. In contrast to previous welfare-based support systems, under the new rights-based model of support they would—in theory at least—receive parenting support as an entitlement. Disappointingly, there are indications this promise has not been realised, with concerns about reduced access to appropriate and timely parenting support for mothers with intellectual disability in the NDIS era (Wedgwood, Collings, Spencer & Hindmarsh, 2021). With the coming of the NDIS, state-based disability services have all but vanished and responsibility for families living with disability sits squarely with the NDIS. With only 15% of Australians living with disability being among the 400,000 NDIS participants who receive individualised support, the majority of those living with 'invisible' disability, like many mothers with intellectual disability, fall through new eligibility gaps between NDIS and state-based support. Thus, despite the NDIS assurance of an equitable and rights-based disability care system that seamlessly complements state-funded services, it seems that neither the federally-funded NDIS, nor state-funded family support systems provide, or fund, parenting and early intervention support adapted to suit mothers with intellectual disability. Both maintain it is the purview/responsibility of the other.

In the current context in which the NDIS has marketized disability services based on the neoliberal construct of people with disability as individual consumers (Edwards 2019), the concern is that personalised support packages will only fund supports targeted to the needs of 'the individual' but not the needs of the parent. That is, a mother with intellectual disability may have her needs assessed as a person living with a disability but any needs she has as a mother will be classified as outside the remit of the 'disability' funding category. In concrete

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[2] For information about the Brighter Futures program visit https://www.facs.nsw.gov.au/providers/working-with-us/programs/children-and-family/brighter-futures

terms, if assessed as requiring support with living skills, the NDIS might fund a support worker to: buy and prepare food for her but not for her child/ren; wash up her dishes but not sterilise her baby's bottles and/or; launder her clothes but not those of her child/ren. Although the National Disability Strategy formally recognises that women with disability require access to support services, including parenting support (Commonwealth of Australia, 2011), the perverse separation of the support needs of the *woman* from the support needs of the *mother*, means that the NDIS may not in reality fund person-centred support for a woman with disability who has parenting-related needs.

Given that an estimated 15% of Australian children live with a parent with disability (AIHW, 2020), there is an urgent need to identify the enablers and barriers to integrated service supports for mothers with intellectual disability. With this in mind, this scoping study examined the interface between the NDIS and TEI services in NSW, focusing in particular on the impact of access barriers to, and enablers of, appropriate and timely support with parenting for mothers with intellectual disability.

3 About the Project

The project was funded by a grant from the National Disability Research Partnership with the aim of exploring how well the NDIS is doing at realising the goal of individualised support for a group of Scheme participants whose lived experience defies a narrow interpretation of an 'individual'. When conceived of in binary terms, where there is either a 'self' or an 'other', an NDIS scheme participant cannot simultaneously be *both* a person with disability *and* a parent with disability. Whereas, if identity is not divided along gender/disability lines then it is accepted that support needs cannot be reduced to either disability or parenting related and is possible to ensure holistic support to meet individual needs. Under the current binary definition, needs are unmet and escalate and create unintended ripple effects. For mothers with intellectual disability, unmet needs can lead to concerns about child safety and welleing and preventable out-of-home care placement. It is this sequence of events that the research seeks to expose and thereby prevent.

3.1 Conceptual framework

The project is underpinned by several key concepts and theories. The first, *ecological systems theory* (Bronfenbrenner, 2005), explains that interactions between a person and their environment represent a nested system of influences that shape their lives based on the relative opportunities and risks they are offered. The second is the *social model of disability* (Oliver, 1990) which promotes a capabilities approach to the provision of supports to overcome functional limitations. It critiques the biomedical model used to conceptualise 'disability' in the NDIS which prevents one group of eligible Scheme participants - mothers with intellectual disability – from enjoying equal access to necessary and reasonable supports. The third is *intersectional theory* which recognises that systems overlap to create multiple forms of disadvantage related to minority social identities (Crenshaw, 1989). This project challenges an individualised conception of disability and shows that parenting is an inherent part of the social role and identity of mothers with intellectual disability. Caregiving is indivisible from disability-related support needs for the woman and the mother with intellectual disability.

3.2 Project Governance

This research was conducted in partnership with a group of mothers with intellectual disability. This group have not had their voices heard in the contemporary era of disability policy in Australia, despite national recognition of their unique needs. An Expert Reference Group of experts with lived experience (mothers) and professional expertise were convened to guide the project and support the work of the four investigators from the University of Sydney. Six mothers with intellectual disability were recruited as co-researchers. Professional experts were representatives of two Disabled Persons Organisations (DPO) [WWDA and PWDA], a peak industry body [FAMS], and a Non-Government Organisation (NGO) with an extensive track record in working with mothers with intellectual disability [WASH House]. These organisational collaborators have a long history of systemic and individual advocacy for the rights of people with intellectual disability to be parents and/or supporting parents by people with intellectual disability. Each organisation nominated a senior representatives to take part in the Expert Advisory Group.

3.3 Project Methodology

3.3.1 Co-design approach

The project used co-design whereby mothers with intellectual disability and organisational allies were part of the research team and worked alongside a team of academic researchers in the design, data interpretation, resource development, and knowledge translation. Co-design methodologies emerged from research traditions that grapple with questions of power, expertise and quality (Zamenopoulos & Alexiou, 2018). Co-design should be grounded in principles of compensation, culture and collegiality to avoid tokenism (see Rudd, Kalra, Walker & Hayden, n.d.). Ensuring parity between experts with lived and professional expertise is an important way to signal that different knowledges are respected and to avoid tokenism and exploitation of people with lived experience. Furthermore, it recognises that experts with professional qualifications are more able to offer advice to the research during their work hours, for which they are already paid. In this project, co-researchers were paid a rate commensurate with professional research assistants employed by the University of Sydney and professional experts provided an in-kind contribution. The research team modelled a culture in step with the spirit of co-design, by fostering an environment where everyone feels welcome and safe to voice diverse and dissenting viewpoints, in order to allow genuine collegiality and for authentic relationships to be forged (Rudd et al, n.d.).

3.3.2 Co-design with co-researchers with intellectual disability

Recruitment of co-researchers

In order for the project to achieve genuine inclusion of mothers with intellectual disability, it was critical that the co-researchers understood their role and felt supported to participate fully. This included creating opportunities for the authentic participation of co-researcher 'experts-by-experience' in Expert Advisory Group meetings with academic and professional experts. The timing made this more challenging, with the project commencing in the second half of 2021 when NSW, in particular Sydney – where the co-researchers lived – was in lockdown for 15 weeks. This introduced some logistical hurdles with recruitment of suitable co-researcher candidates who could not be approached in person. A strength of the project was the strong

existing relationships the academic research team brought to the project. Two Investigators had been engaged by partner organisation, the WASH House, in 2018-2020 to evaluate an NDIA funded project called the Bumpy Road which involved a group of parents with intellectual disability in action research on navigating the child protection system in NSW. The project coordinator for the Bumpy Road project was well suited to be the parent faciliator for this project.

The first step was making contact via phone or text message with the seven mothers who had been part of the Bumpy Road project and two mothers who had been unable to take part due to other factors, including birth of a new child. The parent facilitator gave a brief verbal description of the project goals, the co-researcher role on an Expert Advisory Group and the proposed remuneration structure and answered any questions. Five mothers were recruited in September 2021 and were joined by a sixth mother in November 2021.

Parent Facilitator role

The parent facilitator performed the role of conduit between the co-researchers and academic researchers. This person had coordinated a group for mothers with intellectual disability run by the WASH House for many years and was the project coordinator of the Bumpy Road project, which was funded by an ILC Grant awarded to the WASH House [2018-2020]. She was a familiar and trusted person for the co-researchers on this project. It was her role to provide individualsed assistance to co-researchers. This included troubleshooting around set up of the Zoom videoconference application on their phones or mobile devices and completing the proof of identity and other documentation to be paid as independent contractors by the University of Sydney.

Co-researchers' involvement in Expert Reference Group

Co-design was an integral part of the research and particularly important in harnessing the unique expertise of parents with intellectual disability to create and disseminate knowledge. Steps were taken to ensure that co-researchers were able to participate on equal footing with academic and professional experts in the Expert Advisory Group discussions and that their feedback and suggestions about how to make meetings accessible was taken on board. Immediatley before each Expert Advisory Group meeting, Investigator Collings and the parent

facilitator held a Zoom meeting with the co-researchers to recap on decisions made at the previous meeting and discuss the upcoming meeting agenda. After the meetings the parent facilitator debriefed by phone with co-researchers to check how they felt and collated their feedback about what could be improved to feed back to Investigator Collings. These preparatory and debriefing conversations allowed co-researchers to make their suggestions for how to better run the Expert Advisory Group meetings which resulted in several changes. For example, the co-researchers said they wanted more time during the meeting to reflect and discuss among themselves. Meetings were subsequently split into a 15-minute whole-group discussion, followed by 30 minutes in 'breakout rooms' where the co-researchers could share their thoughts on the topic and concluding with a 15-minute whole-group summary. This scaffolded approach built the confidence of individual co-researchers and resulted in an evolving sense of collective agency and having a voice on the project. This led to richer interactions between the co-researchers and other members of the Expert Advisory Group in meetings held in 2022.

Additional support for co-researcher engagement

In addition, in-person and additional Zoom meetings were held with the co-researchers which were used to give plain English information about emerging findings. At one in-person meeting, the academic researchers circulated hard-copy drafts of resources so the co-researchers could more easily convey suggested changes by drawing on the physical copies. At each stage the co-researchers were actively invited to be leaders. For example, the co-researchers were involved in scripting a series of videos. The videos featured five of the co-researchers (a sixth co-researcher moved interstate during the project and was not able to attend filming) talking about their views of parenting, the support needs of parents with intellectual disability, experiences of services and workers and what constitutes good support. The academic researchers drafted questions for the video interviews and the parent facilitator read these aloud by phone so that their suggestions could be incorporated. The co-researchers were offered the chance to interview each other and two accepted this offer. Being involved in scripting and interviewing increased the communication skills and confidence of the co-researchers to be research leaders.

Skill development opportunity for co-researchers

By working alongside other people with disability, academics and professionals, the co-researchers gained knowledge, skills and confidence as a result of participating in the study. It provided opportunities to further develop interpersonal skills and confidence in expressing their views in a group, listening to and learning from others and new problem-solving skills such as prioritisation and decision-making. As co-researchers, they developed some research skills like recognising patterns and conveying messages in written, visual and audio-visual formats. They were given opportunities to practice presentation skills by recording video clips, designing visual materials and presenting to a public audience at a webinar. As a group who are traditionally excluded from paid work, participation in the project added to their experience and cvs, improving their chances of future employment.

Their involvement in the co-design of a series of 'practice-ready' resources also resulted in two tip sheets and four short videos. A project website was created to store these resources, along with the full report and a plain English version of this report. The Supporting the Woman, Supporting the Mother website is at https://rccf-parenting-disability.sydney.edu.au/.

4. Desk-Based Review

4.1 Introduction

The research team examined grey literature and publically available government information about policy and practice support for parents with intellectual disability under the NDIS and TEI services in NSW. The desk review focused on obtaining data about i) NDIS reporting on participant demographics and support for parent-related needs, and ii) TEI reporting on participant demographics and support for disability-related needs.

Data collection involved:
- a hand search of National Disability Insurance Agency (NDIA) website to retrieve information about parental and disability status of participants;
- a hand search of DCJ website about TEI program to retrieve information about parental and disability status of TEI clients;an
- an internet search for resources that provide information about NDIS and TEI support specifically related to caregiving and/or parents with intellectual disability

Hand search of NDIA documents

In total, seven NDIA reports were reviewed and three were found to contain relevant information about parental status (Table 1).

Table 3: Summary of NDIA reports reviewed for parental status of participants.

Report Name	Year	Reporting on parental status of NDIS Participants Y/N	Link to Source
NDIS Insights Forum	2019	Y	https://data.ndis.gov.au/insights-forums
People with an intellectual disability and the NDIS	2019	N	https://data.ndis.gov.au/reports-and-analyses/participant-groups/people-intellectual-disability-ndis#:~:text=As%20of%2031%20December%202019,participants%20with%20an%20approved%20plan.
Analysis of participants by gender	2019	N	https://data.ndis.gov.au/reports-and-analyses/participant-groups/analysis-participants-gender
Baseline Outcomes for NDIS participants	2020	Y	https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/participant-outcomes-report
Participant Outcomes (Appendix H Part A, B)	2020	Y	https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/participant-outcomes-report/participant-outcomes-30-june-2020
Plan budgets, average payment per participant, and utilisation – longitudinal analysis	2021	N	https://data.ndis.gov.au/reports-and-analyses/other-analyses
Our Guidelines: Mainstream and Community Supports Interface	2022	N	https://ourguidelines.ndis.gov.au/how-ndis-supports-work-menu/mainstream-and-community-supports

*ID: intellectual disability

Hand search of TEI documents

In 2020 the Department of Communities and Justice (DCJ) introduced a monitoring system to track performance of services funded under the TEI program. Service providers were required to report demographic data about service users and client outcomes. In September 2021, the lead investigator consulted with the FAMS to seek advice on the best way to gather information about service users receiving TEI services. This organisation represents members who deliver TEI funded services and its CEO sits on the Expert Advisory Group. The aim was to gain understanding of how disability was documented and responded to within TEI. FAMS explained the project aims and data request to their key liasion contacts from Strategy, Policy and Commissioning at DCJ. It was established that four DEX questions were relevant: clients reporting an intellectual disability; household/ family composition; clients identifying as carers; and clients reporting as NDIS eligible. Each question and the possible drop-down responses are detailed below.

1. **Disability:** total clients reporting disability by each type

2. **Household composition:** number of clients identifying as
   - Sole parent with dependants
   - Couple with dependants

3. **Carer:** number of clients identifying as a carer

4. **NDIS**: Number of clients identifying as
   - NDIS eligible
   - NDIS in-progress

DCJ confirmed that the information from reporting organisations on service users would be made publicly available in aggregated and de-identified form by the end of 2021. This data would be used to estimate how many service users were parents with intellectual disability and to document issues with reporting.

Web search for NDIS and TEI resources

A web-based search was conducted to locate sources about the use of NDIS funded services for the purpose of parenting-related support. The following search terms were used:

- Mothers OR Parents OR Women;
- Intellectual disability OR Intellectual Developmental Disability OR cognitive disability OR impairment OR learning disability;
- NDIS/National Disability Insurance Scheme OR NDIA/National Disability Insurance Agency.

First page search results were examined to extract relevant sources or material for inclusion in the review. Nine sources were identified and data such as year, location, the document type and purpose, and summary of relevant information were recorded on an Excel spreadsheet. Each document was thoroughly reviewed by the research team and four were included in the review. An annotated bibliography was created for each source (see Table 2).

Table 4: Summary of grey literature sources.*included in desk-review*

Reference	Source type	Summary of relevant information
CareAbout. (2021, October 6). *The NDIS helps parents with disability.* Retrieved from CareAbout: https://www.careabout.com.au/ndis/parents-with-disability	Blog Post	The blog post states that NDIS finding can help provide funding and support to help parents with ID. No further information is provided
Independent Advisory Council to the NDIS. (2019). NDIS support for participants who are parents. Australia: Independent Advisory Council to the NDIS. https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5f1a5e5f446e9f2897911caf/1598501122938/NDIS+support+for+participants+who+are+parents+%28September+2019%29+Paper.pdf	Report	This report provides an analysis of the effectiveness of the NDIS in addressing the support needs of participants who are parents. The report outlines current practice under the NDIS and the challenges that these practices cause for participants who are parents and need support related to their parenting. The Independent Advisory Council (IAC) identify the obligation of the NDIS to provide parenting support to participants under the guidelines stipulated in the NDIS Planning Operational Guideline Appendix 1. The IAC advocate for changes to current practice that will support service collaboration between NDIS and parenting supporting services to meet the needs for parents with disability. This report addresses the issues of participants who are parents as a homogenous group and do not distinguish between different types of disability.
NDIS. (2021, June 15). Planning Operational Guideline Appendix 1 - Table of guidance on whether a support is most appropriately funded by the NDIS. Retrieved from National Disability Insurance Scheme: https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-appendix-1-table-guidance-whether-support-most-appropriately-funded-ndis	Appendix	The Planning Operational Guideline Appendix provides information about supports that are funded under the NDIS. The table outlining Child Protection and Family Support provides three categories that participants may receive support related to their parenting needs. This includes 1) Development of daily living and life skills; this includes supporting participant with daily activities related to the parenting that are impacted by their impairment 2) Participation in community, social and civic activities; assist participant to participate in community activities and to facilitate their children's participation in community activities 3) Disability; providing specific parenting training programs specifically designed for the needs of participants that are not available in mainstream services. This provides a basis for which supports related to parenting needs can be requested.
Queensland government. (2019, November 19). *NDIS support for parents.* Retrieved from Child Safety Practice Manual: https://cspm.csyw.qld.gov.au/practice-kits/disability/working-with-a-parent-who-has-a-disability/responding/ndis-support-for-parents	Wesbite Manual	The manual provides basic information stating that the NDIS is available to support parents with disability to reach their goals which can include the goal of 'caring for children in the family home'. There is no information about standardised supports available to parents through the NDIS.

*ID: intellectual disability

4.4 Findings

The findings of the desk review are divided into two parts. The first part discusses reports that provide insights into data which identifies (or not) the present available evidence about parental status of NDIS recipients. The second part summarises the parenting-related support available, under the NDIS, for parents with intellectual disability from i) NDIS and ii) TEI program.

4.4.1 Parenting-related support for NDIS participants with intellectual disability

The review found that the NDIA does not currently report information about both the parental status *and* the childcare-related needs of NDIS participants (NDIS, 2020a; NDIS, 2020b). Available data reports on the parenting status of how many NDIS participants are parents but does not provide breakdown by disability-type. There is also data on the number of NDIS participants with intellectual disability, but without a breakdown of their parenting status.

Although this data is likely to include parents with intellectual disability who are caring for their children aged under 18 years, the report provides no data on what proportion they represent. In fact, the NDIS does not currently publish data on the number of NDIS participants who are parents and/or who have caregiving responsibilities (that is, children living with them).

4.4.2 Availability of parent support under the NDIS

Our desk review search of parental supports provided under the NDIS yielded minimal results, often with vague descriptions of support. We identified only two services that explicitly state parents with disability can access NDIS support to meet their parenting-related goals. The first, the Queensland Child Welfare Service, provides brief information on their website about the right of parents with disability to access parenting support through the NDIS (Queensland Government, 2019). The second, NDIS service provider, CareAbout, published a blog post in 2021 that states that NDIS can assist with providing funding for parenting-related supports for parents with intellectual disability. No further information about the parameters or process of accessing parenting support through the NDIS was provided by CareAbout.

Despite the lack of available information about accessing support for parenting-related needs, there are provisions under the NDIS for this type of support. In 2019, a comprehensive report was commissioned by the NDIA to report on the effectiveness of the NDIS to address the support needs of NDIS recipients who are parents. This report, written by the Independent Advisory Council ([IAC] to the NDIS, 2019), outlines current practices under the NDIS and the challenges for participants who are parents in need of parenting-related support (IAC to the NDIS, 2019). This report identifies the obligation of the NDIS to provide parenting support to participants under the guidelines stipulated in the NDIS Planning Operational Guideline Appendix (NDIS, 2021). However, it fails to distinguish parents by disability type.

The NDIA specifies three categories of support related to the parenting needs of NDIS recipients under NDIS Child Protection and Family Support, comprising:

1. **Development of daily living and life skills**; which includes supporting participant with daily activities related to their parenting that are impacted by their impairment;
2. **Participation in community, social and civic activities**; assist participant to participate in community activities and to facilitate their children's participation in community activities;
3. **Providing specific parenting training programs** specifically designed for the needs of participants that are not available in mainstream services (NDIS, 2021).

Despite both the NDIA and NDIS clearly stating the obligations to provide parenting support to parents with intellectual disabilty receiving support from the NDIS and other service providers, there is little evidence that such support is currently available. The NDIS has guidelines for supports that overlap with child protection and family services (NDIS, 2022). However, this report only addresses the supports available when a child has a disability. No information is provided about supports for parenting-related needs when it is the parent who has a disability (NDIS, 2022). There is currently no publicly available data on how many NDIS recipients with intellectual disability receive parenting-related support.

Overall, the findings show that the gap in service provision between NDIS and TEI services currently hinders parents with intellectual disability from accessing and utilising supports to optimise their parenting capacity.

4.4.3 Parenting-related support for TEI service users with intellectual disability

The TEI Annual Report cites data issues that prevent consistent, comparable and complete data being reported (NSW Department of Communities & Justice, 2022 p 10-11). The relevant issues for this project are that demographic information is unknown for many individual clients. For example, household composition is unknown for 69% of all individual clients; homelessness status is unknown for 44% of all individual clients. The 'Unidentified group' clients are being recorded in lieu of individual clients, in cases where identifying information should be recorded. Addressing these issues is critical if DCJ are to gain insights into service delivery models and to better understand what works and what needs to be improved to achieve better outcomes for clients who are parenting with intellectual disability.

The 2020-21 Targeted Earlier Intervention (TEI) Program annual report was the only document retrieved in the DCJ website search that provided a source of information about TEI clients and the first official report card on the TEI program. The annual report draws on data analysis conducted by the DCJ FACS Insights, Analysis and Research (FACSIAR) Directorate. It uses de-identified data reported by funded service providers from July 2020 – June 2021. TEI service providers are required to report in the Data Exchange, a web-based platform hosted by the Department of Social Services (DSS). The report provides a snapshot of TEI client demographics and services provided across NSW in the 12-month period from TEI program implementation. When the researchers consulted with FAMS about the new DEX reporting fields in September 2021, we were informed there were four fields relevant to our search of information about mothers with intellectual disability. These were disability status iii) household composition iii) carer status and iv) NDIS eligibility. However, in the review of client demographics reported in the annual report there is no reference to carer status or NDIS eligibility.

Data quality issues occur when data are missing, incorrect, inconsistent, or when they are not recorded in a timely manner, severely limiting the usefulness of data. Adapting to the new reporting requirements was a significant transition for the sector and required service providers to review current arrangements for collecting information about clients and learn how to use the new reporting platform. These challenges led to significant delays in the availability of data for FACSIAR and reduced the quality of data provided in the report.

A total of 481service providers in 1,469 different locations across NSW were recorded in the Data Exchange under the TEI Program from 1 July 2020 to 30 June 2021. Providers record services delivered to two categories of clients – identified as 'individual clients' or 'unidentified group clients' – and demographic information is only collected about the former group. There were 118,024 individual clients and 712,416 unidentified group clients in the first reporting period. Most of the individual clients were in the Wellbeing and Safety Stream (71,104/64,457) compared to the Community Strengthening Stream (52,545/647,959). This reflects the more intensive and complex support needs for the former group.

Two thirds (66%) of individual clients in the TEI program were female (77,888) and almost one in ten (11,207) were living with disability. Of this group, over half had a psychiatric condition (5,698, 51%) and more than one in four an intellectual/learning disability (3,132, 28%). Once again, a significant proportion of clients, 14% or 16,257, did not have disability status recorded. Only 31% of individual clients in the TEI program had their household composition recorded, leaving over two thirds, 81,058 (69%), about whom we do not know their living arrangements. For those about whom we know their household composition, they were likely to be either 'couple with dependants' (15,024, 13%) or sole parent with dependent(s) (11,675, 9.9%).

4.5 Conclusions

The desk review findings describes current practice, barriers to accessing support and innovative practice but, due to limited sources, no independent recommendations for practice.

4.5.1 Publicly-available data on NDIS participants:

- does not report the parental status of participants with intellectual disability;
- indicates some participants live with children;
- indicates some participants have caring responsibilities for others, which we can assume includes children and;
- indicates that most participants with an intellectual disability providing care to others report the NDIS does not provide them with enough support.

4.5.2 Parenting-related support through the NDIS:

- is stated in the NDIS Planning Operational Guideline Appendix published by the NDIA but;
- is difficult to access in practice, as shown in a recent IAC report documenting the difficulties many NDIS participants experience accessing adequate and appropriate NDIS support with parenting.

4.5.3 Publicly availability data on TEI clients

- does not report on the gender or caregiver status of clients
- reports on disability type but not way to link this to gender or caregiver status

4.5.4. Disability-related support through TEI services

- disability is a client characteristic reported in DEX
- no specificity around how disability is attended to in TEI

Data quality issues noted above pose a serious limitation on what, if anything, can be deduced about the number of women with intellectual disability who have primary/sole caregiving responsibility for children and who receive TEI services. This represents a knowledge gap that warrants urgent attention by the NSW Government.

4.6 Recommendations

- The NDIS and TEI should collect and publish up-to-date information about the parental and disability status of participants/clients in order to promote a holistic approach to support provision.
- The NDIS and TEI should provide information on their public websites about the availability of independent disability advocates to support people with disability in navigating services.
- The NDIS should adopt the recommendations for future practice provided in the IAC's report. Specifically, the NDIS should adopt:
    o A person-centred approach that is family-focused in recognition that the needs of participants are interconnected with their roles and responsibilities within the family unit.
    o Specialised workers in the child protection system
    o Increased collaboration between NDIS and TEI services

4.7 Limitations

The primary limitations are: a) souring only publicly available information and; b) the lack of publicly available information on parents with intellectual disability who access NDIS and TEI services in NSW. The web-based searches yielded only two passing reference to mothers with intellectual disability accessing parenting support under the NDIS (Queensland Government, 2019; CareAbout, 2021). No service providers were identified as providing clear step-by-step instructions on how to access parenting support nor specifying the kind of parenting supports included under the NDIS. Due to the limited nature of publicly available data on the parenting support provided (or not) to parents with intellectual disability under the NDIS or under TEI services in NSW, the review can only state that there are likely to be significant service gaps for mothers who are caregivers of children aged under 18 and have intellectual disability.

5. Rapid Evidence Review

5.1 Introduction

A rapid review of international evidence was conducted to document promising practices in service integration to support parenting by parents with an intellectual disability. The following question guided the review:

1. What are best practice approaches to service integration to support parenting by parents living with intellectual disability?

We found only a small body of research exploring service integration for parents with intellectual disabilty. The majority of these studies are small qualitative studies reporting on promising or positive practices. However, they are mostly descriptive, with few evaluations of the interventions they recommend. Despite the limited evidence of best practice in service integration for parents with ID, studies consistently report similar positive practices. In this review, five recommendations for positive practice are described including: i) early identification and provision of services; ii) collaboration between services; iii) adopting a person-centred/family-centred approach; iv) provision of specialist services to support parents and; v) the provision of long-term consistent supports. Further discussion is provided about current systemic barriers within Australian services supporting parents with intellectual disabilty. Finally, recommendations on how to improve support of parents with intellectual disabilty within the current service approach are made based on the rapid review.

5.2 Methods

A rapid review was completed of peer-reviewed research published in the international literature. The review method was informed by the Cochrane Rapid Reviews Guide and The National Collaborating Centre's Rapid Review Guidebook (Dobbins, 2017; Garritty, et al., 2021). In accordance with Cochrane guidelines, key stakeholders, including mothers with intellectual disability and professionals who support them, were consulted throughout each stage of the research process.

5.2.1 Literature search

The search strategy was developed in consultation with key stakeholder and academic experts in the field.

5.2.1.1 Search criteria

In accordance with Cochrane guidelines for reviews of qualitative research, the population of interest was defined as parents (particularly mothers) with intellectual disability and the setting of interest was defined as service integration and support for families. Eligibility was limited to peer-reviewed articles published after 2006 and in English only. Search terms were restricted to the title or abstract. All five members of the research team were involved in the development of search terms. Pilot searches were conducted, then the search terms were revised. The final list of agreed search terms were:

- Mother* OR Parent* OR Women OR Woman OR Female* OR Maternal

- AND Intellectual disabilit* OR IDD OR ID OR cognitive OR learning disabili*t OR impairment OR Cognitive deficit* OR Cognitive dysfunction* OR Developmental disability*OR Learning disorder* OR Mental retardation OR Mentally disabled person*

- AND Service* OR Service collaboration OR Service Integration OR Service Provider*

The databases search included Web of Science, Medline, ProQuest Health and Medical Collection, PsycINFO and Scopus.

5.2.1.2 Screening

After screening the titles and abstracts of the 4,639 articles identified by the search, a total of 27 articles were selected and assessed for eligibility. Dual-screening of the 27 potential articles was conducted by two members of the research team (Collings and Wilkinson). Any

discrepancies between the two researchers were discussed and resolved through consultation with the whole research team . A total of 16 articles were selected for full text review.

An Excel Spreadsheet was used to ensure standardised data extraction by the research team. Articles were allocated for full text read and data extraction. At this stage, 11 articles were excluded when found not to focus on service integration and thus outside the scope of the review. The remaining six studies were included in the review (for further information, see Figure 1).

Identification of studies via databases

Identification

Records identified from:
Databases (n =4 659)

Records removed *before screening*:
Duplicate records removed (n =20)

Screening

Records screened
(n = 4 639)

Records excluded**
(n = 4612)

Reports sought for retrieval
(n = 27)

Reports not retrieved
(n = 0)

Reports assessed for eligibility
(n = 27)

Reports excluded: (22)
Studies presented relevant models, not focused on service integration (n = 16)
Studies focused on people with ID*, not parents (n = 4)
Studies focused on disability not ID* (n = 2)
etc.

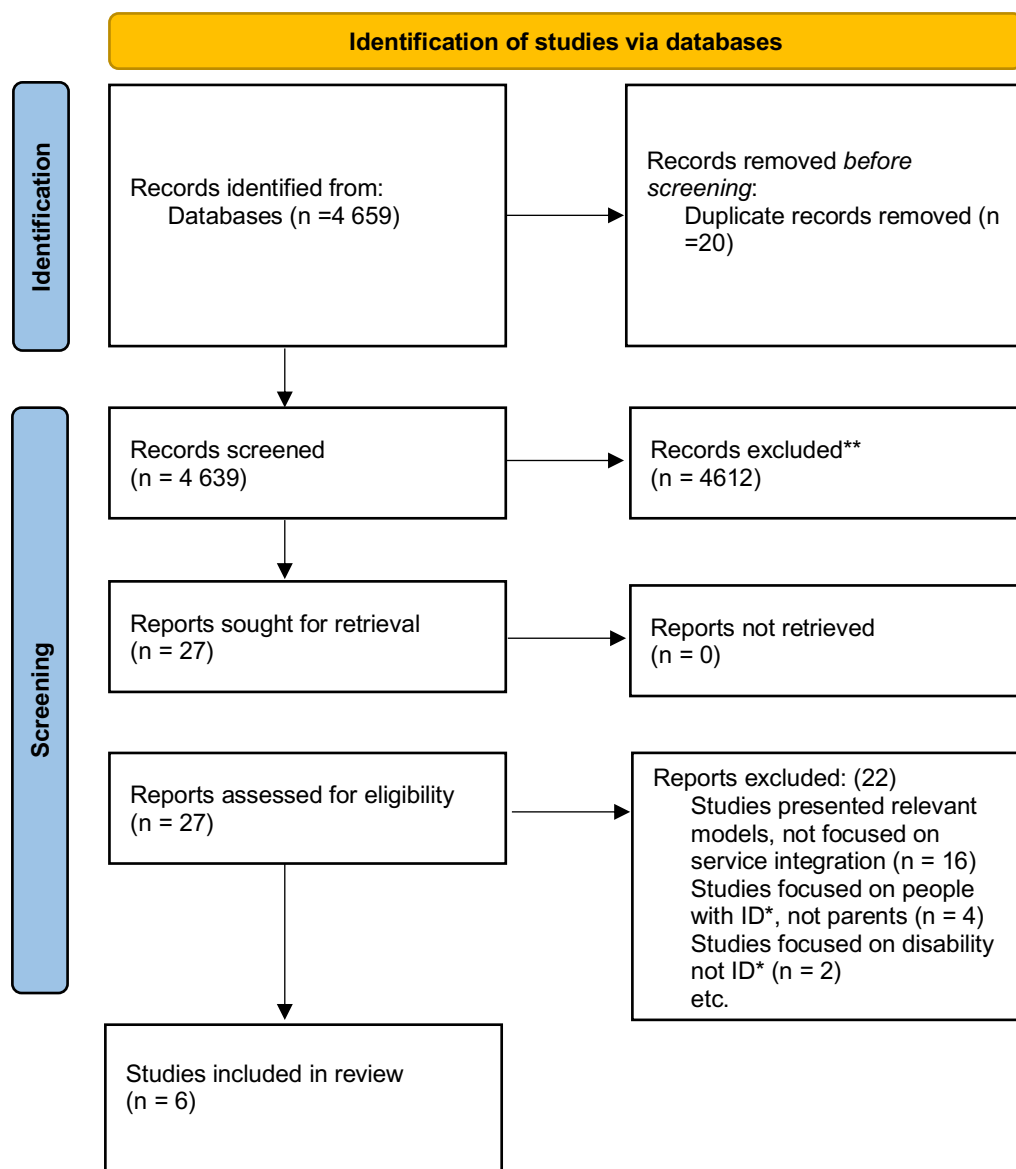Studies included in review
(n = 6)

Figure 2 Prisma Flow

* ID, intellectual disabilty; **records not relevant to service integration

5.2.1.3 Critical Appraisal

Table 3 provides a narrative synthesis of the studies included in the review. Of the six included studies, three were published in the United Kingdom, one was published in Sweden and the other in Canada. Most were based on small qualitative samples ranging from 15 to 185 participants (Tarleton & Porter, 2012; Tarleton & Turney, 2020; Weiber, Eklund, & Tengland, 2016; Young & Hawkins, 2006). One was a large-scale study with a sample size of 15,980 child maltreatment investigations (Pacheco et al, 2021). Definitions of intellectual disability ranged from educational definitions (learning disability; Selbie, 2012; Tarleton & Porter, 2012) to IQ scores (intellectual disability <70 and borderline intellectual disability <85; Young & Hawkins, 2006). Two studies (Tarleton & Turney, 2020; Weiber, Eklund, & Tengland, 2016) did not provide a definition of intellectual disabilty.

The evidence rating system developed by Department of Communities and Justice to rate evidence for Their Futures Matters was used to evaluate the six studies. None were found to meet the criteria for being evidence-based (Their Futures Matter, 2018). Two studies met the criteria for emerging practice (Young & Hawkins, 2006; Tarleton & Porter, 2012), providing promising results from a non-experimental evaluation of a specialist service. A further study highlighted negative results of practice in the child protection system (Pacheco et al, 2021).

Author	Year	Location	Term Used	Participants	Sample size	Study Design	Method
Pacheco et al.	2021	Canada	Cognitive Impairment (CI)	Parent with CI	1,244 parents with CI comparison group 15,980 child maltreatment investigations	Quantitative	Statistical analysis of Canadian Incidence Study of Reported Child Abuse and Neglect
Selbie, J	2012	UK	Learning difficulties (LD)	Professionals	Unknown	Qualitative	4 Focus groups with learning disability teams & practitioners from different universal children's services
Tarleton & Porter	2012	UK	Learning difficulties (LD)	Professionals and Parents with LD	12 parents with LD, professionals working for specialist service (VPSS)	Mixed Method	Matching Needs and Services Audit tool with practitioners and 2 focus groups with parents with LD
Tarleton & Turney	2020	UK	Learning disability (LeD)	Professionals	38 professionals working with 8 families with mothers with a LD	Qualitative	46 Interviews & 8 Case Studies
Weiber et al.	2016	Sweden	Intellectual disability (ID)	Professionals	29 professionals working with parents with ID	Qualitative	7 Focus groups
Young & Hawkins	2006	UK	Intellectual disability (ID)	Mothers with ID	23 mothers with ID and 39 professionals	Qualitative	23 Semi-structured interviews and 39 questionnaires

Table 3.Included studies

Author	Findings	Implications	Evidence Rating TFM
Pacheco et al.	Parents with CI are 2-4 times less likely to be referred for matched services (i.e., relative to need) post child removal, including home based\reunification services (except DV services, AOD counselling)	The is a need to develop equitable and the capacity to deliver inclusive, evidence-based parenting supports and service for parents with ID	Not Rated
Selbie, J	Factors that strengthen service integration: consultation meeting with all service providers at commencement of services, agreement of recording keeping and support processes, family focused service model	Building connections between services early and having clear process of communication strengthen the effectiveness of collaboration	Not Rated
Tarleton & Porter	Service had a positive impact on children of parents with LD and confirmed that the service was beneficial for professionals, parents with LD and their children.	Beneficial components of specialist service: practical support, parenting groups, relational working alliance and a go-between service facilitating collaboration and communication contribute to more positive outcomes for parent with LD and their children.	Emerging
Tarleton & Turney	Successful practice approaches promoted empowerment, were relationship-based and tailored to the needs of the parent, involved multi-agency collaboration that recognises the needs of parents and children.	Suggests adoption of a family-centred model and prioritising service integration to promote effective service provision	Not Rated
Weiber et al.	No consistent screening for intellectual disability. Service integration: professionals identified that support for families worked best when collaboration occurred between different services supporting parents e.g. SUF groups gathered professionals from different sectors to collaborate about supporting families.	Need for the development of consistent prenatal screening processes to identify ID and provide early intervention where appropriate. Promotes the adoption of a collaborative approach	Not Rated
Young & Hawkins	Both parents and professionals expressed a high level of satisfaction from using the service. Majority of parents received either weekly or fortnightly support home visits from the service and most valued help with practical needs related to budgeting, administration, support and empowerment.	Holistic, long-term, family-centred specialist services suggests more positive outcomes for parents with ID and their children	Emerging

Table 3:5 Summary of Rapid Review Studies

5.3 Results

All six studies included in the review reported on aspects of service integration that ensured appropriate support for parents with intellectual disability[3]. This section explores the five compenents outlined in the studies: early identification and intervention; collaborative practices; adopting a person and family-centred approach; specialist service provision and; long-term service provision.

5.3.1 Early identification and intervention

Early identification of intellectual disability among pregnant women and new mothers is considered a crucial step in parent support. Research conducted in response to a case review in the United Kingdom (UK), which identified parental learning disability as a contributing factor for child serious injury, developed a local protocol to support the safety and wellbeing of children (Selbie, 2012). The protocol included enhanced service collaboration through dedicated teams of child protection and disability support service workers involved with a family headed by a parent with intellectual disability. Focus groups with these teams identified that screening for learning difficulties and team collaboration strengthened service integration (Selbie, 2012). Focus groups with social workers in Sweden also highlighted the need for early identification of intellectual disabilty in order to enhance the effectiveness of support for mothers with intellectual disability (Weiber et al., 2016).

5.3.2.1 Collaborative Practices

Collaborative practice including having a clear division of responsibilities among professionals is also identified as a key factor to promote effective collaboration between services. Learning development teams in the UK and SUF (i.e., collaboration, development and parenthood)

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[3] A variety of terms and definitions to clarify the parameters of intellectual functioning were used in the studies exploring service integration for parents with intellectual disability . The terms included intellectual disability, cognitive impairment and learning disability. For the purpose of this review, a broad definition of intellectual functioning has been adopted to encompass all definitions of intellectual disability. The term intellectual disability will be used to encompass all definitions of intellectual functioning described in the studies in this review.

groups in Sweden, identified that establishing delineation of responsibilities for record keeping and support provision was essential to the effectiveness of the team (Selbie, 2012; Weiber et al. 2016). Alternately, other studies suggest that collaborative practice is best executed through the nomination of a key worker responsible for working with all services involved with parents. Some contexts have implemented the key worker model through providing specialist services for parents with intellectual disabilty and their children (Tarleton & Porter, 2012; Young & Hawkins, 2006).

Collaboration between services working with parents with intellectual disabilty is a key factor influencing the effectiveness of service provision and outcomes for parents with intellectual disabilty. There are various components of service provision that are essential to the effectiveness of support. The components are interconnected with the need for an integrative service approach, as the provision of appropriate services and collaboration between different providers of support, are the key contributors to the outcomes of support. Although studies have consistently recommended the development of systems of collaboration for support services working with parents with intellectual disabilty, the adoption of these recommendations has predominantly been implemented in the form of time-limited, localised interventions (Selbie, 2012; Weiber et al.,2016). Developing a sustainable and comprehensive system of service collaboration is essential to the effective and efficient provision of services to parents with intellectual disabilty.

5.3.2.2 Adopting a person/family-centred approach

The adoption of an approach that focuses on the needs of the parent with intellectual disabilty or the family unit suggests more positive outcomes for children and parents. In two evaluations of specialist services supporting parents with intellectual disability in the UK it was identified that one of the key positive outcomes of both services was the provision of practical supports that were centred around the specific needs of the family (Tarleton & Porter, 2012; Young & Hawkins, 2006). The type of support provided in these specialist services was decided in collaboration with parents, often providing support with budgeting, administration and everyday tasks. Tarleton & Turney (2020) in an evaluation of eight case studies of effective practice also found that adopting a person-centred approach that tailored supports to the needs of the parent was an essential component of positive practice examples. Adopting a person-centred approach that works in collaboration with other service providers were often

interconnected as components of promising practice (Tarleton & Porter, 2012; Young & Hawkins, 2006; Tarleton and Turney, 2020)

5.3.2.3 Specialist support services

Specialised services have the potential to provide support tailored to the specific needs of this cohort delivered by professionals with training and experience in this area. Although there are limited evaluations of these services, initial findings suggest that specialised services improve the outcomes of parents with intellectual disability and reduce the likelihood of child protection involvement (Tarleton & Porter, 2012; Young & Hawkins, 2006). Two evaluations of specialist services suggested positive outcomes including: increased collaboration between services, provided capacity building support and, advocacy improving parent engagement with child protective services. Overall, both evaluations identified improved outcomes for parents receiving the service (Tarleton & Porter, 2012; Young & Hawkins, 2006).

5.3.2.4 Long-term service provision

The provision of long-term services over short-term supports was also identified to be a component contributing to more positive outcomes (Tarleton & Turney, 2020; Young & Hawkins, 2006). Research has identified that parents with intellectual disabilty often have difficulty developing skills within short timeframes (Macintyre, Stewart & McGregor, 2019). The provision of ongoing, long-term support is necessary to equip parents with the skills needed to parent independently. A case study evaluation by Tarleton & Turney (2020) identified that long-term consistent provision of supports was essential in promoting positive outcomes for families. Likewise, Young & Hawkins' (2006) evaluation of a specialist service found that weekly or fortnightly visits to families over the duration of their children's dependent years (0-18 years) were effective in assisting parents to retain custody of their children. At the point of the evaluation, 13% of clients had received the service for over 10 years (Young & Hawkins, 2006).

5.4 Conclusion

Only a small body of studies explored service integration for parents with intellectual disabilty. However, the results and recommendations for promising practice are consistent. In the context of the current state of knowledge, there are two primary actions needed to improve the outcomes of parenting by parents with intellectual disability. First, there is a need to develop interventions and practice informed by the current recommendations of research. Second, evidence-based evaluations of empirically based interventions need to occur to establish best practice approaches to supporting parents with intellectual disability.

The current findings of research suggest the implementation of multiple components to improve the outcomes for parents with intellectual disability and their children. Early identification is considered a key factor. In current practice, many pregnant women with intellectual disability are undetected and do not receive additional or specialised support unless they come into contact with child protective services due to reports of neglect or abuse (Macintyre et al., 2019; Ward & Tarleton, 2007). This further exacerbates the stereotype within child protective services that parents with intellectual disability are incapable of parenting due to their disability (Pacheco et al., 2021). Implementing processes to identify intellectual disability in the prenatal stages of health care has the potential to improve the provision of appropriate supports to help parents develop the necessary skills at the start of their parenting journey and prevent interactions with child protective services (Ward & Tarleton, 2007).

Current practice has been critiqued internationally as insufficient to support successful parenting by parents with intellectual disabilty. Negative stereotypes, crisis-point referrals and provision of inadequate or inappropriate supports are consistent barriers prevalent across international contexts (Macintyre et al., 2019; Pacheco et al., 2021; Ward & Tarleton, 2007). More specifically, a recent Australian study explored gender barriers in applying and receiving adequate support under the NDIS from the perspective of women. The study highlighted that several of the participants felt that their caring responsibilities were not adequately supported or recognised by the NDIS or were ambivalent about asking for help due to concerns about being perceived as unfit mothers (Yates, Carey, Hargrave, Malbon & Green, 2021).There is a need for systemic change to address the current barriers that prevent parents with intellectual disability from accessing support and which sustain a state of crisis response to the needs of parents.

6. Qualitative data synthesis

6.1 Themes

The synthesis of previously collected qualitative data from a small sample (n =7) of parents with intellectual disability identified the following three key themes about contributors to child protection involvement and subsequent child removal:

1. Lack of competency-enhancing familial support.
2. Lack of support with core adaptive living skills.
3. Difficulties accessing and engaging with mainstream support services.

6.1.1 Lack of competency-enhancing familial support

The parents in this project, with the exception of one parent, spoke about being estranged from family or being in contact with a family member who had limited capacity to offer support or whose involvement was unsupportive. One parent explained, while she had a place to live, a condition imposed by Child Protection was she return live with her family after having her baby. This is a common condition imposed by Child Protection on parents with intellectual disability to ensure 'round-the-clock' monitoring of the parent- child relationship by a non-disabled adult (grandparent or kin). This mother stated:

" I just didn't want to be at home, I didn't want to deal with my brother's bullshit, So my older brother started ruling the house, and it's just like, "Well, you've been out of this house for so long, and yet you come back and like nothing has changed. This is our house; you follow our rules." (parent 5)

Another parent reported how her own mother tried to support her but was restricted in what she could provide.

"[M]um was sort of in between. Trying to help my sister. Trying to help me. Trying to work. She works night shift. She was having trouble there."(parent 2)

Having to rely on family for support was also a source of tension. Family members are often ill-equipped to know how to support a parent with intellectual disability in a way that is

collaborative and competence-enhancing . Such tensions can lead to strained relationships. The one parent who identified her family as a positive support, noted:

> *"What I mean about mum, she's supportive, but she's not in other ways. Like she'll come into my house and she'll say that it's a mess, clean it. 'Mum, bug off, this is my house."*
> *(parent 6)*

Moreover having to rely on family members, particularly grandparents, can result in relationship breakdown. Such as for the following parent who's own mother was placed in the unenviable position of having to protect her grandchild.

> *"My mum dobbed me into DOCS. I lost – that's why I don't get along with my mum very well. It's still very hard. If it wasn't because my kids, I wouldn't even talk to her." (Parent 8)*

6.1.2 Lack of support with core adaptive living skills

A criterion for diagnosis of intellectual disability includes significant limitation in at least two areas of adaptive behaviours. For parents with intellectual disability the additional demands of being responsible for a child as well as oneself can highlight difficulties in adaptive behaviours such as meeting expectation in terms of domestic and personal care, budgeting, problem-solving and interpersonal communication skills. For the majority of these parents the primary reason for child protection involvement and child removal was due to concerns of neglect. As on parent explained

> *"Then the DOCS used to come to our place every week to make sure the place was clean. Sometimes they'd come unexpectedly, you know, without my house clean. I'm going, "You come at the wrong time. You've got to come at the time that I'm expecting you to come." They come in the morning or the afternoon and sometimes in the morning I just got up and I'm just getting ready."(parent 3)*

Lack the adaptive skills to meet acceptable household standards, according to Parent 2 resulted in her children being removed.

> *"I ...couldn't keep up with the housework. So, community services removed them for that. And they took the youngest at three days old from the hospital, simply for the fact that the other kids were in care... They did charge us with neglect, simply for the house.*

Another parent whose child was also removed for neglect said

> *"they pretty much kept putting me down for things that I couldn't control, and it was so frustrating."*

6.1.3 Difficulties accessing and engaging with mainstream support services

Parents' intellectual disability served as a barrier for them being able to access mainstream support services, particularly parenting related services. Limited conceptual and social skills made it difficult for parents to engage in, for example, mainstream parenting groups or education programs. To engage with services, a number of parents spoke about needing the support of a disability advocate to facilitate communication. This was particularly the case when engaging with Child Protection services and in contexts where communication relied on the parent being able to read documents.

> *"community services were like, "Well, she needs help with parenting, but also help her with understanding..., what's her rights, what's agreed." Getting to understand those type of things, which I understood to an extent, but put a piece of paper in front of me with writing on it, I'm not going to understand the capacity of what you're asking." (parent 3)*

Parents reported that mainstream stream services were largely inaccessible because they were not inclusive or failed to apply Universal Design for Learning. Furthermore, little effort was made by mainstream stream services to accommodate their needs. For example one parent reported:

> *FACS said "[partner without disability] can do the course and she can tell you what happens." Well, it's not as effective as actually, as being there. (parent 4)*

Parents also reported having services imposed on them rather being given a choice of supports given service providers used. This is illustrated in the following comment:

> *"Community services brought in a different service to help me when x was born; a service came in…she was helping us with how to bath x, how to feed x, how to do this with x, even though I understand how to feed a child" (parents 5)*

6.1.4 The potential of the NDIS to address these three key contributors

The majority of the parents in the Bumpy Road Project were NDIS participants, however, only a few parents had access to NDIS prior to their children being removed. Because their experience of the NDIS was not central to the aims of the Bumpy Rod Project there is limited qualitative data specifically about their experience with the Scheme, particularly in relation to their goals to participate in the daily personal activity of raising their child or children. What data there was suggested parents were uncertain how they could use their NDIS plan to be supported to meet their parenting responsibilities. As Parent 5 explained:

> *"We didn't really know the ins and outs of what NDIS does for you, and no-one explained to me, "Oh, the NDIS package can help you with a lot of different things", like helping with my parenting capacity, helping me with getting to and back from visits, or catching up with meetings that I need to go to."*

Each of these three contributors to Child Protection involvement and the potential for child removal could be potentially mitigated through the provision of support through the NDIS. According to the NDIS funding guidelines, parents with intellectual disability should have access to support for maintaining their independent living in the community. As adults with intellectual disability, becoming a parent should not mean they have to return to, or rely on, their family for support to maintain or support their independent living.

Secondly, the NDIS should fund help with household tasks to allow parents with intellectual disability who are NDIS participants to maintain their home environment. The findings from the broader evidence provided in the background and supported by the qualitative synthesis

show that parents with intellectual disability are likely to lose custody of their children due to their inability to maintain the home environment.

Thirdly, the NDIS should fund assistance enabling the social and community participation of parents with intellectual disability to build relationships with other parents. This should include transport and support to attend play groups and other such programs, as well as other therapeutic assistance to build core life skills competencies and to manage behaviours of concerns that impact on their daily personal activities and subsequently their relationships with others, including their child or children.

6.4.1 Recommendations for policy and practice

- Commitment by all levels of government to improving data collection, monitoring and reporting capability such that the prevalence, needs and outcomes of parents with intellectual disability and their children can be accurately ascertained and results used to plan and target services to improve outcomes.

- Commitment by State and Territory Governments to ensure families headed by parents with intellectual disability can access the early intervention services they need not only when they become parents but over the longer-term in recognition that they will need longer to develop parenting skills and a support scaffold to adapt their learning to children's changing needs.

- Commitment by the Commonwealth Government to initiate and lead a review of the NDIS to investigate barriers to disability and state-funded mainstream service integration for family living with disability and to urgently review reporting capability and data transparency.

- Commitment by the NDIA to adopt a family-centred approach to working with families headed by parents with intellectual disability, including those who are caregivers of children with disability, which recognises that parenting is an occupation that takes place within a family unit and cannot be isolated from other aspects of a person's disability and disability-related goals.

- Commitment by State and Territory Governments to design and test service models to achieve inter-agency collaboration across different sectors supporting families with parents with intellectual disabilty (e.g., SUF groups in Sweden) to assist with coordination and cohesion of support. This includes formal mechanisms for regular communication, clear

role delineation and provision of suitable and holistic supports by different service providers working with a family with complex needs.

- State-based health services and early childhood clinics to trial a screening tool to identify parental intellectual disabilty during prenatal health checks and to provide health professionals with training in the use of the screening tool (e.g. screening tool developed and tested by McConnell et al 2021 in Canada).

- State and Territory Governments to formally recognise parents with intellectual disability and their children as a vulnerable group requiring priority attention and to commit to funding specialised parenting programs that assist them to develop parenting skills through mainstream family support and early intervention program areas and to create a specialist disability service team with State and Territory statutory authorities.

- State and Commonwealth Governments to commit resources to Disabled Person's Organisations for free and nationally available independent advocates for parents with intelletctual disability who are involved in care and protection matters.

6.4.2 Limitations

The primary limitation of this review was the small number and type of studies that explore service integration for parents with intellectual disabilty. The majority of the studies included in this review were small-scale qualitative studies that limit the generalisability of data. There is also limited availability of evaluations of interventions that have implemented the recommendations of research. This review adopted a rapid-review approach due to time constraints which may have caused some relevant studies to have been missed due to the implemented search strategy.

6.4.3 Conclusion

There is a need for further and more robust research evaluating the gaps in the current system and promising practices to support parents with intellectual disabilty and promote collaboration between services. At present, research exploring promising practice consistently reports similar recommendations to improve support and outcomes for parents who are parenting with intellectual disabilty. This includes the need for inter-agency collaboration, early identification and provision of support, provision of specialist services, adoption of a family-centred

approach and long-term consistent provision of services. These recommendations provide a potential roadmap to improve support and the outcomes for parents with intellectual disabilty and their families.

Acknowledgements

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