



# Violence prevention and early intervention for mothers and children with disability: Building promising practice

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ANROWS acknowledges the Traditional Owners of the land across Australia on which we work and live. We pay our respects to Aboriginal and Torres Strait Islander Elders past, present, and future, and we value Aboriginal and Torres Strait Islander histories, cultures, and knowledge. We are committed to standing and working with Aboriginal and Torres Strait Islander peoples, honouring the truths set out in the [Warawarni-gu Guma Statement](#).

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# Violence prevention and early intervention for mothers and children with disability: Building promising practice

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ANROWS acknowledges the lives and experiences of the women and children affected by domestic, family and sexual violence who are represented in this report. We recognise the individual stories of courage, hope and resilience that form the basis of ANROWS research.

Caution: Some people may find parts of this content confronting or distressing. Recommended support services include 1800 RESPECT–1800 737 732 and Lifeline–13 11 14.

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# Abbreviations

ADHD	Attention deficit hyperactivity disorder
AVO	Apprehended violence order
DFV	Domestic and family violence
FACS	Family and Community Services
FRS	Family Referral Services
GP	General practitioner
ILC	Information, Linkages and Capacity Building
IPARVAN	Integrated Prevention and Response to Violence, Abuse and Neglect
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
ODD	Oppositional Defiance Disorder
SCU	Southern Cross University
TA	Temporary accommodation
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VAN	Violence, Abuse and Neglect



# Executive summary

This report presents the findings from a research study that aimed to provide new knowledge on the impact of early intervention violence prevention support, with a specific focus on the experiences and voices of women and children with disability (8–18 years) who are at risk of domestic and family violence.

Domestic and family violence (DFV) early intervention programs are intended to identify risks to the safety and wellbeing of parents and children and ensure that timely responses are delivered before risks escalate. However, there are well-recognised challenges to implementing these responses, especially for families with additional support needs (Bowen & Swift, 2019; Dyson, Frawley & Robinson, 2017; Tayton, Moore, Campo & Kaspiew, 2014). Many organisations offer services that are time-limited and rely on a network of services to which families can be referred. Disability in mothers and/or children is a particular aspect of families' lives that makes it harder for early intervention initiatives to effectively support them within the time frames in which they are eligible to receive support.

Services that support people with disability often have very limited capacity to respond to risks of DFV, while services focused on violence prevention have little background or resourcing for identifying and addressing disability support needs (Dyson et al., 2017; Fraser-Barbour, Crocker & Walker, 2018; Howe & Hargrave, 2016). This may result in risks for these families of either unmet need or of inappropriate response, such as interventions by statutory child protection services, due to lack of available alternative support. Despite these challenges, innovative and responsive practices are occurring to support families with disability. However, little is known about the ways that DFV early intervention services respond to women and their children to meet their needs and preferences, and build their resources and capacity, organisationally and at wider social levels.

This research is based on the Family Referral Services (FRS) program in New South Wales, and is a case study of early intervention violence prevention services. The NSW Government-funded FRS service network was established throughout the state to enable ease of access to services for families who are at risk of DFV, but do not meet the threshold

for statutory child protection intervention. FRS assess the support needs of children, young people and their families, and provide referrals to appropriate local support services. The FRS program also functions to build the knowledge of service providers about local support services in their catchment area, and strengthen coordination and collaboration.

In this context, the project identifies and documents positive practice for mainstream early intervention DFV services to better engage families with a child or parent with disability. It aims to answer the following research questions:

1. What are the characteristics of programs and services that provide effective support to families with multiple, intersecting support needs related to violence prevention and disability?
2. How do mothers with disability understand and experience their interactions with family support services? What do they view as facilitators and barriers to support from services?
3. How do children with disability (8–18 years) understand and experience their interactions with family support services? What do they view as facilitators and barriers to support from services?
4. How and under what circumstances do Family Referral Services (FRS) provide support to families who are at risk of domestic and family violence when either or both mother and child/ren have disability?
5. How do FRS respond to the needs of families with children and/or mothers with disability? What supports client-centred, timely responses, and what constrains them?

## Background: Research and policy context

The provision of integrated responses for women and children with multiple support needs is an emerging policy priority. Commonwealth, state and territory governments have all developed DFV strategies designed to support and protect victims, and to hold perpetrators accountable. These policies are underpinned by the recognition that DFV is constituted through relationships of gender and other social categories, including disability.

Notwithstanding this, the evidence base on programs and services for women and children with disability experiencing DFV remains fairly small. It is possible to identify a set of interrelated themes in the research literature about positive practice for prevention of and intervention in DFV for women and children with disability. These centre around:

- fundamentals of good practice (e.g. trauma-informed practice; workforce training; access to information; safety planning) (Frawley, Dyson, Robinson & Dixon, 2015; Woodlock, Western & Bailey, 2014b)
- cross-sector collaboration to support women and children with needs related to both disability and DFV and meet other service needs (Dyson et al., 2017; Neave, Faulkner & Nicholson, 2016; Plummer & Findley, 2012; Tayton et al., 2014)
- intensive case management, which can incorporate aspects of community development and outreach, and encourage women to direct their own support (Healey, 2013; Tayton et al., 2014; Woodlock et al., 2014b)
- accommodation services and immediate financial support, to prevent the escalation of crisis (Tayton et al., 2014)
- accessible information and online resources, which provide information and access to support, including peer support and community education (Domestic Violence Resource Centre Victoria, 2017; Healey, Howe, Humphreys, Jennings & Julian, 2008; Lund, 2011)
- education and training for women and children with disability experiencing DFV (Lund, 2011)
- empowerment and social support (Frohman & Ricci, 2016; Lund, 2011).

This evidence is in dialogue with a policy context relating to DFV, which is complex and changing rapidly. This complexity is compounded by the intersections of DFV policy with disability policy, particularly the National Disability Insurance Scheme, also a complicated policy intervention that is being adapted through its implementation.

## Methodology

The project applied intersectionality theory and inclusive disability research approaches to address some of the ways

that gender and disability intersect with other forms of difference to influence and compound discrimination in the lives of women and children.

Intersectionality describes living on multiple axes of oppression simultaneously (Shaw, Chan & McMahon, 2012; Stubbs, 2015). An emerging body of research on disability applies intersectionality theory (Kayess, Sands & Fisher, 2014; Thill, 2019) to extend Crenshaw's (1991) original analysis of race and gender as intersectional, and examines other areas of social identity and difference that are also axes of oppression. We drew on this work in researching the experiences of women and children with disability.

We apply the definition of disability used in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006): "Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others." This definition directed our focus to how women's and children's disability intersects with:

- practical and functional issues relating to their day to day living, that is the ways they navigate their sensory, physical, intellectual or psychosocial impairments
- social factors that affect their capability (e.g. social isolation or complex family circumstances)
- the way that systems are affecting their experiences (e.g. access to funding, housing, safeguards, interagency collaboration).

Methodologically, applying inclusive, participatory approaches in collecting and analysing qualitative data in this research was significant in ensuring the research team practised ongoing reflection, and in privileging the perspectives of women with lived experience of disability and DFV (Nind & Vinha, 2014; Robinson, Fisher & Strike, 2014).

The project was advised by women with disability in its inception, and then from the point of funding, through an advisory group of women with lived experience who provided expert perspectives on a series of issues about project design, recruitment, adaptations to the methods, emerging results and

implications. Opportunities to seek advice on research design and methods were also taken with FRS senior practitioners and with key practitioners and advocates through a national workshop, where the team shared early results for discussion.

The multi-method study comprised:

- a state of knowledge review focused on evidence of proven and promising responses to early intervention violence prevention for families with a child or parent with disability
- a policy review examining the DFV, child protection and wellbeing, and disability policy contexts at a national level and within New South Wales, where the research was based
- qualitative research about the experience and implementation of early intervention violence prevention support, using the FRS program as a case study. The research was based in four FRS program sites in metropolitan and regional New South Wales and involved qualitative interviews with mothers (n=27), children and young people (n=7); FRS workers (n=20) and the FRS Senior Officers state group (n=8); other service providers (n=6); and policy stakeholders (n=6).

In total, 27 mothers were interviewed. While no mothers were asked about their specific diagnosis or impairment type, 15 of the 27 participants reflected on their experiences of disability—often complex experiences that intersected with trauma, including anxiety, depression and post-traumatic stress disorder. Some spoke of having multiple disabilities. Children with disability were present in 23 of the 27 families and, of these, in nine families more than one child had disability. Five of the 27 families identified as Indigenous. Ten of the 27 families were from urban locations, and the remaining 17 lived in regional towns and outlying areas.

Seven children and young people participated in interviews; their ages ranged from 8–19 years, with a mean age of 13.4 years. All had a diagnosed disability, and all but one had multiple disabilities. Most had disabilities related to autism, attention and trauma. Five of the children participated in a joint interview with their mothers, and two also completed individual interviews afterwards. The remaining two young people preferred to be interviewed independently.

## Key findings

### Children and young people's perspectives and priorities

Children and young people talked about positive aspects of their lives, which included family and peer relationships and activities; and negative experiences, which included bullying, loneliness and some effects of impairment. They were engaged with a range of formal and informal services such as youth groups, therapies and disability services. All had a diagnosed disability, most on the autism spectrum, and many had multiple diagnoses, which included trauma-related conditions such as anxiety, depression and conduct disorders.

Most of the children and young people did not talk about receiving support directly from FRS. Some of the children spoke about FRS as helping their mothers, and saw it as a general support to their family. In this way, the experiences of the children and young people with FRS and other support services were generally positive. However, they did not perceive their involvement with FRS as having an impact on the things that were most important to them as young people, such as social engagement, friendship, and positive experiences in schools and other everyday spaces.

### Mothers' perspectives and priorities

The mothers in the research had a wide diversity of life experiences. Several were studying, and a few were employed or undertaking volunteer work. Informal supports from family (mostly parents and adult children), neighbours and a few close friends were the main sources of support for many families. The mothers each had between one and eight children, though in some instances children were not living with their mothers, or were adult children.

Families had engaged with a range of services, most of which were for their children (speech therapy, occupational therapy, psychologists, paediatricians, playgroups and early childhood services). Other services they engaged with included disability support services, charity organisations, non-government organisations and programs, and government services.

A small number of mothers talked directly about living with disability, but it was much more common that women spoke about the effects of impairment on their lives (for example, how anxiety or depression affected them) than their identity as a person with disability. The mothers who identified as women with disability stressed the importance of being treated with respect, and described a sense of having to prove themselves as capable. A significant proportion of the women in this study did not openly identify as women with disability, although they were prepared to speak about many issues in the interviews that constituted disabling barriers.

The ways that mothers spoke about disability and impairment in their lives are important. Some of these are beyond the scope of this project, and relate to personal identity and the ways that impairment, disability and policy intersect. It is fertile ground for further research. However, the ways women viewed disability in their lives also affects their willingness to enter into a range of conversations that directly affect the way that FRS are provided to them and the kinds of supports it can offer.

Mothers discussed the priorities in their lives as closely linked with feeling safe, and ensuring their children were safe. Their concept of safety was very much connected with resources: having basic needs met and access to supports, community networks and people to talk to were important. Mothers also talked about the importance of asking for help when needed, and it was clear that the mothers interviewed found satisfaction in investigating available support and being effective advocates for their children. However, the mothers' interviews also show that responsibility for finding support often falls on families, and that families often have to make significant efforts to get the services they need and to which they are entitled. Families experiencing multiple adverse events, and those with very low resources, may not have the capacity to undertake this advocacy and investigation. The consequences are that those families who most need support, because of their adverse experiences, are those least able to get it.

## How Family Referral Services operate

The primary purpose of FRS is to provide information, initial support and referrals to families who need support, with a focus on early intervention and prevention in the area of child protection and wellbeing.

Families who contact FRS have diverse support needs, and follow different pathways to the service. In this project, a small number of clients approached FRS directly (self-referrals). Mothers who came to FRS independently had found information or the service themselves because of a high-profile location in a shopping centre or school.

FRS refer clients to a range of services including early intervention programs for children at risk of entering the child protection system, counselling support, legal advice and disability services. FRS staff also undertake significant advocacy work on behalf of clients, with a range of different services, including preschools and schools. The key supports that FRS providers and families described were for brokerage; disability-related links and referrals; domestic violence support, referral and other support services; and general or other support.

The service design for FRS is based on time-limited support to facilitate assessment and referral, rather than direct service provision. This time limit on support is based on assumptions that services are available and immediately accessible to families. However, access to services can be difficult for families for many reasons. Despite time limitations, FRS staff described working with families in time frames that were suited to needs, rather than rigid time frames. Several described how they held increased numbers of clients in their caseloads, but had periods where lower levels of support were needed while families waited for referrals to be accepted. Many of the mothers interviewed appreciated this approach, finding the number and range of services they needed to deal with confusing and overwhelming. This underlines the importance of flexible service responses, and a need for support coordination to assist families with navigating the service system.

## Effects of the National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) was in the roll-out phase at the time of the research (2018), and the engagement of families with the NDIS was a significant and repeated concern for both families and FRS providers. Many of the families in this research found the NDIS difficult to access and navigate. However, the positive effects of access to new resources for needed equipment, therapy and support was clear.

In order to receive support under the NDIS, most of the children with disability in the families in this study had been assessed for disability. Many of the children had been diagnosed with conditions relating to behaviour (attention deficit hyperactivity disorder [ADHD], oppositional defiant disorder [ODD], on the autism spectrum and so on). Some workers were concerned about the link between behaviour and trauma, and the potential for labelling children's behaviour as part of a disability when it may be a reaction to trauma. This was important because the most effective early intervention responses to trauma and to disability in children are different. The effects for children of being misdiagnosed with disability can be significant and potentially long-lasting.

Other challenges raised about the NDIS included delays in plan approval and funding for services and supports; that some services approved for funding did not meet the families' needs; and families could not always access the services they have been funded for as there were limited providers.

## Positive practices

FRS workers shared a range of practices that constitute fundamental good practice principles, such as building trust and showing respect to all clients; following through on promises made (e.g. returning calls as promised); making efforts to meet families face to face; and allowing clients the time and space to engage when they are ready.

In addition, the research uncovered a number of positive practices that built trust and confidence in the families and

supported helpful outcomes. These were focused around:

- *timeliness and scaffolded planning*: providing an initial response to families within 48 hours; using brokerage funds to help families meet urgent needs (especially to prevent people falling into crisis); and then focusing on referral and longer-term planning
- *personalised support*: developing referral plans with families, and making the many calls required to put them into action; staying in contact to keep families abreast of progress; working behind the scenes to ensure that referrals were successfully implemented
- *flexibility*: universal service design meant that no diagnosis or identification of disability was needed in order to receive support and that support was not restricted to a specific program or package; a holistic approach to assessing the needs of the family in the context of their everyday lives encouraged an understanding of disability as part of the wider context of women and children's lives
- *building and sustaining local sector relationships*: emphasis on local relationship development and maintenance by individual workers, through communities of practice and at structural levels (e.g. presence of FRS in schools, local hospital maternity unit, Centrelink)
- *improving service coordination*: regular interagency meetings focused on improving support to clients; collaborative practice with other organisations; secondments across sectors; location in key spaces to build relationships and open "soft" referral opportunities (FRS in Schools)
- *building cultural safety with Aboriginal families*: ensuring Aboriginal workers are available to clients; emphasising the voluntary nature of FRS; recognising the extended family; warm referrals to ensure services are culturally safe for families.

These practices in large part are not innovative, but are good and positive practice. Individually, they are perhaps not noteworthy. However, for women and children who have complex personal circumstances, such as the families in this study, the combinations of good practice described above are not always in operation in the services they use.



## Challenges in meeting needs

The research identified a number of challenges in meeting the needs of families when mothers or children had disability. These centred on:

- *The disconnect between DFV and disability policy and service delivery:* stakeholders felt policy goals had not translated into achievable service delivery indicators that brought together DFV and disability. There were few services or resources to support DFV policy for women and children with disability.
- *The confidence and skill of workers to speak with families about disability:* while there were some skilled practitioners confident in working with women and children with disability, there were many who expressed a lack of confidence, knowledge and awareness about how to speak with women about disability in the context of DFV, particularly intellectual disability.
- *Sector and inter-sector capacity:* tensions exist in trying to support families who have a well-founded fear of discrimination in child-protection systems and in being a voluntary service connecting with a mandated child protection system, and there are limitations for women with disability on access to available services.
- *Gaps in services and systems:* a referral-based service system struggling in a climate of constrained resources and “thin markets” (where there are limited or no services to refer clients); the timeliness of FRS depended on services being available, and delays impacted the capacity for early intervention to be effective.
- *Integration and coordination across sectors and services:* difficulties in coordinating support for families with complex sets of needs across multiple sectors, compounded by fragmentation of service types, and the fact that few services were funded to work with clients on a long-term basis.

## Discussion

The focus of this research on service delivery underlines the points at which systemic gaps are most affecting families in their day to day lives, and the potential points of intervention to improve practice.

The practices themselves are not especially surprising. Multiple people told us that there is nothing magical or different about supporting women and children with disability. However, we have also identified points that were not so well known about why blockages were happening, and how people were working to reconcile them. This is new information, which is useful in thinking about how to progress practice across disciplinary boundaries.

The strengths of the FRS model, as with early intervention and referral services in other jurisdictions (Dyson et al., 2017; Tayton et al., 2014), are in the flexible and accessible ways of working, the priority given to families’ immediate needs and those needs that families identify as most important, and the sustained efforts made by staff to connect and maintain connections with other services. The risks of this model for families is that FRS themselves cannot provide long-term specialist support, and many families need that; nor can they offer specialist mental health, disability or DFV support, which many families also need. The benefits are that a relationship with FRS will enable families to connect with those specialist services, at least in areas where they are available, and provide additional support in navigating service systems.

The research found that the focus of FRS’s service delivery is for adults more than children, and the priorities of children in improving social connectedness and building relationships were not directly supported by FRS. Given the known vulnerabilities of children and young people with disability, it is important that services for families can provide support to children as well as adults. There may be a role for FRS in providing more specific support to children and young people, and this would require specific resources including, in some areas, training and workforce support.

FRS’s focus is on family needs and priorities, rather than on mobilising strict eligibility criteria or standardised service delivery that follows strict rules to adhere to a manual or protocol. This is a productive foundation on which to build positive practice because it aligns with the social model of disability, in which the support needed to fully participate in life is a more important point of intervention than diagnosis or disability category (Shakespeare, 2013).

A core concern of this project is the capacity of FRS and other DFV and related community services to work effectively for families in meeting support needs related to disability and violence prevention. Several stakeholders felt that FRS have the ability to straddle a disconnected service system, but that they were not resourced to provide case management support, which requires relationship building. Others were less confident in the ability of FRS staff to recognise and respond to disability-related needs in women and children, and said that it was critical that staff were all appropriately trained to improve their capacity and confidence.

This capacity-building of workers needs to be structured into the program design and resourced. This is particularly important because the assessment approach is holistic, focused on collecting the person's story, building a picture of their need and responding to it—and minimising the filling out of forms. This means that workers need to have the skills to have conversations that explore how disability affects women and children's experiences of navigating safety and harm, and their priorities for support. When many FRS workers themselves acknowledged a level of discomfort and lack of confidence in talking about and addressing issues facing families where children, or especially mothers, have disability, this is particularly problematic. It is unlikely that poor practice will be called out when colleagues witnessing it do not feel confident in how to offer constructive advice and positive practice alternatives.

Families with disability and those in which violence is present are often at risk of statutory child protection intervention, and even where child protection services are supportive and enhance safety, families may avoid them because of shame and fear (Cripps & Habibis, 2019; Humphreys & Healey, 2017). The role of FRS in providing early intervention child protection support was highly valued across a range of policy and practice sectors, and the integration of FRS with secondary and tertiary child protection services could jeopardise this. However, service providers' experiences of this integration appear to be positive. Sustained research on families' experiences would be valuable, including longitudinal studies.

Resources are needed in DFV service systems to improve responsiveness to disability, and in disability services to

improve responsiveness to DFV. This will counter well-documented gaps and challenges in family support and disability services, which are compounded when families are living with current or past experiences of violence (Maher et al., 2018; Mikton, Maguire & Shakespeare, 2014). It is important that these resources go beyond funding for short-term programs or service enhancements, particularly as access to service coordination over time was emphasised by stakeholders and parents in this research, as it has been in previous research (Breckenridge & Huppert, 2010; Dyson et al., 2017; Humphreys & Healey, 2017; Maher et al., 2018). Without such investment, individual workers are forced to rely on the quality of their own inter-professional networks, as services change and those that provide online referral information cannot keep this information updated.

It is also important that the purpose and limits of the NDIS as a mechanism to meet families' needs are not lost as a result of service delivery gaps. It is critically important that support is available to meet children's immediate needs after a crisis; that this support is not contingent on a diagnosis; and that long-term support is provided to meet disability or other needs. In a context of unmet need, there is a risk that early intervention DFV services such as FRS will invest efforts in ensuring a child or mother applies for an NDIS package for therapeutic interventions, even though this may not meet their most important needs. There may be short-term advantages to a diagnosis of disability because a diagnosis may have implications for service eligibility. However, if the support needs of children are caused by their traumatised response to an experience of violence, a diagnosis of disability may result in the failure to provide the support that is needed. A diagnosis will follow children through their school lives and beyond, and a diagnosis made in haste or by a practitioner lacking skills in understanding the effects of trauma on children may ill fit children's long-term needs and aspirations (Crnic, Neece, McIntyre, Blacher & Baker, 2017).

Notwithstanding this, this study shows that barriers to effective and efficient use of the NDIS clearly need to be addressed for families with disability facing DFV. This includes potential learning from the elements of the FRS program that are helpful and supportive for families with disability, particularly supported referral, flexibility in service provision, access to

brokerage funds and continuity of support. Families want and need longer term support to manage ongoing, complex support needs.

### Implications for policy and practice

A framework for training and capacity-building is suggested to support the development of positive practice in workers and organisations. It should aim to:

- shift culture by taking a diversity approach to disability and impairment
- skill workers and organisations to feel confident and able to respond to the needs of families with disability who are at risk of violence
- build a bank of positive practice that is locally tailored and responsive to needs and preferences
- develop/amend policies to provide pathways that better support access to needed supports for women and children with disability experiencing/recovering from DFV, and which bridge existing gaps between DFV and disability.

The need for national policy to recognise the intersectional nature of DFV and disability and provide pathways for practice is undiminished over time. As new national agreements are in negotiation, the time is ripe to reinvigorate these discussions to ensure that both the national disability and family violence strategies account for the embedded intersections, and that responsibility for action on violence prevention is not vested in the NDIS.

### Conclusion

Women and children with disability who have experienced violence have historically not been well served by support systems. Intersectionality theory shows that power operates through multiple aspects of social relations, and that experiences of the effects of power are experienced cumulatively rather than as the sum of individual identity categories, but services and systems tend to still be set up along the lines of individual categories and responsibilities. Efforts to integrate these categories often require more resources, and take longer to achieve than anticipated.

Despite this, services and people with lived experience have diverse strengths and capabilities, and can draw on resources to meet support needs and ensure the safety of adults and children. The positive practices identified in this report are in some respects as familiar as the challenges and failures, but also represent a basis for continued work in improving systems and practice.



# Introduction

Domestic and family violence (DFV) early intervention programs aim to identify risks to the safety and wellbeing of parents and children and provide timely responses before risk to families escalates. A series of challenges to the effectiveness of these responses are well recognised, particularly for families with complex or additional support needs. These include the limited network of available services to refer families to, and the time-limited nature of service provision (Bowen & Swift, 2019; Dyson, Frawley & Robinson, 2017; Tayton, Moore, Campo & Kaspiew, 2014).

Disability in mothers and/or children is a particular feature in families' lives that makes it harder for early intervention DFV programs to support them well within available time frames. At a practice level, there are gaps between disability and violence support sectors, which means that services that support people with disability often have very limited capacity to respond to risks of family violence, while services focused on violence prevention have little background or resourcing for identifying and addressing disability support needs (Dyson et al., 2017; Fraser-Barbour, Crocker, & Walker, 2018; Howe & Hargrave, 2016). This may result in risks for these families of either unmet need or of inappropriate response, such as interventions by statutory child protection services due to lack of available alternative support.

At a policy level, several current national policies that frame DFV represent disability primarily as a risk factor or stressor in families, and as a risk for effective service provision (see, for example, the discussion of the *National Plan to Reduce Violence against Women and their Children 2010–2022* and the *National Framework for Protecting Australia's Children* in the Policy review section of this report). The effect of this framing of disability in the DFV context is an underexplored question in research.

In this climate, some flexible and responsive practice is being implemented to support families with disability who are at risk of DFV. However, little is known about the ways that early intervention DFV services respond to women and their children to meet their needs and preferences, and build their resources and capacity, organisationally and at wider social levels.

It is within this context that this project aims to provide new knowledge on the impact of DFV early intervention support, with a specific focus on the experiences and voices of women and children with disability. It addresses critical gaps in understanding cross-disciplinary intervention points at which effective support can be delivered to people with disability.

This report presents findings from a review of current policies; evidence of proven and promising responses to early intervention DFV prevention for families with a child or parent with disability; and qualitative interviews with parents and children with disability, and with staff and stakeholders from four Family Referral Services (FRS) in New South Wales. These FRS were chosen as case studies of early intervention practice due to their focus on supporting families, identifying their needs and connecting them with local services, and, through this, seeking to “prevent escalation and address issues arising from the experience of domestic and family violence” (NSW Health & Women NSW, 2016, p.3). All Australian jurisdictions have comparable models of family support services or initiatives that are designed to facilitate integrated support services and intervene early where families are at risk to prevent the involvement of statutory child protection services, ensure the safety of women and children, and coordinate services and support.

FRS were established in New South Wales to assess the support needs of families and children and young people who are under the threshold for statutory child protection intervention, and link them with available and appropriate local support services. This could include concerns relating to DFV as well as other forms of violence, abuse and neglect. FRS also play a role in building the capacity of service providers in their local networks about support services available to families in their catchment areas, and in strengthening collaboration and service coordination.

The FRS program objectives (NSW Health, 2014) are to:

- improve access to support for children, young people and families at risk of harm by providing information, referral and other assistance for families to receive support from local services

- improve coordination and collaboration in the delivery of local services to clients through systemic advocacy and service system support
- support optimal alignment of local services to meet local need.

The next section presents the findings of the state of knowledge review. The study methodology is detailed after this. Following the methodology, the key findings from the research are presented, focusing first on the perspectives and priorities of the children and mothers; then describing the ways that early intervention violence prevention support was provided in this context. The features of the program particularly relevant for supporting families with disability are highlighted, before a discussion of the impact of the National Disability Insurance Scheme. The findings section closes by featuring positive practices and challenges in meeting the needs of the families. The concluding section of the report details implications for building on existing positive practice.

# State of knowledge review

This section presents findings from a review of academic and grey literature, including available information on websites of relevant government agencies providing DFV and disability programs to the families of interest for this study. It focuses, where possible, on evidence of proven and promising responses to early intervention violence prevention for families with a child or parent with a disability. As noted in the Executive summary, and confirmed through this review, there is a growing literature on the failures of services to support families with a disability who are at risk of family violence, and on the experience of violence for women with disability. We refer readers to reports by Australia’s National Research Organisation for Women’s Safety (ANROWS)—by Dyson, Frawley, & Robinson, (2017) and Maher et al. (2018)—for thorough reviews of these topics. However, there is considerably less evidence on proven and promising practice. Research-informed grey literature provides the most robust source of evidence for this review, reflecting the newly developing interest in this field.

## Methodology

A narrative review of academic and grey literature was conducted for proven and promising practice in early intervention DFV prevention for families when a child or parent has disability. A narrative approach was considered an appropriate design to simultaneously review academic and grey literature, encompass both policy and practice emphases, and to provide interpretation and critique to deepen understanding across the literature types (Greenhalgh, Thorne & Malterud, 2018). Searches were completed using the UNSW Sydney library databases, Google Scholar and Google Advanced Search, along with a manual search of the reference lists of key articles since 2007 (a ten-year range). The following databases were searched for academic literature using the keywords “early intervention + disability/ family + domestic violence”: FAMILY: Australian Family and Society Abstracts, Social Work Abstracts, Violence and Abuse Abstracts, Education Research Complete, Social Work Abstracts, Family and Society Studies Worldwide, Family Studies Abstracts and Oxford Scholarship Online. Using the same keywords and time period, Google Advanced Search generated more relevant sources for this review, which is focused on programs, initiatives and promising practices

(but not legislative frameworks and legal protections); little of the academic literature covered these areas. A number of reviews, commissions, and national and state action plans identify gaps and service needs of families with disability experiencing DFV. All documents were reviewed for any reference to relevant programs or services; however, a thorough discussion of their findings and strategic aims is not included in this report.

## The scale of the problem

While this review focuses on responses to improve practice, it is nonetheless important to remind readers of the significance of the problems facing women and children with disability. The scope and prevalence of violence perpetrated against girls or women with disability is significantly higher than the broad figure of one in six women without disability who have experienced physical or sexual violence (Australian Institute of Health and Welfare [AIHW], 2019). The most reliable available prevalence data comes from the Personal safety survey, which estimates that 2.5 percent of women with disability experienced partner violence from a current or previous partner, compared to 1.3 percent of the wider population of women (Australian Bureau of Statistics, 2019). Moreover, women with disability experienced far higher rates of emotional abuse (32% versus 19%) and sexual violence (25% versus 15%) than women without disability (AIHW, 2019, p. 92). The figure is probably higher as there are girls and women with disability who are unable to independently report violence and abuse. In addition, many are unlikely to come forward due to reliance on perpetrators for daily support, or a fear of not being believed (Frohman, Dowse & Didi, 2015). Children with disability are often not specifically included in disability or DFV policies, and it is difficult to locate reliable data on their experiences of DFV. Research on the prevalence of sexual violence, however, indicates that children with disability are at very high risk and this is likely to be relevant to their risk of other types of violence: in their meta-analysis, Jones et al. (2012, p. 899) estimate that 13.7 percent of children with disability experienced sexual abuse, and that they have a 2.88 times higher risk of sexual violence than children without disability. Alongside this, children with disability experience high rates of bias-based bullying, interpersonal and systemic discrimination,

and disability-related abuse (such as lack of access or having communication aids removed) (Robinson, 2018).

## Understanding disability

In this context, it is helpful to be clear about the way that we approached disability in this project. In the research, people were invited to be involved in two ways—they self-identified as people with disability or the worker who invited them into the project was of the view that they experienced disability, in which case they were invited to the project as people who had received help when going through difficult times. Children were invited to the project based on their mothers' views that they had disability.

Our efforts to reach mothers who had a more organic view of disability and impairment was pragmatic (in terms of building recruitment), but also grounded in disability theory. Recent scholarly approaches to disability have moved beyond the now well-known social model of disability, which distinguishes between impairment (conditions, illnesses and injuries experienced by people) and disability (the physical, social and structural barriers that affect inclusion and citizenship of people with impairments) (Shakespeare, 2013). These newer approaches consider how material experience (e.g. living with anxiety and being a parent to a child with autism) intersects with policy settings, service architectures and funding rules—and the discourses that shape and are shaped in these contexts. These *assemblage* approaches to disability are complex, but offer new and exciting ways to consider the relationships between people with lived experience and service systems (Feely, 2016).

## Findings

### Barriers to effective support for women and children with disability

The provision of integrated responses for women and children with multiple support needs is an emerging policy priority, as described in the policy review below. Notwithstanding this, the evidence base on programs and services for women and

children with disability experiencing DFV remains fairly small. One of the most comprehensive reviews of groups and communities at risk of DFV includes women with disability (Tayton et al., 2014, p. 54). It notes the “striking lack of DFV services aimed specifically at women with disability and mental ill health” and the lack of research about the effectiveness of such programs and interventions (see also Mikton, Maguire & Shakespeare, 2014; Woodlock, Healey et al., 2014). Similarly, Frawley, Dyson, Robinson, and Dixon (2015, p. 18) found that:

insights have been gained from this review about factors that need to be considered in developing these responses [but] there are very few actual models of tertiary responses presented in the literature.

The Tayton et al. (2014) review included evidence regarding the effectiveness of prevention and early intervention programs for groups at risk of domestic violence, including women/children with disability. However, it should be noted that of the at-risk/target groups identified, there was less evidence on support for people with disability than other groups.

For this report, the most useful sources for identifying principles, services and programs were from research that focused on:

- promoting the perspectives of women with disability (Dowse, Soldatic, Didi, & van Toorn 2013; Woodlock, Western, & Bailey, 2014)
- identifying and addressing practice barriers (Dyson et al., 2017; Frawley et al., 2015)
- analysing the effectiveness of policy and practice for practice responses (Healey, Howe, Humphreys, Jennings, & Julian, 2008).

There is broad recognition that women with disability face increased risk of DFV and barriers to service access; however, recent research confirms the urgent need for policy and practice to address this (Bowen & Swift, 2019; Corr, Milagros Santos, Fowler, Spence & Skubel, 2019; Maher et al., 2018). In most instances where DFV co-exists with disability, mothers and children with disability are not able to live in

the community with access and choices equivalent to others (Olney & Dickinson, 2019).

Families with disability experience compounding difficulty in accessing supports available in the general community. The National Disability Insurance Scheme (NDIS) will not fund support that is provided by mainstream public services (e.g. health, housing, education), yet many families need specialist assistance to navigate mainstream service systems successfully. As a result, families often cannot secure information or access to support (Olney & Dickinson, 2019). A key criticism of the implementation of the NDIS highlighted in the *NDIS Cost Analysis Report* was a lack of clarity over the roles and responsibilities of different federal and state government-run services (Productivity Commission, 2017). A reality shared by many families with and without disability is that challenges and unmet needs rarely sit neatly within one sector. Cohesive collaboration is often required across multiple departments and systems in order for the needs of people facing complex problems to be effectively met (Dickinson & Carey, 2017).

A study by Collings, Strnadová, Loblinzk and Danker (2019) provided additional evidence that violence prevention and intervention services are particularly under-resourced and ill-equipped to respond to the needs of women and children with disability. Research by Olney and Dickinson (2019) found that responses to these challenges should include:

- introducing an improved, efficient, streamlined approval process for plans and resource acquisitions
- training and resourcing for NDIS staff, and specialist and mainstream support service provider staff
- slowing the rate of scheme implementation, to allow time for service providers to become better equipped to interact and respond to participant needs in this new policy landscape.

## Principles for prevention and intervention

There is notable research in Australia on preventing and responding to violence against women with disability (see, for example, Dowse et al., 2013; Dyson et al., 2017; Maher et al., 2018); and this literature identifies key themes that are relevant to effective service provision. Dowse et al. (2013)

specify principles to underpin policy and practice:

- access to (relevant and accessible) information, education on DFV and related issues, and capacity building for women and girls with disabilities
- awareness training for the broader community
- education and training for service providers
- service sector development and reform
- inclusive legislation, national agreements and policy framework
- evidence gathering, research and development.

Research undertaken for ANROWS (Dyson et al., 2017; Frawley et al., 2015) similarly identifies promising approaches to service delivery for women and children with disability experiencing DFV. These include:

- that services have an understanding of the experiences and needs of women and girls living with disability in order to accurately collect data and identify appropriate tertiary responses
- that services provide adequate staffing to meet the needs of service users
- that services are physically and programmatically accessible, and strengthened by cross-sector collaboration. (Frawley et al., 2015, pp. 18–19)

Dowse et al. (2013) set out strategies to support the implementation of these principles:

- addressing barriers to service provision
- participatory practices that include women with disability in decision-making in services
- meeting sector development issues of training, skills sharing and regulation
- improving cross-sector collaboration
- ensuring more strategic approaches to data capture and use to inform strategy and policy.

A consistent theme in the literature is the need for improved physical accessibility of tertiary DFV services (responding after violence has occurred), and for improved sector collaboration between DFV services and disability services (Cameron, 2016; Dyson et al., 2017; McClain, 2011; Women's Health West,



2013; Woodlock, Healey et al., 2014; Woodlock, Western, & Bailey, 2014) A number of sources also note a scarcity of housing support, in part because DFV accommodation services lack capacity in working with women with high support needs. Dyson et al. (2017, p. 4) note that accessibility of services goes beyond physical accessibility, and applies to relational, social and economic domains; and that services must also be “approachable, acceptable, appropriate, affordable and available to women with disability”. McClain (2011, p. 8) found that accessibility also entails “broader issues of attitudes, atmosphere, inclusivity, and ability to be referred to, and participate in, the variety of available programs and services appropriate to the individual’s needs”. Frohmader et al. (2015) note that information in accessible and appealing formats is an essential part of communicating in accessible ways about services to women and children with disability.

Another strong theme is the need for workforce education and training. Woodlock, Healey et al. (2014) identify the need for training and education in both DFV and disability services to improve their understanding of violence against women with disability. Lund’s (2011) review of community-based services and interventions for individuals with a disability who have experienced interpersonal violence provides a useful review of the scope and effectiveness of access to abuse prevention services for people with disability. It identified a lack of training and cultural awareness of specific needs (e.g. the Deaf community) as barriers to access (Lund, 2011, p. 176). In terms of workforce development, Dyson et al. (2017) contend that:

- In order for service planning and delivery to adequately encompass the complexity of their clients’ lives, an intersectional lens must be used when working with women with disability.
- Case planning needs to be inclusive of not only safety needs, but also the social and relational needs of women with disability.
- The experiences of people with disability need to be captured in DFV service data collection, and this data needs to be used to inform research, practice and evaluation.
- Cross-sector collaboration is common practice to inform and enhance tertiary service responses for women with disabilities.

Dyson et al. (2017, p. 22) found that the most common ways services responded to the needs of women/children with disability was to adapt generic services, and that the most common service adaptations included:

- changes to processes and procedures, making buildings accessible, adapting resources (such as using bigger print), developing disability action plans, providing interpreter services and employing workers who are skilled in disability services.

Some services did provide intensive case management, an approach that is explored further in the next section. It is also worth noting here some of the features of effective DFV services, as identified by Dyson et al. (2017); these do not represent specific types of programs or services but, rather, overarching features that characterise effective practices across all types of services and programs, including:

- positive and respectful relationships with staff at services
- service coordination and collaboration that can be facilitated through cross-sector collaboration and training initiatives, which helps to ensure there are no gaps in service delivery for service users who have moved locations.

Another research project, Voices Against Violence (McGuire, 2014; Woodlock, Healey et al., 2014; Woodlock, Western, & Bailey, 2014), produced a series of reports based on qualitative research with service providers and with women with disability. Woodlock, Western, & Bailey (2014, pp. 49–50) identified that a key challenge to meeting the needs of mothers and children with disability who are experiencing or at risk of violence is that mothers are often afraid to seek support or report violence because they fear that their children will be taken from them. The same report identified a number of areas that need to be addressed in preventing and responding to violence against women with disability. A number of these are directly related to prevention and early intervention:

- education on violence prevention for people with disability
- information on abuse for women with disability
- stronger cross-sector collaboration
- training for service providers
- accommodation and housing

- mutual support for women with disability who have experienced violence (Woodlock, Western, & Bailey, 2014).

These projects establish a strong base for further research about the scope of programs and services available across Australia, and the extent to which they are meeting the integrated needs of both women and children.

The large majority of the programs and services identified focused on women with disability. Children with disability were less often the target group. Most literature on children with disability does not mention the needs of those who also experience DFV. A small number of interventions that target children with a disability who are at risk of abuse or neglect have been identified in the literature (see, for example, Edgecombe & Ploeger, 2006). However, these interventions were not developed in a context of family violence, but more often in a context of crisis due to unmet needs for support due to disability (Breckenridge & Huppert, 2010).

## Principles of positive practice

The programs and promising approaches identified in the literature can be categorised under broad themes, which are discussed below. The practice examples were selected for inclusion in Table 1 according to their individual capacity to:

- engage across multiple sectors applying a client-centred approach to supporting families experiencing DFV
- use intensive case management approaches
- provide accommodation services
- provide information and online resources, education and training
- provide skills in empowerment and social support following instances of DFV.

### Cross-sector collaboration

As noted above, cross-sector collaboration is needed to support the needs of women and children with disability experiencing DFV (Neave, Faulkner & Nicholson, 2016; Plummer & Findley, 2012; Tayton et al., 2014). Disability services do not always appear capable of addressing the complexities of these women and children. Conversely, DFV services indicate they are not

always prepared to meet the additional needs of women and children, due to physical barriers to access, a lack of training among staff to understand the needs of individuals with intellectual disability, or attitudinal barriers to serving this specific group (Dyson et al., 2017).

Although specific programs are not identified, Dyson et al.'s (2017) research with services identified collaboration and referral as an approach to service delivery that was adopted by the tertiary DFV services surveyed for their study.

It should be noted that a number of these initiatives may also be relevant to other themes identified in the review (e.g. where there are collaborative approaches to delivering refuge accommodation or intensive case management). Also, in some cases, the examples listed are not programs specifically for the target group but, rather, funding is provided to support a staff member/worker to facilitate better collaboration across local services, namely disability services, domestic family violence services and emergency accommodation services.

Dyson et al.'s (2017, p. 12) review of the effectiveness of tertiary responses found that one of the "crucial aspects of a successful program is the expertise of staff". Programs that support staff training and professional development to work effectively with women and children with disability experiencing or at risk of DFV are therefore also important.

### Intensive case management

Intensive case management is also identified as an effective approach to families with co-occurring support needs (Healey, 2013; Tayton et al., 2014; Woodlock, Healey et al., 2014) because it can incorporate aspects of community development, taking a community of practice approach, and outreach (Healey, 2013). The flexible approach of a specialist "blended" service was found to be valuable by Dyson et al. (2017), because it encouraged women with disability to direct their own support according to their priorities.

### Accommodation services

Tayton et al. (2014, p. 53) found that,

in relation to women with disability, stakeholders identified a lack of emergency accommodation for women with disability due to physical access issues as well as services lacking confidence in supporting women with “high needs”.

### Accessible information and online resources

Research with DFV and disability service providers and people with disability experiencing violence (Healey et al., 2008; Lund, 2011; Tayton et al., 2014) suggests there is often a need for more information and resources, such as through the websites and awareness and education programs. Websites can support women with disability “to achieve their rights through information sharing, peer support and community education” (Domestic Violence Resource Centre Victoria, 2017, p. 20).

### Education and training

In addition to online resources, education programs and training are also identified as a way to support women and children with disability experiencing DFV. Lund’s (2011) review of services for people with disability who have experienced interpersonal violence found potential in two psycho-educationally based abuse prevention programs (Hughes et al., 2010 cited in Lund, 2011).

### Empowerment and social support

Another approach identified in the literature as important for the prevention of DFV against women with disability was the need for empowerment and the importance of social support (see, for example, Frohmader & Ricci, 2016). Lund (2011, p. 178) cites an evaluation of a prevention program based on self-directed decision-making “in which women with intellectual disabilities make decisions based on evaluations of personal goals and potential consequences”. Woodlock, Healey et al. (2014, p. 19a) found that women with a disability who attended support groups felt supported by other women and the groups also served as a conduit to other community services and supports. A United Kingdom support program for survivors of domestic abuse with significant intellectual disability was evaluated by Peckham, Howlett & Corbett (2007,

p. 308), who found that the 5-month (20 sessions) program that focused on education and support was successful in “improving sexual knowledge and in reducing trauma and depression, although challenging behaviours worsened at first before improving”.

Examples of programs and practice examples are summarised in Table 1.



**Table 1:** Promising practices and initiatives

Core theme	Practice examples
<b>Cross-sector collaboration and workforce training</b>	<p>Practice examples here drew on continuous skills and resource acquisition to break down both physical and situational barriers for women with additional needs accessing DFV services:</p> <ul style="list-style-type: none"> <li>• Safe Steps Family Violence Response Centre. Provides telephone crisis counselling, referral, information and support to women and providers. A central contact point for Victorian DFV and other services seeking advice. <a href="https://www.dvrcv.org.au/safe-steps">https://www.dvrcv.org.au/safe-steps</a></li> <li>• Woorarra Women's Refuge (Victoria). One of the earliest tertiary violence services to develop a disability action plan with leadership by women with disability (WWDA, 2013)</li> <li>• Barwon South West Integrated Family Violence sub-regional committees (Victoria). Aim to build locally responsive, connected service networks and partnerships. While disability is not prominently featured, the project includes a partnership with Women with Disability Victoria <a href="http://www.womenshealthbsw.org.au/wswfvp">http://www.womenshealthbsw.org.au/wswfvp</a></li> <li>• Gender and Disability Workforce Development Program (Victoria). Funded through Victoria's <i>Action Plan to Address Violence against Women and Children</i> (Victorian Government, 2012) and implemented by Women with Disability Victoria. <a href="https://www.wdv.org.au/our-work/our-work-with-organisations/workforce-development-program-on-gender-and-disability/">https://www.wdv.org.au/our-work/our-work-with-organisations/workforce-development-program-on-gender-and-disability/</a></li> <li>• <i>Triple Disadvantage: Out Of Sight, Out Of Mind</i>. Training project developed and implemented by Violence Against Women with Disabilities Project, auspiced by Domestic Violence &amp; Incest Resource Centre Vic. Includes training material. <a href="http://wwda.org.au/wp-content/uploads/2013/12/triple1.pdf">http://wwda.org.au/wp-content/uploads/2013/12/triple1.pdf</a></li> <li>• The 1800 RESPECT Disability Pathways Project worked closely with advocates in the disability violence field to improve service referral pathways and responses for people with disability affected by sexual assault or DFV. Outcomes build capacity in counsellors, improve information quality for people with disability and professionals, and raise awareness. <a href="https://www.1800respect.org.au/about-us/disability-pathways-project/">https://www.1800respect.org.au/about-us/disability-pathways-project/</a></li> </ul>
<b>Intensive case management</b>	<p>Practice examples using intensive case management provide additional resources to enable skilled staff, extra time and effective cross-sector collaboration:</p> <ul style="list-style-type: none"> <li>• Family Violence Intensive Case Management Model. Within an integrated DFV team model, an intensive case manager provides concentrated case management to women with disability experiencing DFV (Women's Health West, 2019). <a href="https://whwest.org.au/resource/fv-women-disabilities/">https://whwest.org.au/resource/fv-women-disabilities/</a></li> <li>• Making Rights Reality. A program for adults and children with disability who have experienced sexual assault or DFV. Developed and offered by South Eastern Centre Against Sexual Assault, in partnership with Springvale Monash Community Legal Centre and the Federation of Community Legal Services. <a href="https://www.secasa.com.au/services/making-rights-reality-for-sexual-assault-victims-with-a-disability/">https://www.secasa.com.au/services/making-rights-reality-for-sexual-assault-victims-with-a-disability/</a></li> </ul>

Core theme	Practice examples
<p><b>Accommodation services and immediate financial support</b></p>	<p>Practice examples of accommodation and immediate financial assistance are responsive to the circumstances of women with disability and able to respond quickly to their needs when in crisis:</p> <ul style="list-style-type: none"> <li>• The ACT Crisis Services Scheme (ACT Domestic Violence Crisis Services) is a generalist DFV service introduced in 2014. It includes a specific focus on addressing the physical barriers for women with disability trying to escape domestic violence. <a href="https://dvcs.org.au/who-dose-it-affect/people-with-a-disability/">https://dvcs.org.au/who-dose-it-affect/people-with-a-disability/</a></li> <li>• The Disability and Family Violence Crisis Response in Victoria is a specialist family violence service initiative that provides immediate protection to women and their children with disability who are experiencing DFV. By providing flexible brokerage support, it is able to respond to the needs and circumstances of families with disability. <a href="https://providers.dhhs.vic.gov.au/disability-and-family-violence-crisis-response">https://providers.dhhs.vic.gov.au/disability-and-family-violence-crisis-response</a></li> <li>• Brisbane Domestic Violence Service takes an integrated approach to providing support. The service works to provide a safe environment by meeting flexibly in ways that best meet the needs of a very diverse community, within the context of a long-term and trusted social inclusion building organisation, Micah Projects. Micah has established credibility with people in marginalised circumstances. <a href="https://micahprojects.org.au/services/#domestic-and-family-violence">https://micahprojects.org.au/services/#domestic-and-family-violence</a></li> </ul>
<p><b>Accessible information and online resources</b></p>	<p>These accessible information resources for women with disability are practice examples that provide information about violence and abuse; information and context around violence prevention and personal safety; and targeted information about access to particular resources (such as accommodation):</p> <ul style="list-style-type: none"> <li>• The Family and Community Services NSW website contains information about violence for women with disability. <a href="https://www.facs.nsw.gov.au/domestic-violence/my-situation/im-a-person-with-disability">https://www.facs.nsw.gov.au/domestic-violence/my-situation/im-a-person-with-disability</a></li> <li>• The Looking After Me Resource Kit (facilitator guide) includes information provided by the Disability Advocacy Resource Unit about personal safety and relationships for women with intellectual disability. <a href="http://www.daru.org.au/resource/looking-after-me-resource-kit">http://www.daru.org.au/resource/looking-after-me-resource-kit</a></li> <li>• Women with Disabilities Victoria promotes the health and wellbeing of women with disability. It has multiple projects and resources to support women with disability to achieve their rights through information sharing, peer support and community education. <a href="http://www.wdv.org.au">www.wdv.org.au</a></li> <li>• The Domestic Violence In Regional Communities website includes information about disability services and finding disability accommodation. <a href="http://www.dvirc.org.au/Disability/disabilityindex.htm">http://www.dvirc.org.au/Disability/disabilityindex.htm</a></li> <li>• 1800 RESPECT has developed the Sunny app, co-designed with women with disability to provide information and support to women with disability who experience violence or abuse. <a href="https://www.1800respect.org.au/sunny/">https://www.1800respect.org.au/sunny/</a></li> </ul>

Core theme	Practice examples
<p><b>Education and training about DFV</b></p>	<p>Practice examples of education and training about DFV for women with disability:</p> <ul style="list-style-type: none"> <li>• Sexual Lives and Respectful Relationships (Vic). Information and training delivered by teams of women with and without disability. An action research approach to educating people with an intellectual disability. <a href="https://www.slrr.com.au/">https://www.slrr.com.au/</a></li> <li>• Be Safe Be Sure Project (NSW): A year-long project on safety and sexuality for women with intellectual disability. <a href="http://wwda.org.au/wp-content/uploads/2013/12/BeSafeBeSure1.pdf">http://wwda.org.au/wp-content/uploads/2013/12/BeSafeBeSure1.pdf</a></li> <li>• Domestic Violence and Intellectual Disability Training Program (NSW). This training program aims to build knowledge in women with intellectual disability and service providers who work with them through parallel training (Tayton et al., 2014, p.158). This program was positively evaluated (Robinson, 2014)</li> <li>• Resource manuals have been produced for DFV providers supporting women with disability. These include: <ul style="list-style-type: none"> <li>• 1800 RESPECT (Department of Social Services) is the national sexual assault, domestic and family violence counselling service. Includes guidance for professionals about responding effectively to people with disability who have experienced violence and abuse; links to webinar and training information for staff; and safety planning. <a href="https://www.1800respect.org.au/inclusive-practice/supporting-people-with-disability/">https://www.1800respect.org.au/inclusive-practice/supporting-people-with-disability/</a></li> <li>• <i>Women with Disability and Domestic and Family Violence: A Guide for Policy and Practice</i>. A guide for services responding to families with members with disability who experience violence. Developed and produced by People with Disability Australia in partnership with Domestic Violence NSW. <a href="http://dvnsw.org.au/pwd_doc1.pdf">http://dvnsw.org.au/pwd_doc1.pdf</a></li> <li>• <i>WWDA Resource Manual on Violence Against Women With Disabilities</i>. <a href="http://wwda.org.au/issues/viol/viol2006/vrm2007/">http://wwda.org.au/issues/viol/viol2006/vrm2007/</a></li> <li>• <i>Getting Safe Against the Odds—A Guide for Service Providers</i>. <a href="https://www.dvrcv.org.au/sites/default/files/Getting%20safe%20against%20the%20odds%20%28pamphlet%29.pdf">https://www.dvrcv.org.au/sites/default/files/Getting%20safe%20against%20the%20odds%20%28pamphlet%29.pdf</a></li> </ul> </li> </ul>
<p><b>Empowerment and social support</b></p>	<p>Practice examples of social support and empowerment approaches for women with disability:</p> <ul style="list-style-type: none"> <li>• WWILD Sexual Violence Prevention Service works with people with intellectual disability who have been victims of sexual violence, other crime or exploitation, providing support, therapeutic education, information and resources. <a href="https://wwild.org.au/">https://wwild.org.au/</a></li> <li>• The Human Rights Toolkit for Women and Girls with Disability was developed by Women with Disabilities Australia to build the capability of women and girls to understand and advocate for their rights, including around bodily integrity, safety and the right to be free from DFV. <a href="http://wwda.org.au/papers/toolkit/">http://wwda.org.au/papers/toolkit/</a></li> </ul>

# Policy review

As noted by Flanagan, Blunden, valentine and Henriette (2019), Commonwealth, state and territory governments have all developed DFV strategies designed to support and protect victims, and to hold perpetrators accountable. These policies are underpinned by the recognition that DFV is constituted through relationships of gender and other social categories, including disability.

The policy context relating to DFV is complex and changing rapidly, and the review conducted for this project reflects the policy landscape at this point in time, with a specific focus on the experience of DFV by women and children with disability. This complexity is compounded by the connections of DFV policy with the NDIS, which is also a complicated policy intervention being adapted through its implementation. For clarity, this review canvasses two main areas affecting women and children in this research: the DFV and disability policy spheres. However, we note that there are also many other areas of women's and children's lives where policy is pertinent, including housing, education, social security and health.

## Domestic and family violence policy context

At a national level, policy around DFV is shaped by legislation and flagship strategies to guide high-level responses. Royal Commissions into violence, abuse, neglect and exploitation of children and people with disability have also shaped policy and practice in critical ways. The Royal Commission into Institutional Responses to Child Sexual Abuse (2012–17) not only created a watershed in terms of new policy and practice responses to all forms of violence, abuse and neglect of children and young people, but also opened a space for discussion of the abuse and personal safety of children with disability through research-informed recommendations and into policy and practice (Breckenridge & Flax, 2016; Llewellyn et al., 2016; Robinson, 2016). Its findings, which are relevant to DFV as well as its own specific remit of sexual abuse, included that people with disability are often not well supported by specialist services, including services to support adults and children who have experienced violence, and its recommendations include that “local institutions

[should] work collaboratively with key services to ensure child safe approaches are culturally safe, disability aware and appropriate for children from diverse backgrounds” (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017, p. 12, R6.12).

## Commonwealth

The *National Plan to Reduce Violence against Women and their Children 2010–2022* (the National Plan) provides the framework for action to reduce violence by the Commonwealth and state and territory governments (COAG, 2011). The National Plan aims to reduce violence by improving the way that governments work together, increasing support available to women and children, and creating innovative and targeted change. Delivered through four 3-year action plans (COAG 2012; DSS 2013, 2016, 2019), indicators have been set to measure change around prevalence, women's feelings of safety in communities, deaths due to DFV and sexual assault, and proportion of children exposed to DFV. There has been limited recognition of the particular circumstances or heightened experience of violence for women with disability and their children in the National Plan and its action plans. National priority three of the Fourth Action Plan applies an intersectional lens to lived experience of women and children affected by violence, calling for services to learn from the diverse lived experiences of victims and survivors, and “prioritise[s] the needs and voices of victims and survivors, show[s] an understanding of different experiences of trauma, [and] take[s] into account the needs and experiences of different cultures” (DSS 2019, p. 26).

The *National Framework for Protecting Australia's Children* (Council of Australian Governments, 2009) sets out six key outcomes and expectations for how the Commonwealth, state and territory governments and non-government organisations will work together to protect Australia's children.

The six supporting outcomes are (DSS 2009, p. 11):

- children live in safe and supportive families and communities
- children and families access adequate support to promote safety and intervene early

- risk factors for child abuse and neglect are addressed
- children who have been abused or neglected receive the support and care they need for their safety and wellbeing
- Indigenous children are supported and safe in their families and communities
- child sexual abuse and exploitation is prevented and survivors receive adequate support.

The framework takes limited account of the particular safety needs of children with disability, presenting disability in parents and children as a risk factor for abuse. However, there is increasing recognition of the needs of both of these groups over time, and the Integrated Prevention and Response to Violence, Abuse and Neglect (IPARVAN) framework (NSW Ministry of Health, 2019b) (see “New South Wales”, below) reflects a substantial and welcome evolution of thinking about disability and situational vulnerability.

## New South Wales

States and territories carry a considerable responsibility for the development and implementation of policy that activates support for women and children who experience DFV. Given the focus of the research at sites within NSW, we focus here on the NSW policy environment.

In NSW, DFV and child protection are priorities across a number of policy areas and sectors, and at the level of central social priorities set by the NSW Premier. These represent a high level of policy visibility and focus for these areas. There are differences in emphasis between the initiatives on early intervention and prevention on the one hand, and crisis responses and tertiary interventions on the other.

The *NSW Premier’s Priorities*, announced in June 2019, include a focus on DFV and on vulnerable children (Berejiklian, 2019). Both of these relate to tertiary interventions, specifically the recurrence or continuity of harms. The target for DFV is a reduction in the number of domestic violence reoffenders by 25 per cent by 2023; the targets for “keeping children safe” are to decrease the proportion of children and young people re-reported at risk of significant harm by 20 per cent by 2023, and double the number of children in safe and permanent

homes by 2023 for children in, or at risk of entering, out-of-home care (Berejiklian, 2019).

The *NSW Government’s Domestic and Family Violence Prevention and Early Intervention Strategy 2017–2021* (NSW Ministry of Health, 2016, p. 5) has six priority areas, all of which are relevant to women and children with disability:

1. people understand the effects of domestic and family violence on individuals and the community
2. there is a shared awareness and understanding of what constitutes gender-based violence [...]
3. services respond to people’s multiple experiences of violence and discrimination
4. population groups at higher risk of domestic and family violence receive support that fits their needs
5. the system adopts new and innovative ways of working and being effective
6. approaches to prevent and intervene in domestic and family violence are integrated in whole-of-government policy and programs.

Priorities 3–6 have particular salience for the capacity of the service system to recognise and respond to these families. The population groups included in priority 4 are:

Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse communities, people with disability and mental ill-health, people who identify as gay, lesbian, bisexual, transsexual, intersex and queer, children and young people and people living in regional, rural and remote communities. (NSW Ministry of Health, 2016, p. 7)

Their Futures Matter is part of the NSW Government’s response to the 2015 Independent Review of Out of Home Care (the Tune review) (Tune, 2015). This was the first major review since the Wood (2008) Special Commission of Inquiry into Child Protection Services in NSW. The response to that inquiry was *Keep Them Safe*, of which FRS were a part. Like the Wood Special Commission, the Tune review found that fragmentation and service gaps characterised some parts of the service system and that crisis responses rather than early intervention support remained prevalent.

Key findings of the review (Tune, 2015, pp. 12–13) include the following:

- Vulnerable children and families have needs that cross the boundaries of government agencies.
- The shared outcomes approach has not improved the outcomes for children and families with complex needs.
- The system is designed around programs and service models instead of the needs of vulnerable families.
- Access to timely help remains a challenge.
- The system is crisis oriented [...] [a] relatively small proportion of investment is focused on targeting drivers of demand for child protection intervention, including domestic and family violence, drug and alcohol misuse and mental illness.

The “system transformation” component of Their Futures Matter includes four strategic priorities that address early intervention support:

1. The needs of children, young people and families are at the centre of decisions.
2. The needs of children, young people and families will be addressed earlier.
3. Children, young people and families receive the right service at the right time.
4. A responsive and highly skilled workforce for better outcomes. (NSW Government, 2019)

The Violence, Abuse and Neglect (VAN) Redesign Program (NSW Ministry of Health, 2019a) is a NSW Health program designed to enhance the capacity of the public health system to provide 24-hour, trauma-informed and trauma-specific integrated psychosocial, medical and forensic responses to sexual assault, DFV, and child physical abuse and neglect. The *Integrated Prevention and Response to Violence, Abuse and Neglect Framework* (the IPARVAN framework) (NSW Ministry of Health, 2019b) is a key component of the VAN Redesign Program. The framework outlines the vision, guiding principles, objectives and strategic priorities to strengthen NSW Health response to violence, abuse and neglect. The IPARVAN framework includes people living with disability who have experienced or are at risk of experiencing violence, abuse and neglect, and highlights that “equitable, accessible

and consistent service responses are provided through a broad VAN response as well as through targeted responses to high risk and complex needs”; it also emphasises that services and responses should make “reasonable adjustments to services to meet people’s needs, such as accounting for disability” (NSW Ministry of Health, 2019b, p. 47). However, the extent to which the framework will ensure the provision of “consistent and equitable responses” or the nature of “reasonable adjustments” for people living with disability who have experienced violence, abuse and neglect remains unclear.

The supporting document for the framework, *The Case for Change* (NSW Ministry of Health, 2019c), provides an analysis and summary of the research and clinical literature underpinning the framework. Key principles include:

- a public health approach, which incorporates the social determinants of health and a spectrum of responses from primary prevention to tertiary responses
- trauma-informed and person-centred care
- recognition of the prevalence and impact of co-occurring forms of violence
- recognition of priority population groups (i.e. “particular groups of people and individuals experience multiple challenges that heighten the likelihood, impact or severity of violence”, including children and people with disability)
- integration at the levels of systems, organisations and practice (NSW Ministry of Health, 2019c, p. 23).

The forthcoming evaluation framework is intended to ensure that the framework is accountable in the provision of responses. Additional key resources supporting the framework are those developed from a 2019 research project, which was conducted in response to the need to improve “understandings of violence, abuse and neglect and to dispel widespread myths, mistakes and misinformation concerning them” (Costello & Backhouse, 2019, p. 8). In identifying priority populations, the framework and resources specify intersectionality in describing the heightened risk of violence for some groups, including children and people with disability.

Family Referral Services were established as part of the child protection reforms in response to a special commission of



inquiry into the child protection system in NSW (Wood, 2008). They were a key referral point for the Child Protection Helpline, Child Wellbeing Unit and other mandatory reporters where a child or young person was deemed to be below the threshold of “risk of significant harm” (NSW Health, 2014). FRS have two core functions: client intake and referral with time-limited support; and service system support and systemic advocacy to strengthen coordination and collaboration among local service providers.

FRS are predicated on a holistic assessment approach. The goal of assessment is to develop an understanding of both strengths and needs in the family, and to build a picture of the issues, factors and problems facing the family. The assessment involves exploration of:

- family history and prior experiences, including crises and traumatic event
- current circumstances and family needs, including family issues, service needs and cultural needs
- protective and risk factors for children and parents/carers.
- families’ capacity to help themselves, that is, utilising their strengths. (NSW Health, 2014, pp. 15–16)

FRS guidelines include a standard about ensuring that FRS are accessible to and inclusive of people with disability. These focus around four areas: liveable communities; employment and financial security; systems and processes; and attitudes and behaviours. There are measures for ensuring that FRS staff are trained and experienced in working with people with disability and have access to specialist support where required; premises are accessible; and recruitment policies support the employment of staff with disability (NSW Health, 2014).

An evaluation of the FRS in Schools initiative (Hall & Wurf, 2016) found that the elements of the program that emphasised inter-disciplinary collaboration were particularly well received by parents and students, and increased the capacity of FRS providers to respond to the needs of at-risk young people.

At the time of writing, FRS are in the process of redesign as part of the Their Futures Matter reform, informed by the

results of the Tune review of the out-of-home care system in NSW (NSW Department of Family and Community Services, 2016). This service network will be called Family Connect and Support (NSW Government, 2018). It aims to prioritise the needs of children, young people and families in prevention and early response to prevent escalation into the statutory child protection system, and strategy documents indicate a prioritising of the needs of vulnerable children aged 0–5 and children and young people affected by mental illness (NSW Government, 2019).

## Disability policy context

The current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2019–2022) is anticipated to have major implications for existing and future disability policy and systems. The commission is inquiring into “all forms of violence against, and abuse, neglect and exploitation of, people with disability, in all settings and contexts” (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020). This is the first large-scale inquiry into violence and abuse of people with disability in domestic and family contexts. There have been two recent parliamentary inquiries into abuse of people with disability (Community Affairs Reference Committee, 2015; Family and Community Development Committee, 2016), focusing on disability services.

The National Disability Strategy 2010–2020 was developed to guide national response to Australia’s ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The strategy involved six key improvement areas:

- inclusive and accessible communities
- rights protection, justice and legislation
- economic security
- personal and community support
- learning and skills
- health and wellbeing.

Responsibility for ensuring access to mainstream services, programs and activities for people with disabilities is a shared

responsibility between the National Disability Insurance Agency (NDIA) and Commonwealth, state and territory government services (Council of Australian Governments, 2015; National Disability Insurance Scheme [NDIS], 2018).

Commonwealth, state, territory and local governments are working together to develop a new National Disability Strategy for beyond 2020, which is when the current strategy finishes. It is anticipated that the way the new strategy will interact with mainstream agreements, the NDIS, the National Disability Agreement and the UNCRPD will be a significant focus of the strategy. Consultations and Productivity Commission reports have highlighted the need for future disability policies to better reflect contemporary policy settings and reduce service gaps and lack of availability of supports ("thinning markets"). The consequences include unmet need for advocacy services and community access and inclusion for people with disability (Productivity Commission, 2019) and should be reflected in the revised disability policy frameworks, if the frameworks are to be effective. Concerns are also raised for whether new policy frameworks will contain:

- more effective responses from the criminal justice system to people with disability who have complex needs or heightened vulnerabilities
- crucial synergies between the specialist and mainstream violence prevention sectors. (Productivity Commission, 2019, pp. 65–66)

The NDIS is the primary mechanism for funding disability support and establishing grant-driven activity to drive the promotion of community inclusion. The NDIS is a significant change in disability policy in Australia, ending the block-funding of disability services and replacing it with a

personalized service model, in which packages of funding from a single pool are allocated to eligible individuals, according to their level of need and self-defined goals, to purchase services and support. (Olney & Dickinson, 2019, p. 276)

A series of operational guidelines direct key elements of the NDIS, such as access, planning, decision-making and types of support (National Disability Insurance Agency, 2020). If the NDIS is to be successful, people with disabilities will need

to have access to both specialist and mainstream services (Olney & Dickinson, 2019).

The Information, Linkages and Capacity Building (ILC) stream of the NDIS aims to create connections between people with disability and their communities by funding community organisations to deliver projects in communities across four streams: national information; building individual capacity; economic and community participation; and mainstream capacity building. The ILC is the NDIS funding mechanism to build capacity in mainstream organisations to better support people in many life domains, including with violence and abuse (NDIS, 2019).

The NDIS Quality and Safeguards Commission was set up independently of the NDIS. It was established to monitor and improve the safety and quality of supports and services provided to people who use the NDIS. The commission regulates NDIS providers and aims to provide national consistency, promote quality and safety in services, resolve problems and identify areas for quality improvement (National Disability Insurance Scheme Quality and Safeguards Commission, 2019).

Current national initiatives that are intended to support the implementation of disability policies include:

- *Zero Tolerance: Focus on Rights, Target Abuse* (National Disability Services, 2018), which is designed to “empower people with disability” through understanding “behaviours of concern” and recognising service features that may increase risk for specific groups at increased risk of abuse by building “targeted intervention and prevention approaches for groups at increased risk of abuse” (National Disability Services, 2018). The impact of this initiative has yet to be evaluated.
- 1800 RESPECT, the national sexual assault, domestic and family violence counselling service, in collaboration with Women with Disabilities Australia and Medibank Health Services, led a 6-month project to explore how to best improve service responses to women with disability experiencing DFV. The project engaged 100 women and girls with disability to actively contribute to the research through a range of active research participation strategies (Frohman & Ricci, 2016). The report resulted in 43 recommendations, the impact of which are yet to be evaluated.



## New South Wales

The *Disability Inclusion Act 2014* (NSW) has two main functions. It commits the NSW Government to making communities in NSW more accessible and inclusive for people with disability. It also regulates specialist disability supports and services and safeguards for these services, and provides guidance for the change to the NDIS. The commitments in the Act about inclusion and access continue beyond transition into the NDIS.

Disability inclusion action plans are required by all local councils under the Act. These plans are intended to improve access to local services, facilities and jobs for people with disability, and to change perceptions about people with disability. Councils must report on progress against the plan annually, and review the plan every four years (Local Government NSW, 2020).

The Ageing and Disability Commission of NSW is a new body that aims to “work closely with other government and non-government services to better protect older people and adults with disability from abuse, neglect and exploitation from someone they know” (NSW Government, 2019a). The commission meets a gap in investigation and response to violence, abuse and neglect of people with disability outside of formal services. Its remit is to “step in where no other complaint or investigative body can in NSW, by looking in to and investigating cases of abuse, neglect and exploitation of older people and adults with disability”, focusing on abuse by familial and informal supports and community members (NSW Government, 2019a). In addition to investigatory roles, it also has a community awareness-raising role about abuse prevention and a role to government on systemic issues.

## Reflections for policy, practice and research

One of the critical findings of the review into effective programs and promising approaches is that the historically time-limited nature of funding and fragmented approach to service design and delivery has meant that the needs of women and children with disability are not well met. Local programs and initiatives have been established at specific times in response to need, advocacy and funding availability, and have resulted in gaps

in adequate and appropriate supports/services at different periods of time and in different locations. Funding at the local level, in addition to larger funding initiatives at the state and federal levels, has offered opportunities for (mostly) small-scale programs and evaluations. With successful cross-sector collaboration and partnerships, these programs have proven successful, although are often demonstrated through anecdotal evidence rather than rigorous evaluations. While local programs can be effective because they can respond to the specific needs of their communities, overarching strategies at the national and state levels are needed to ensure there is a baseline level of support for all women, and better opportunities for communication and collaboration across services and jurisdictions. Services themselves would also benefit from learning from each other about effective service delivery models.

The field would benefit from further research into the effectiveness of programs and models for women and children with disability (however, Dyson et al. [2017] appear to have addressed this gap to some extent).

While there has been some recent attention to promoting the perspectives of women with disability in research about family violence, this review highlights the absence of children and young people with disability in this area. While needing a careful approach, their ideas and priorities for safer lives are much needed. A small amount of work has been done in this space with children generally (NSW Advocate for Children and Young People, 2017) and children with disability (Robinson, 2016). Children with disability are almost completely absent as a target group for support in family violence initiatives. However, Royal Commissions and other sources have consistently identified needs and service gaps, and policies and programs are increasingly recognising that different groups of people have different needs, that some groups are at higher risk than others and that in many cases integrated responses are necessary to provide effective support (see e.g. Robinson, 2016).

As Breckenridge, Rees, valentine and Murray (2016) have noted in the context of integrated services for DFV more broadly, relatively few of these programs are subject to sustained evaluation. This information can be critical when

decisions are being made, at the local or national level, to extend program funding for longer periods of time, to more locations, or to expand the scope of the target groups. Further systematic research and evaluation is required to understand if/how/to what extent the good practice models identified through this review can be extended or expanded to provide more consistent and ongoing support for families with disability experiencing or at risk of DFV. Considering the overwhelming support for cross-sector collaboration and partnership in this field of service delivery, further research could be undertaken with service providers and program staff identified through this review and projects.

These findings are significant in the current policy context. The National Disability Agreement, the National Disability Strategy 2010–2020, the National Standards for Disability Services and the NDIS all form part of Australia’s federal disability strategy working to reinforce a national commitment to ensuring the rights of all people with disability are protected under the UNCRPD (United Nations, 2006). The *National Plan to Reduce Violence against Women and their Children 2010–2022*, the National Framework for Protecting Australia’s Children and all state policy instruments are designed to enable rights to safety and freedoms and protections against abuse and violence.

A criticism of the existing design across all federal and state policy instruments is that they do not effectively account for the multiple intersections across both specialist and mainstream service sectors required to respond holistically to the needs and safety of people with disability. A consistent plan to recognise key intersections between mainstream and specialist disability, family cohesion and restoration services, and child protection services is lacking. Women and children with disability are included in both federal and state policy instruments. What is often omitted from these statutes are strategies and approaches that intersect across multiple federal and state jurisdictions built on foundations of continuous consultations and collaborations with families with disability.

# Methodology

## Aim

This project aimed to provide new knowledge on the impact of early intervention violence prevention support, with a specific focus on the experiences and voices of women and children with disability.

The project methodology was designed to build knowledge at multiple levels:

- at a local practice level: to identify promising and effective practices in service delivery, disseminate information on these to a practice, policy and research audience, and contextualise those practices in relation to the established evidence base
- at a programmatic and policy level: to provide new knowledge on the circumstances in which women with disability, and women who are the mothers of children with disability, seek and are provided with effective support
- at a conceptual level: to advance understandings of the nature and prevention of violence experienced by women and children with disability, and the circumstances in which safer environments can be facilitated.

## Research questions

To achieve this aim, the research questions were:

1. What are the characteristics of programs and services that provide effective support to families with multiple, intersecting support needs related to violence prevention and disability?
2. How do mothers with disability understand and experience their interactions with family support services? What do they view as facilitators and barriers to support from services?
3. How do children with disability (8–18 years) understand and experience their interactions with family support services? What do they view as facilitators and barriers to support from services?
4. How and under what circumstances do Family Referral Services (FRS) provide support to families who are at risk of domestic and family violence when either or both mother and child/ren have disability?
5. How do FRS respond to the needs of families with children and/or mothers with disability? What supports client-centred, timely responses, and what constrains them?

## Theoretical framework

The purpose of the research was to better understand the myriad of intra-social intersections women and children with disability face when engaging with specialist and mainstream family support services. To do this, the project applied intersectionality theory and inclusive disability research approaches to address the various ways in which gender and disability intersect with other forms of difference to influence and compound discrimination in the lives of women and children.

Intersectionality theory has generated a broad field of study into the forms of inequality and differences among women (Cho, Crenshaw, & McCall, 2013). Originating in analysis of the discrimination experienced by African American women formed by the intersections of race and gender (Crenshaw, 1991), intersectionality theory provides a means of analysing the interacting effects of those aspects of identity that constitute, and are constituted by, social relationships of power and oppression. Those which are especially salient for this project include disability, gender, age, geographic location and Indigeneity. Importantly, the lived experience of intersectionality is not as the sum of multiple types of oppression, but as the effect of the simultaneous experience of them. Intersectionality describes living on multiple axes of oppression simultaneously (Shaw, Chan & McMahan, 2012; Stubbs, 2015). It has been argued that women with disability have been less well served than others by intersectionality theory because disability, and its manifestations, has not tended to be considered by scholars of intersectionality (Shaw et al., 2012). However, there is an emerging body of research on disability that makes use of and extends intersectionality (Kayess, Sands & Fisher, 2014; Thill, 2019).

Crenshaw's (1991) argument that categories of social identity and difference are relevant to intersectionality theory when they are also axes of oppression is a productive analytic lens for researching the experience of women and children

with disability, because people with disability also face discrimination, disadvantage and exclusion because of their disability. Women and children with disability facing violence may also be members of historically oppressed groups—such as being from an Aboriginal or Torres Strait Islander or culturally and linguistically diverse background, being young, being part of lesbian, gay, bisexual, transgender or intersex communities, and/or living in a regional, rural or remote community. The specific dimensions of experience that are of particular interest to this project are disability, gender, age, geographic location and Indigeneity.

The project began from a position of acknowledging and responding to the increased disadvantage experienced by women and children with disability who are at risk of violence. In the context of service delivery, these disadvantages can stem from the limitations and failures of mainstream institutions, such as:

- the capacity of schools and health care services to meet their needs and ensure their safety
- the workforce capacity of mainstream organisations to support people with disability
- the workforce capacity of disability organisations to identify and respond to DFV
- inappropriate responses from child protection agencies
- organisational constraints related to funding, service models and overall service system capacity.

These disadvantages may have particular salience and, indeed, may be heightened in Aboriginal and Torres Strait Islander communities. This is due to many complex factors, including low levels of cultural competence within organisations, and higher levels of socio-economic disadvantage faced in Aboriginal and Torres Strait Islander communities.

Furthermore, previous research has demonstrated that developing a sense of place, sustaining a secure sense of personal identity and maintaining personal relationships in regional and rural areas can be difficult for many people (Leyshon, 2008; Pretty, Rapley & Bramston, 2002). The relationships between identity, place and support from service systems are of keen interest in this project. Cloke (2006) points to ways in which conceptions of rurality are changing—particularly due to an increasing blurring between

the urban and rural in geographic and economic terms. Sense of place has a particular resonance and cultural weight for Aboriginal and Torres Strait Islander communities.

The project also acknowledges, and is designed to include as a focus of analysis, the importance of the social positions of children, especially children with disability. Drawing from scholarship on the sociology of childhood, the particular perspectives and circumstances of children and young people are recognised and addressed in the project. In responding to children as having preferences, needs and priorities that may or may not align with those of their mothers, and which respect children as expert informants on their own lives, the research addresses a gap in knowledge about the views of children with disability about DFV, and their experiences of it (James, Jenks, & Prout, 1998).

Poorly recognised in current policy approaches, the perspectives of children with disability are particularly urgently needed to inform the implementation of the National Framework for Protecting Australia's Children 2009–2020 (Council of Australian Governments, 2009), where they feature little and are primarily described in terms of risk factors increasing vulnerability to DFV.

The second framework informing the study is inclusive disability research. Inclusive disability research originated in multiple theoretical bases arising from the self-advocacy movement, and approaches that recognise the structural and social barriers that impede inclusion for people with disability (Barnes & Mercer, 2004; Nind & Vinha, 2014; Robinson, Fisher & Strike, 2014). Inclusive, collaborative research privileges the voices of people with lived experience of disability, in alignment with the phrase, “nothing about us, without us” (Atkinson & Walmsley, 2010). Applying inclusive, participatory approaches in collecting and analysing qualitative data in this research was significant in ensuring the research team practised ongoing reflection, ceding autonomy to those who have lived experience of disability and DFV, and aligning with professional supporters. Collaborating alongside women and children with disability and practitioners provided opportunity for self-reflection and a more equal distribution of control over the research narrative. The following section describes our approach.

## Research design

The research design applied knowledge from disability studies and children's studies to the *National Plan to Reduce Violence against Women and their Children 2010–2022* (COAG, 2011). It contributed to knowledge on disability as a phenomenon of systems, structures and communities, moving beyond a deficit model that constructs disability as a risk factor in parents and children.

## Co-production

In keeping with the principles of inclusive research, we spoke with some of the women involved in a previous project on a related topic of the experiences of tertiary violence services of women with disability (Dyson et al., 2017) to get advice about our research idea prior to seeking funding. During the early research design stage, a new advisory group of four women with disability was formed. The four women who met during the course of the project provided expert perspectives on a series of issues about project design, recruitment, emerging results and implications. We recruited mothers with complex and extensive experience across multiple domains of DFV and disability and mothers with experience of cognitive disability. We were somewhat surprised that we were only able to recruit one mother with children with disability who was not herself a woman with disability to the advisory group.

The women's group met on a semi-regular basis, according to their availability and the key project milestones. As the group was geographically dispersed, we only met altogether—with every member present in person or via phone and Skype—on one occasion. The other six meetings were a mixture of individual and small group catch-ups, according to preference and availability of the women. A plan was developed with the group at the outset of the project to frame their involvement for the life of the project, aiming for eight meetings. They provided advice about designing the project so that it would be inviting and comfortable for women and children, and specific advice on interview methods and questions (and on adapting these after we piloted them), and contributed to analytical discussion on emerging themes and what they might mean. Their role continues as the project moves into the knowledge translation phase, and they will provide

advice and be involved in designing resources to share the key information in accessible ways. We hope to involve members of the group in knowledge exchange seminars or other face-to-face activities.

In addition to this ongoing advice from women, several opportunities were taken to consult with FRS managers in the four sites about ways to strengthen methods and materials. This advice was used to strengthen the quality and relevance of the interview schedules for families, workers and policymakers, and adapted approaches for mothers and children.

As the research reached the final stages, key stakeholders working in DFV early intervention initiatives nationally (identified in the State of knowledge review) were invited to a national workshop in October 2019. The workshop enabled the research team to communicate findings in workshop style. Emerging results were presented in the workshop to inform principle development. Implications for the NDIS and other related policy and practice areas were emphasised in the feedback from stakeholders (schools, health, early childhood, child protection, DFV services). Policy and practice professionals, as well as those with lived experience of disability and DFV prevention programs, provided expert critical reflection and contextualised the findings in terms of their own programs or situations. This advice, and that provided by the women with disability who acted as project advisors, has been drawn into this report, informing the conclusions and implications for policy and improving practice.

## Information, consent and interview design

An advertisement inviting participation in the project (Appendix A), comprehensive information and consent forms with easy-English alternatives for mothers and children (Appendices B, C, D and E) and a schedule of interview questions and supplementary questions (Appendices F, G, H, I and J) were designed to support consent for mothers and children. These provided key details on the purpose and aims of the research; its contribution to the wider examination of early intervention and prevention of DFV services for all individuals and families; key details on how the research was to be conducted; an overall structure of how the interviews would be conducted; and the format of the interviews.



The interview sets for mothers and children were planned as a two-step process during one interaction with the researchers:

1. The first step was a joint interview between mother and child/ren. This initial phase of the interview was instrumental in setting up the layout of important sites and relationships to refer back to in the following phase. Conversation in the first interview was supported by visual or conceptual “mapping” of the family and their perceived positioning within their community and connections to supports and services.
2. Individual interviews for mothers and children comprised the second step. These were designed to enable mothers and children to reflect more critically about the supports they received (or did not receive) in a safe and private space and allow for follow-up on comments that may have been raised in the joint interview. The second phase also enabled researchers to reinforce rapport and understanding.

The joint interview schedule (Appendix F) included general framing questions, focused on finding out about the general circumstances of the families, their connections to formal and informal support networks, and the kinds of assistance they were seeking from FRS.

In the second phase of the interview sets, separate interviews were offered to mothers and children. Questions used to frame conversations for mothers (Appendix G) focused on the experience of using the support services; how families felt about changes in their lives; their views on help-seeking and safety; and advice to other families in similar circumstances. The children and young people’s interview contained simpler questions in related domains (Appendix H). These focused on care in relationships; children’s level of knowledge about FRS; their ideas about what might be helpful for their family; and ideas about what might be helpful for their own sense of safety and wellbeing.

There was a considerable amount of flexibility applied to the approach to interviewing participants as the research team responded to the circumstances and preferences of participants. Alternative and accessible methods were offered to mothers and children in the joint and individual interviews, including pictorial mapping, walk-along interviews, game-

based methods and symbolic communication to support narratives. Pictorial mapping was a key part of the interviews with all participants, offering an easily tailored way for the researchers to “unpack” the relationships, use of services and priorities.

This team has used these methods in several studies with young people and adults with a wide range of support needs and personal preferences, and found pictorial mapping in particular very helpful for people who find it hard to express themselves in detail through words. It encourages the use of drawing, symbols and connecting between people and places (Robinson et al., 2014; Robinson, Graham, Fisher & Hill, 2018). Walk-along (or go-along) interviews were used with a small number of children, who preferred not to sit at a table and talk formally (Castrolade, 2018). Other worksheet-based activities were included in the final composition of resources to provide scaffolded ways for participants to discuss feelings and ideas (Triesman, 2017), although in the end these were not used beyond activities to keep children entertained.

A sensory box for both adults and children was also used as an optional means for young people or adults to feel grounded and engaged in a soothing or sensory activity while engaging with the researcher/s. For children, the boxes included sensory toys, activity cards, easy games and nice-to-touch objects such as large, smooth pebbles and play dough. The boxes for mothers included hand creams, nail polish, nice smelling objects and nice-to-touch objects similar to those in the children’s boxes. Children’s boxes were very popular, mother’s boxes less so. Selections of specific activities were made based on what might prove most helpful in helping a young person or adult comprehend the question asked of them and assist them in illustrating their experiences. Participants (mothers and children) were offered \$30 gift vouchers to thank them for their time and contributions.

Interviews with FRS providers (Appendix I) were designed to capture the services provided and service providers’ perspectives on how disability in mothers and children is recognised and responded to, along with ideas about positive practice and ideas for improvement. Interviews with other stakeholders, such as related service providers and policymakers (Appendix J), focused on key issues affecting

the capacity of early intervention services to support families where disability is present and views on what underpins effective practice.

## Adaptations to design

The project design and methodology were adapted to reflect the advice from the women's advisory group and the FRS teams. These adaptations reflected the practical constraints of conducting empirical qualitative research with community-based organisations and families with disability, and also have ongoing implications for identifying and supporting families with disability. In particular, FRS work with many families who are struggling with effects of impairment, and who do not have a diagnosis and do not identify as having disability. Some FRS staff did not feel confident in talking with families about disability, which was a constraint on recruitment.

Field materials were distributed for comment via the women's advisory group. The advisory group members were invited to carefully scrutinise the information and consent forms, the interview schedule and the therapeutic interviewing materials. The research team explained to the group the purpose of each component and how it would be used with mothers and children with disability. The research team asked the group members to consider their personal impressions of the resources and whether they considered them suitably relatable and balanced in terms of being comprehensive in nature without being too convoluted.

Following feedback from the women's group and FRS providers, language was simplified and more flexibility to the schedules was added so that children could more clearly be encouraged to complete interviews with or without their mothers, according to the comfort of the pair.

Following guidance from the women's advisory group, advice from FRS program management was fielded. Program managers reviewed the field materials to support recruitment efforts. The research team redesigned the project flyer to accompany research recruitment material that moved the emphasis from language about disability to an invitation to a conversation if:

- you receive support from an organisation that helps families to find the support that they need (like FRS)
- you needed extra support for your family at a time when life was quite hard
- your or your child have a disability or additional stresses that make it hard to manage sometimes.

These adjustments reassured the providers who had concerns about speaking with potential participants, and so assisted with recruitment (see Appendix A).

## Recruitment

The four FRS sites were recruited to the research prior to the awarding of funding. Through the state FRS convening body, an expression of interest was sought from all FRS providers to be involved in the study. Of the seven organisations funded to provide FRS in New South Wales, four volunteered to be involved.

Prior to engaging research sites for participant recruitment, the research team undertook an independent online desktop review of each of the four research sites. Desktop reviews were carried out to ensure all researchers were familiar with the structural composition of each research site. The reviews for each site contained the following information: FRS services provided by the organisation, the geographic area they provide services within, strategic priorities, any significant reference to how they support people and families with disability, and a wider service context in which the provider operates (to give the research team a sense of how they may be able to cross-refer women and children who have additional support needs).

In keeping with conditions of ethical conduct, researchers were removed from all direct recruitment decisions. Researchers agreed with program managers on a recruitment approach. Researchers requested each of the four FRS sites to invite five women and five children to participate. Participant eligibility was broad, involving mothers who had used FRS within the past 18 months, self-identified as having disability (either through intake or caseworker knowledge) and who have any range of impairment or disability type; neither mothers nor children needed to be eligible for any

disability-related assistance programs or payments (e.g. the NDIS or the Disability Support Pension). Children and young people were identified as 8–19 years of age (the original age range was 8–18 but the sample contains one 19-year-old, included because they were present at the family interview and volunteered for interview). Children of mothers who self-identify as having a disability were eligible for inclusion in the study regardless of whether or not they themselves had a disability. All children who participated in interviews were children with disability. Participant selection was determined by a caseworker’s ability to discern who was both eligible and interested in participating. Researchers agreed to contact caseworkers within the FRS program. FRS caseworkers would reach out to families within their caseloads. Families were able to choose either to provide their contact details via caseworkers for the researchers to call them, or to call the researchers themselves.

Principal communication regarding recruitment remained between the research team and program managers. Program managers communicated recruitment specifications to FRS workers who selected individuals whom they believed would be interested and willing to participate. Each of the FRS services discussed this at team meetings. Recruitment for participants in the four research sites began in August 2018. In each research site, the program manager and caseworkers were consulted as a group or individually. During the initial consultation, managers and caseworkers were introduced to the research project. Researchers presented an overview of the project aims, and specific inclusion criteria relating to who researchers were interested in talking to, and how they as caseworkers could help facilitate participant recruitment.

The initial phone call between researchers and mothers was used for screening purposes, as well as to set up the interviews, check women’s consent, talk through implications of involving children in the interviews, and arrange a time to meet. Several women decided not to proceed with children’s interviews based on this conversation, feeling that their children either had little to contribute about FRS or that the subject of safety would be too confronting, especially in cases where there were recent experiences of family violence.

Recruitment of senior officers to interviews about policy and practice implications of the FRS program was developed following the policy review. Following analysis of the policy map, senior managers in the FRS program, relevant senior officers in New South Wales and federal DFV and disability policy jurisdictions, and related senior practitioners were approached for individual or small group interviews. After the senior managers were approached for interview, recruitment of individuals who could represent views of the major policy jurisdictions (with oversight of the key areas identified in the policy review) was arranged by their organisations.

## Sample

Interviews were conducted with a range of people with expertise about early intervention violence prevention, including women and children with disability; FRS workers and managers; stakeholders in allied organisations working in violence prevention; and policy and government representatives in state and federal DFV and disability jurisdictions. Interviews were conducted between November 2018 and September 2019.

Participants were located across metropolitan and regional locations in New South Wales. Women and children were connected to service sites located in one metropolitan and two regional areas.

In total, 27 mothers were interviewed. While no mothers were asked about their specific diagnosis or impairment type, 15 of the 27 participants reflected on their experiences of disability—often complex experiences that intersected with trauma, including anxiety, depression and post-traumatic stress disorder. Some spoke of having multiple disabilities. Ten of the 27 families were from urban locations, and the remaining 17 lived in regional towns and outlying areas.

Children with disability were present in 23 of the 27 families and, of these, nine families had more than one child with disability. Five of the 27 families identified as Aboriginal and Torres Strait Islander.



**Table 2:** Interview participant sample

Participant group	n=
Mothers	27
Children and young people	7
FRS workers	20
Stakeholders: FRS senior officers group	8
Other service providers	6
Stakeholders: policy	6
<b>Total</b>	<b>74</b>

**Table 3:** Interview type

Participant and interview type	n=
Mother only	22
Child only	2
Joint interview only	3
Child interview following joint	2
Mother interview following joint	2
<b>Total</b>	<b>31</b>

Seven children and young people participated in interviews. Of those interviewed, children and young people's ages ranged from 8–19 years, with a mean age of 13.4 years. All had a diagnosed disability, and all but one had multiple disabilities. Most had disabilities related to autism, attention and trauma. Five of the children participated in a joint interview with their mother, and two also completed individual interviews afterwards. The remaining two young people preferred to be interviewed independently.

Individual and small group interviews were conducted with FRS providers in each of the four sites, based on the preferences of the providers. Numbers interviewed in each site ranged between four and seven workers. Interviews focused on the experiences of FRS providers in supporting women and children with disability, constraints and facilitators to effective support, training and development needs, and any changes needed to support improved practice (e.g. rules governing the use of brokerage funding, information sharing, referral and screening instruments).

Interviews with FRS managers were conducted separately and focused on the role of mainstream and early intervention systems in identifying and responding to women and children

at risk of harm; cooperative and collaborative practices within the local service system; and local innovative practices in response to need.

Interviews with New South Wales and federal policy and service stakeholders, including health, DFV, child protection, social work, early childhood, community service, education support in school and disability services, were conducted by telephone. These focused on the strengths and challenges of the FRS service model and early intervention services more broadly, innovative practices in building integrated services, and reflections on the circumstances in which trust and respect between services, and between services and clients, can be built.

## Data analysis

Coding of interviews collected from participant interviews began as soon as there was an adequate data set to begin code generation. A coding framework was developed and the interviews coded using NVIVO research software. Data was initially coded according to the research questions and sub-questions, and then sub-coded according to the inductive themes emerging from the priorities of the

participants. Themes emerging from participants' responses to the interview questions were progressively built into the analytical framework, and these were cross-analysed between members of the research team and discussed as a group as the data built (Frauenberger, Good, Fitzpatrick, & Iverson, 2014; Richards & Morse, 2013).

## Ethical considerations

Ethics approval for the research was obtained through the human research ethics committee at one of the participating organisations. Secondary approvals were obtained through the participating universities, UNSW Sydney and Southern Cross University (SCU).

A risk of harm or discomfort for participants was present in this project due to the topic of the research. Working with children and young people with disability who have experienced trauma also presented potential risks (National Health and Medical Research Council, 2018). Although the topic and content of interviews and focus groups focused on service use and preferences for support, rather than on abuse, there was a risk of psychological distress or other harm to people with disability, which may have arisen for those who raised experiences of abuse, fear or lack of safety, as well as broader experiences of social isolation or loneliness. This risk and discomfort was approached by researchers establishing a base of rapport and understanding between them and the participant, and reassuring them that the nature of the research was focused on their experience of receiving supports from FRS and not on the causes or influences that led them to seeking their support.

A set of guidelines was established as part of the ethical framework for the research to guide researchers' interactions with research participants in the event they experienced distress or disclosed potential harm, and to provide fieldworkers with referral and support information if needed. Careful attention was paid to physical or verbal cues exhibited by participants, with attempts to pre-empt potential discomfort by diverting to a different question or checking in with how they were feeling. No situations of discomfort or distress with children arose. One mother withdrew from the study after finding speaking about the issues distressing. On following the established

guidelines for supporting her at the time and in the following days, it did not appear that participating in the initial part of the research interview caused lasting distress to her. These guidelines included ceasing the interview, reassuring the mother, advising the FRS support worker (with the mother's consent) so she could receive follow-up support, and follow-up by a senior member of the research team.

The research team was experienced in conducting research of this nature with this participant group and understood how to develop and implement methods that minimise risk of harm, such as a trauma-informed approach to interviewing. This approach is situated in a context of trauma-awareness (e.g. that trauma generates extreme sensitivity to sensory overload; that trauma responses are involuntary and can be seen in behaviour, emotions or disengagement; and that triggers are individual), and the consequent need to establish interview processes that emphasise safety, trustworthiness, choice, collaboration and empowerment (Keesler, 2014; Lambert, Gill-Emerson, Horan, & Naughton, 2017). This is scaffolded by training interviewers so that they can recognise and respond to a person's trauma effectively in a research context and provide appropriate support and follow up. The risk of distress to participants was addressed through both the employment of very experienced researchers, and through the development of a protocol for disclosures of harms that have not been addressed in the lives of people with disability. This includes guidance for researchers and facilitators on responding to harms at a range of levels, reporting criminal conduct and allegations of abuse, and providing accurate and targeted referral for people who need ongoing support.

The capacity of participants with cognitive disability to participate in the research in each location was also a risk. This was mitigated by the methodology, which provided ample support to people when they needed or wanted it. For example, the fieldwork with all participants began with a mapping exercise that helped the researchers establish whether mother or child might be receptive to being offered some of the research tools developed for the project, which were easily adaptable to suit people with a diverse range of cognitive ability (see "Information, consent and interview design" above). Using qualitative, narrative-rich methodologies and robust tools supported the informed participation of people

with disability, along with ensuring multiple opportunities to withdraw consent.

Care has been taken to anonymise the contributions of participants in the research. Family members either chose (or were allocated if they preferred not to choose) the pseudonyms used in the report. Employees of the agencies are referred to by their roles rather than pseudonyms, to minimise the risks of identifiability, given several organisations have small numbers of staff and the limited number of men in the total sample.

## Limitations

Several challenges were experienced around recruitment. Recruitment to the study was conducted through FRS providers and relied on their skill in identifying disability in their client group and approaching women and inviting them into the research. It was difficult for providers in all of the sites to identify the number of women requested for interview, and it took several months for all of the sites to be able to recruit, even with good will and clear effort. The research team had not anticipated that a significant minority of FRS workers would have difficulty in identifying people with disability and, further, would be uncomfortable in speaking with potential participants about the subject of disability. Despite conversations about our broad and non-diagnostic approach to disability, several FRS workers remained very uncomfortable about approaching women to participate in the project. One of the four sites withdrew as a result of this discomfort. Recruitment of a replacement site caused delays to fieldwork, but the process revealed knowledge about practitioner attitudes and levels of skill in having conversations they deemed uncomfortable that were important for the research.

A second site faced specific challenges in recruiting mothers relating to their previous negative experiences of participating in research, the remote location of mothers from the service base, and the fact that some families were not very willingly engaged with the service. Despite extensive effort, no participants were able to be recruited at this site. The complexity of issues affecting FRS in this area was captured

by adding additional stakeholder interviews. It is part of the limitations of this study that those who may have had negative experiences with FRS may be under-represented.

Fewer children were recruited to the study than we had hoped. As the fieldwork progressed, it became clear that there were several reasons for this. Mothers were protective of their children, and several declined the invitation for the child/ren to participate, particularly those with recent traumatic experiences of DFV. FRS worked frequently with mothers while children were at school, and in many cases, children had little knowledge of what the service had provided to the family. Finally, in several families, the children were too young to be involved in the study. We had initially hoped to interview up to 20 children, and expected between 12–15 children and young people as a realistic sample. In Table 2, the participant sample shows that seven children and young people participated in interviews. However, the experiences of a further 30 children and young people with disability were represented in the research less directly through interviews with mothers.

# Key findings

## Perspectives and priorities of children and mothers about living with disability

This section discusses how children and young people and their mothers talked about the good and difficult things in their lives and how getting help when they needed it, or not, affected their lives.

### Children and young people's perspectives and priorities

The children and young people interviewed all talked about the different activities they enjoyed doing, which included soccer, reading, dancing, playing computer games and composing rap music. They also talked about what was most important to them. Family, friends and pets mattered, and family were fundamental in helping young people feel safe.

The young people were also engaged with a range of formal and informal services:

- camps and youth activity groups
- counselling, speech therapy and occupational therapy
- education and (for older young people) employment services
- disability-specific services such as respite and support to take the young person on outings.

Children and young people with disability often face abuse and exclusion at school, and other infringements of their right to participate and belong (Flynn & McGregor 2017; Robinson, 2018). Participants in this study talked about positive things in their lives, which included family peer relationships and activities; and negative experiences, which included bullying, loneliness and effects of impairment.

The interviews were designed to allow participants to talk about or not talk about their experience of disability as they wished. Siblings Caitlin and Aidan framed their disabilities—autism and Attention Deficit Hyperactivity Disorder (ADHD)—as a negative experience, as something they and their mum needed help with and as causing them difficulty in their relationships with peers. They argued over who experienced the greatest

intensity of effects from their disability, evidenced by who was prescribed the most medication:

[Aidan:] I have to go on tablets.

[Caitlin:] You take, like, four tablets a day? I take six tablets a day.

[Aidan:] That's mean. I'm really bad too.

The other young people talked about their experiences in different ways, and they negotiated their disability in relation to their identity differently. Jason identified as a person with additional needs, and Robert as having anxiety. Robert talked about circumstances that are risky for him in terms of feeling distressed (such as riding on the bus when there are other young people on board). He used strategies for managing that risk when he was feeling anxious, and spoke about how being with family and listening to music makes him feel better:

Usually I put on my headphones when I get angry or sad and it makes me feel better. That's why I write to get my emotions out when I do my music. (Robert, young person)

Verity is a young adult currently living at home, whose life is constrained by the limited support that is available to her. She enjoys the company of her support workers, as they facilitate her social engagement and time out of the house, and they make her feel safe, but her time with them is limited:

I've got two workers who take me out and do things with me. Whenever they get a shift with me they're out with me. Most of the time I would be here, which is annoying. I can't say my life is perfect right now. (Verity, young person)

Bella and Oliver, the only participants still in primary school, both spoke positively about school. Bella liked to help her peers at school, and recently received an award for being a good helper.

The following vignette demonstrates the importance of a light touch to navigate the sensitive context of potential DFV so that children sustain a positive view of their family life.

Oliver's family had come into the FRS when he spoke about his home life to adults at school in a way that led them to be concerned about DFV. His mum Rebecca said that she found the initial contact from the FRS worker difficult and embarrassing, as Oliver had been talking about her severe anxiety, not domestic violence. She did, however, see a lot of value in the opportunity to take up support for NDIS information and assistance to improve access to speech therapy for Oliver, which she had been unable to progress for a long time. Rebecca said she really liked that her family were not treated like "clients": "The FRS really seems to care about you. Not everyone treats Oliver like that, with his speech problems."

Oliver didn't see any service engagement. He remembered a lady talking to his mum, but he wasn't sure why she was there. She was nice. When asked what extra help their family might like, Oliver said a dragon so they could all fly would be nice.

By contrast, most of the teenagers interviewed had negative experiences at school. Robert and Verity, who are both no longer in school, talked about not enjoying school because of difficulties with peer relationships. Verity was, and continues to be, bullied, and was struggling to manage it, and Robert was frequently suspended for fighting and damaging school property. Caitlin and Aidan found school hard socially and academically, after having to change schools when they spent some time in out-of-home care.

Jason also struggled through high school and says he did not have any friends at school. Jason was also not supported sufficiently in the classroom, which meant his difficulties with writing were not addressed. More recently, FRS linked him in with a program to subsidise a laptop so he can more easily complete work at school, and he is now working with a school learning support officer and completing some of his schooling through distance education.

Apart from Jason, children and young people did not talk about receiving support directly from FRS. Some of the children spoke about FRS as helping their mothers, and saw it as a general support to their family. In this way, the experiences of the children and young people with FRS and other support services were generally positive. However, they did not perceive that their involvement with FRS had an impact on the things that were most important to them as young people, such as social engagement, friendship and positive experiences in schools and other everyday spaces.

## Mothers' perspectives and priorities

The mothers in the research had diverse life experiences:

- The number of children mothers had ranged from one to eight, though in some instances children were not living with their mother, or were adult children.
- Several were studying, and a few were employed or undertaking volunteer work.
- Informal supports from family (mostly parents and adult children), neighbours and a few close friends were the main sources of support for many families.

They talked about activities that they enjoy and made them feel good about themselves:

- family, and keeping their children safe and happy (most important)
- gardening, prayer, eating well, counselling, completing TAFE certificates, getting nails done, going to the gym, crocheting and knitting and playing video games.

Families had engaged with a range of services. Most of these services were for children and included speech therapy, occupational therapy, psychologists, paediatricians, playgroups and early childhood services. Others included:

- disability support services
- charity organisations
- non-government organisations and programs, such as Brighter Futures early intervention programs



- government agencies with responsibility for social security and disability payments, housing agencies, and family support and child protection agencies.

### Disability and impairment—Slippery and individual concepts for mothers

The ways that mothers spoke about disability and impairment in their lives is important. Some of these issues—about personal identity and the ways that impairment, disability and policy intersect—are beyond the scope of this project. They are fertile ground for further research. However, the ways women viewed disability in their lives also affects their willingness to enter into a range of conversations that directly affect the way that FRS are provided to them and the kinds of supports they can offer. This is of keen interest for this project.

As with the interviews with children and young people, mothers were invited to talk about their disability (or not, if they preferred). Mothers had a fluid sense of identity as a person with disability. This is not surprising—different systems have different diagnostic or labelling criteria for entry, and so there can be multiple settings where people are or are not considered to have disability (Shakespeare, 2013). Further, the experience of discrimination and stigma can be particularly bruising for women with disability who are in contact with the legal and child protection systems (Breckenridge & Huppert, 2010).

A small number of mothers, in the course of the interviews, talked directly about living with disability. These were mostly women with physical disability or learning disabilities. It was much more common that women spoke about the effects of impairment on their lives (e.g. how anxiety or depression affected them) than their identity as a person with disability. A significant proportion of the women in this study did not openly identify as women with disability, although they were prepared to speak about many issues in the interviews that constituted disabling barriers. We saw the effects of this in the recruitment to the research, where FRS workers did not feel that many women with disability used the services, but readily identified women who they could invite into the study

who needed additional support due to the effects of physical, emotional and psychosocial impairments.

The mothers who spoke about themselves as women with disability to the researchers talked about their engagement with disability services for assistance with household tasks, running errands and budgeting, and about education services from whom they received additional learning support. They stressed the importance of not feeling judged or treated “like a child” and given respect from their support workers. One mother talked about the way she conceptualises disability, and how she uses this frame when interacting with people she may not know very well in different public settings, such as at TAFE:

I always make sure I prove to them I can do stuff ... I'm a person, I've got feelings just like they do. Keep in mind that everybody has some disability in them, even, what I call them, non-disability people, or normal people. They have got a disability in them but in certain ways. Like, mental health, that's part of a disability. (Tanya, mother)

Many of the mothers had psychosocial impairments, related to the trauma they had experienced. They referred to these as complex combinations of anxiety, depression and post-traumatic stress disorder. For some of the women, this was a common experience among their family and friends, and not something they found noteworthy. Others spoke about long journeys towards recovery, working hard and feeling more hopeful about a more positive future for themselves and their children.

I'm struggling with my own demons. I suffer from depression really bad and anxiety, post-traumatic distress. At the moment, I'm just, “Wow”. It's great, because I can come down here and talk to one of the [FRS] workers even though I'm not with them at the moment. I can still come and talk to them when I start feeling like I'm on the edge. (Sharon, mother)

Several mothers identified the importance of managing their own wellbeing in order to keep their families safe. For a number of women, this revolved around recognising the importance of having routines and both initiating and maintaining treatment for their mental health. FRS



support had been a key contributor for a number of women in establishing patterns that helped them feel calmer, more in control of difficult situations and more secure in their parenting (as demonstrated in Sharon's experience, above). For the small number of women who were at risk of having their children removed from their care, this was a stressful, high-stakes issue. For example, one mother who had suffered a terrible loss spoke about how her efforts to maintain a balance could be easily tipped:

When they questioned me about my antidepressants ...

I was like, "Well I'm doing the right thing by me and my children by getting myself help that I need." So I feel like my routines help my sanity and helps the kids as well keep in their happy zone which keeps me happy and safe and keeps them happy and safe. (Chloe, mother)

As the following vignette illustrates, the lives of the mothers were complex, and they were navigating multiple issues simultaneously.

Laura is a woman with multiple disability who has bipolar disorder and uses a wheelchair for mobility. She left a violent relationship a year ago and said she feels happier and safer since the separation. Her teenage daughter, who also has disability, is in her ex-partner's care.

FRS provided support to Laura in finding refuge accommodation, food vouchers and advice on how to keep safe from a violent partner. When the violence was really bad, her FRS support worker gave her advice on seeking a family violence order, and on a few occasions they spoke to Laura's ex-partner on Laura's behalf to ensure her safety:

She'd pick me up and make sure that I had accommodation and that I had food and that I was safe. She kept me away from drugs. She told him to keep his distance and ... and [that she'd] put a [family violence order] out on him if he didn't behave himself. They also spoke to him at different times. (Laura)

FRS helped Laura to find permanent, safe accommodation and wrote letters of support for her rental agreement. Her FRS worker would check in with her daily, reminding her to take her bipolar medication and to see how she was going.

FRS helped her connect with the NDIS and helped her specify the things she needed addressed to live a good life: occupational therapy, art therapy, cleaning service, care workers, taxi and transport, and wheelchair provisions. Laura said she had recently had a request declined under the NDIS for the purchase of a mobility scooter.

Laura said the support she received was faultless and felt the FRS workers "went out of their way" to help. She would have liked it to continue longer so she could access shopping/food vouchers, support for getting an AVO and possibly even support for her ex-partner on how to deal with issues that lead to problematic alcohol and other drugs use, and violent behaviour.

## Parenting children with disability

Some mothers talked about the challenges their families experience because the assistance they receive for helping them with their children's disability-related support needs is so limited. Some talked about a sense of isolation, as they had few people in their lives who could understand and relate to their experiences; others talked about having little time to themselves.

The need for parents to be advocates for their children with disability is a common challenge for many families (Boshoff, Gibbs, Phillips, Wiles, & Porter, 2016). One mother talked about her roles as both parent and advocate, seeing both as essential for quality of life for her child:

I'm her advocate and carer. Yeah. As well as her mother. I just feel like that's just part of your role as a parent when you have a child with a disability. You just take on that role as an advocate and that's what you do. At the end of the day I need to make sure her needs are met and she's fully respected and she gets the rights to what she needs and her supports. I see that even as a mother I'd be doing that so I don't find that as any different role for me. (Chloe, mother)

A primary area that mothers raised as a space where they felt a need to advocate for their children was at school. Mothers talked about instances where their children required special support needs in the school, and this either was not approved or was not resourced. This placed extra burdens on families, and demanded extra resources that they did not have.

The paediatrician said to me the other day that he's probably now at that stage where when he turns up to school it's all too overwhelming, because he hasn't been there, he's missed so much. (Lara, mother)

There are therefore potentially positive effects for children and parents with disability from the location of an FRS worker in a school, as is happening in one location.

In families where both parents and children have disability, the presence of disability support was important, and so was the ongoing impact of support provided to parents when

they were children, especially as parents' own experiences influence what they want for their children. One mother, Lori, did not receive the support she needed in school, and so has low literacy as an adult, which brought many challenges and constraints, including not being able to have a driver's licence and needing support with everyday administrative tasks. Reflecting on her experiences associated with her own disability, Lori said that what she wants most in life is for her child to be able to read. To this end, the family is working with a disability service and providing intensive speech therapy to ensure her son has a positive transition to school.

Some parents talked about the importance of peer support in parenting, both generally and specifically in supporting their children with disability. For example, one mother talked about the lack of understanding and support for the particular circumstances she faced in supporting her child who had a rare syndrome. She had recently connected with a family with a child who has the same disability as her own child, which she found to be a significant source of knowledge and "a massive support".

Parents also talked about limits on their participation in employment because of the demands placed by schools and service systems on parents of children with disability. The rules and configurations of these systems often do not allow full-time employment: for example, children may only attend school part-time, parents may need to be on call for emergencies that schools cannot manage and specialist appointments are often during business hours.

## Prioritising safety

When asked about what is most important to them, mothers' responses were generally focused on the topic of safety. Mothers discussed the priorities in their lives as closely linked with feeling safe, and ensuring their children were safe. Their concept of safety was very much connected with resources: having basic needs met, access to supports, community networks and people to talk to were important.

Safety to me is being in a secure place and knowing that the people who are really close to you are going to help you be safe and help me protect my children. I like to have

my kids feel like I can protect them and make them feel safe. I feel like if I feel safe my kids are going to feel safe. (Kimberley, mother)

One mother talked about how early intervention support services have made a difference to her child's safety, and how having this ongoing support improves both her sense of safety and the resilience of their family. The family was having real challenges because of unmet needs for behaviour support for the young child, which included safety concerns. FRS were instrumental in referring the family to other support services, such as the Brighter Futures early intervention program, and also liaised with the police and child protection services on the mother's behalf during times of crisis. One result has been that the home is now more safe and secure for the child, and this also supported the family to keep the child at home.

## Views on support-seeking

Given the project interests in the intersecting spaces of disability and DFV, it was anticipated that the mothers would have a range of views about seeking support for services. A number of mothers had experience of the child protection system, including having children removed from their care. Others had experience of statutory child protection or justice agencies in the past, which had not been positive experiences.

Some of the mothers who participated in this study talked about their perspectives on seeking help, and thought that it was acceptable and positive to ask services for help when needed. A few commented that they initiate relationships with services when they require support from services.

However, others commented on their reluctance to seek help. Like many families, they felt the effects of ideologies of self-sufficiency and responsibility, but their constrained circumstances and resources meant the effects of these could be severe. For instance, Zoe encouraged others to ask for help, but personally would never ask for help and has been independently supporting herself since she was a teenager: "I've managed this long by myself ... I just don't like to ask for help. That's just me." (Zoe, mother)

This view was shared by other participants, who reported that asking for help made them feel bad about themselves, as though asking for help meant that they were failing. This perspective has been ingrained since they were children. Imogen talked about how deeply she felt she had failed her children to have to ask for help:

I think you just feel like you're a failure ... I know I did. If you need to ask for help to feed your kids, to put food in their mouth, then what sort of mother are you? You've failed. Go and kill yourself, you failed. That's the honest feeling. (Imogen, mother)

Imogen started attending a playgroup, which she was referred to through her local FRS, and this was a turning point for her:

Talking to other mothers as well to realise that I wasn't the only one struggling and that they used to not say anything either and then they realised that asking for help would get you help and it's a lot better. At first, I didn't talk to anyone and then I started talking and started having conversations with them. So, it opened my eyes a bit more that, hey, you're not the only one that is going through a hard time and these mothers have asked for help. (Imogen, mother)

Mothers described support, some of it provided through FRS, as being available in different ways. In some cases, it was via support workers, who provided help with household and care activities. In some cases, it was through social connections and the opportunity to recognise shared experiences and address feelings of isolation and shame. While the benefits of these diverse experiences can be difficult to measure and quantify in terms of violence prevention, they were often highly valued and speak to the potential for flexible early intervention that fosters participation and feelings of belonging.

## Advice to other mothers

Participants were asked about the advice they would give to other mothers who were in similar situations to themselves. Several commented on the importance of acting at the point when help is needed, rather than hesitating, because the situation could then become worse. In addition to this, they said that parents need to be proactive and learn about the

different supports and services to find the help best suited to their needs. One mother spoke about how important she felt it was to seek out support for children with disability:

My best advice would be to get as much information as you can, especially about the services. After the early intervention stopped at [age] seven I spent a year trying to work out okay, well what can I do, what groups are available, what supports are there. At first, it looks like there's not much, but the more people that you talk to, the more services that you get integrated with, the more support that there actually is. (Rebecca, mother)

Participants learned about available services through the internet and word of mouth. Mothers also highlighted the value of being engaged with their local community to become aware of all the supports and resources offered by the different services. Many of the mothers talked about the different self-care and leisure activities they engaged in, and that it was important to have things to look forward to. A couple of mothers talked about the importance of finding time and space for activities, for both children and adults:

You've got to have other stuff, you can't just sit at home 24/7, so therefore you've got to find out where you can get a job, or what social activities there are. While the kids are doing that, maybe us adults might go do something else, or you've got to find leisure in social activities in the community. (Sue, mother)

The responses from mothers when asked about the advice they would give others speaks to the importance and benefits of agency and choice, and it was clear that the interview participants found satisfaction in investigating available support and being effective advocates for their children. However, these responses also indicate the responsibilities placed on parents to identify and take up services, and the efforts that are often required to secure support that families need and to which they are entitled. Families experiencing multiple adverse events, and those with very low resources, may not have the capacity to undertake this advocacy and investigation, and the consequences are then that those families who most need support because of their adverse experiences are those who cannot get it.

## How Family Referral Services operate

### Referral to Family Referral Services

As described in the policy review in this report, the primary purpose of FRS is to provide information, support and referrals to families who need support, with a focus on early intervention and prevention in child protection and DFV contexts. Families who are in contact with FRS programs have diverse support needs and follow different pathways to FRS. According to interviews with FRS workers, some clients approach FRS directly (self-referrals), but most are referred by other agencies, particularly mandatory reporters. For this project, most of the mothers were referred to the FRS programs by agencies, including the NSW Department of Families and Community Services (now Department of Communities and Justice), which is the statutory child protection agency; police, and the Police Child Wellbeing Unit; Domestic Violence Court and Advocacy Services; family support non-government organisations; health services; schools; and early education and care services.

The mothers in this study who came to FRS independently found information in prominent locations or found the service itself because of its location in shopping centres or central parts of town, as Amber's experience illustrates:

Honestly, I was at the shops at the time with my friend ... I go, "Bugger it, I'll just go see what's up here while I'm about." So, I pressed the [lift] button, called up with my friend. She needed help with her son and I just talked for the boys. I talked to the lady who was at the front desk ... She said, "Come back at 12:30", so we both did and my friend went to her appointment and I went to my appointment, then we went home. (Amber, mother)

Other participants reported that they were referred to FRS through a variety of ways. Some were referred through health or allied health workers, such as social workers at local hospitals. Others were referred through their child's school, and in a couple of instances the FRS worker sitting in the school identified the family as needing support. Less commonly, clients found FRS through a non-government service or a police referral, or transitioned to FRS as a pathway

of continued support when exiting the Brighter Futures early intervention program.

Department of Housing told me to come here ... for help with food and what else, housing now because I was in temporary accommodation. They [FRS] hooked me up to a women's shelter over at [suburb]. I was in there for a month and got my house and now I'm through it. (Amber, mother)

The importance of service accessibility in encouraging referrals from a diverse range of sources was emphasised by both FRS providers on the ground and stakeholders in NSW state government DFV management and policy positions. The location of FRS programs in generalist community organisations, shopfronts and in two cases in a shopping centre (western Sydney) and in a school (central west NSW) was seen by a majority of participants to raise the profile of FRS and encourage women to come into the program for appointments and, in the case of FRS located in shopping centres, to make use of facilities to touch base, check email or change babies' nappies.

Another example of efforts to extend the reach of FRS included developing a partnership with an Aboriginal organisation that runs DFV training. Although not focused on disability, it was noted that many families in the community had children with disability and that the organisation worked at community and kinship levels by "spreading the word in that community and getting the community to work together around reducing family violence" (FRS practitioner).

The collaborative relationships between FRS staff and other key child protection and DFV providers were mentioned as key facilitators of successful support for families where there were child protection concerns but lower levels of risk. As the following reflection shows, FRS were seen to play a role in supporting women and children to avoid involvement in the statutory child protection system where possible.

If we can see if mum has been protective, et cetera, and called police and she's trying to do the right thing, then we see that there's some strength there and protective factors. It wouldn't necessarily be coming out responding in a statutory manner. You would be referring to probably FRS

to make contact with mum to provide the opportunity to be linked in with counselling and supports and playgroups and ongoing support for the kids, as well. That type of stuff. (FRS practitioner)

The voluntary nature of FRS services was seen by the FRS providers as valuable, and several workers commented that many of their clients appreciated the distinction between the opt-in support and statutory child protection services.

I work with a lot of domestic violence clients in this service and almost all of them, maybe bar one, I left the ball in their court because they didn't want me to necessarily make a referral. They weren't ready or they wanted to be in control of that next step. So I find specifically with the domestic violence as opposed to other issues people might be facing that my practice style is to let them follow up and I would follow up with them and see what decisions they've made around that choice to refer or not. So much is at risk. (FRS practitioner)

One of the four FRS programs accepted clients who were referred by the Children's Court as part of care and protection matters. The FRS manager explained that, although people were ordered by the court to engage with FRS, FRS themselves had no authority to mandate engagement:

It's a bit of a catch for them that we're involuntary but it's still our job ... to put services in place. We do find that a lot because we get a lot of referrals even from police and the police will say, "The family could benefit from blah, blah, blah" and then once we ring the family it's something completely different. They might say, "No. I don't need that but I need this." (FRS manager)

FRS are also intended to have capacity to support families where a parent has support needs associated with disability, whether or not a formal diagnosis is in place. A range of practice was described about how information about disability was collected. In some FRS programs, information was collected as part of the assessment process. In others, it appeared that information from secondary sources (such as police reports) was included, but questions were not asked as part of intake. Providers described practice that was flexible according to the needs and preferences of the family, such as meeting them at



their home when possible (in some FRS sites); making effort to develop warmth and rapport in their initial interactions; and building trust by allowing families to lead the referral process (as describe above). These practices are adaptable to the needs and preferences of people with disability, if accompanied by disability- and culturally aware practice. This is important because many mothers who have experienced violence or other trauma may have a disability that they do not identify or they are not comfortable discussing with service providers, and mainstream service providers are often not comfortable asking adults about their disability.

## Assessment and service provision

During interviews, FRS staff and managers described their intake and assessment procedures. When an FRS provider receives a referral, the first step is to engage with the client and then undertake an assessment in order to develop a case plan. FRS refer clients to a range of services, including early intervention programs for children at risk of entering the child protection system (e.g. the Brighter Futures program), counselling support, legal advice and disability services (NSW Health, 2014).

FRS staff also described undertaking significant advocacy work with a range of services on behalf of clients, including the NDIS and other disability support, housing, Centrelink, health, preschools and schools. When FRS staff identify families' support needs and make referrals to other services, clients often face lengthy waiting lists, so FRS keep in touch with clients in the interim. FRS also function as a drop-in point for clients who are seeking information about a range of issues. In one FRS, for example, clients could access the internet and a phone for free.

The key supports that FRS providers and families described providing to families in this study were:

- Brokerage: FRS staff spoke of paying for wheelchair-accessible and regular taxis to enable clients to get to FRS.
- Disability-related links and referrals: many FRS staff spoke of working with families through their NDIS applications, accompanying them to appointments and advocating strongly for the families' need for support.
- Domestic violence support: support included finding temporary housing or women's refuges, emergency relief for essentials for women with disability fleeing DFV, engaging DFV services and applying for AVOs.
- Referral and other support with other services: staff noted that families often struggle to pay for the cost of a diagnosis, and they work with them to develop payment plans. They also spoke of the limited services available for families.
- General or other support: FRS staff felt that they played a key role in lessening the stress levels that families often experienced when seeking support and took the time to listen to clients' concerns.

While the FRS program has guidelines about intake and assessment, and providers reported that there is a question about disability in these, there are no eligibility criteria or requirements around disability. The approach that FRS workers and managers described was to adapt their standard service provision to the information needs and/or service requirements of clients with disability. Workers described a range of practice approaches here, which appeared related to their experience and skill levels. For example, one worker discussed home visiting for new clients who were overwhelmed by anxiety or other psychosocial disability, or who had physical disability that made it hard for them to come into the office, and spoke at length about strategies to build rapport and trust. Another said they relied on the intake form to know which clients had disability, and referred to disability services.

The importance of assessment for children was also raised in the FRS context of child protection and early intervention. An FRS worker with experience in both DFV and disability services emphasised the importance of supporting mothers who may be struggling with children with disability who have not received diagnoses (and are therefore not NDIS-eligible) and assist them to get diagnoses so that they can access the NDIS. She felt that services like FRS had a critical role to play in this capacity, to enable families to access support at an earlier stage.



## Case coordination, active holding and completion

As the policy review in this report described, the service design for FRS is based on time-limited support to facilitate effective assessment and warm referral, rather than direct service provision. This time limit on support is based on the assumptions that services are available and immediately accessible to families. However, participants in this project reported that access to services can be difficult for families for many reasons, which is consistent with findings from other research (Purcal, Hill, Meltzer, Boden, & Fisher, 2018). FRS workers and managers reported that many services have long waiting lists, are some distance from families and are inaccessible by public transport. The complexity of families' situations meant that they had immediate needs to be addressed (e.g. housing, food, nappies or other essentials) before other issues could be identified and supports put in place or referrals made. As one FRS manager explained, the brokerage funds available through FRS meant they could meet immediate needs by assisting with rent arrears or food hampers, which then provided the client and service provider with space to plan to meet longer-term needs:

Then you're able to start looking at the more long-term goals that need some intervention. That might be around counselling or with the mental health or there may be disabilities undiagnosed and then looking to apply to NDIS and going through all that process. (FRS manager)

Clients who make contact with an FRS provider, and who need a referral to another service, will receive that referral within 48 hours. However, FRS workers said that in practice, referral processes may take longer to be completed. Depending on clients' wishes, FRS practice is to either refer the client to a service or let the client contact the service when they are ready. Although not a designated case management or case coordination service, many FRS workers effectively provided case management or coordination for families until they were receiving support from other organisations. FRS staff said that they generally had caseloads of around 15 clients, but they can also have clients in "active holding" because they are not yet engaged with other services:

We would put them in what we would call active holding, then make sure their immediate needs are catered for,

whether they were being given a food voucher just to make sure everything's fine at the moment and they've got support. (FRS practitioner)

Some clients can remain in active holding for a matter of days, while others can be in active holding for several months. When clients are in active holding, FRS caseworkers check in with them regularly until they are accepted into another service. When referred to a service, FRS follow up with the service to check if the client has accepted, is waiting for or has attended an appointment. FRS staff spoke about remaining involved with families until they are engaged with other services and spoke of having to undertake "behind-the-scenes" work in order to ensure that families connect with the services they have been referred to.

FRS staff were aware that when families are reluctant to use services, often characterised as "failure to engage", this was generally because of substantive concerns or barriers, and they sought to address these barriers by re-engaging, finding new alternatives and persisting.

So, it's that staying in touch that's really important, because so often they'll go to a service and they will hear from them, or they'll call twice and they don't answer, and then all of a sudden, well, they haven't engaged, whereas for us, it's at least three phone calls, a cold call, leave your card in the mailbox and then we'll call you one more time. (FRS practitioner)

When the client has engaged with the service(s) they are referred to, their case is closed, and reopened if they contact FRS again. FRS staff reported that often clients will return to FRS despite having been referred elsewhere and that this was not necessarily a bad thing:

Sometimes you think, "Oh look, we didn't do a good job in the first place" but I think sometimes they've come in the door for housing and then once they build that relationship with us and that trust they're coming back in for other things. (FRS practitioner)

## Features of the program relevant for supporting families with disability

FRS staff described working with clients in time frames that were suited to needs, rather than rigid time frames. Several described how they held increased numbers of clients in their caseloads, but had periods where lower levels of support were needed while families waited for referrals to be accepted. This is important partly because it may take time for some families to connect with services. The FRS experiences of working with clients underlines the importance of flexible service responses and a need for support coordination to assist families with navigating the service system. Many of the mothers interviewed appreciated this approach, finding the number and range of services they needed to deal with confusing and overwhelming. This was particularly the case for women with several children, and those with children with disability who needed multiple therapies.

Mothers felt reassured that even though their engagement with FRS was time-limited, they still felt as though they could receive help from FRS in the future if needed. However, some suggested that FRS needed to be ongoing or, at the least, provided beyond 12 weeks. Several mothers commented that 12 weeks is long enough to focus on immediate issues or to provide crisis support, but after crisis needs were addressed, a series of deeper or chronic issues needed resolution so that they did not slip back into crisis again. At this point, they felt that the support from a service and a worker that they had an existing relationship with was important in addressing some of these sensitive and difficult issues. This was also important for support to ensure that the services the women and children were referred to had picked up the referrals and were providing quality service. Although the FRS provides active holding for families until the FRS referrals are complete, waiting lists are such that some families come into the FRS already on lists, and waiting times can extend months beyond the intended time frame of the FRS program, as Tamara's experience shows:

There's no follow up to ensure continuity of care, or continuity of service connection ... We've been sitting there in limbo. There's no one there to help us. For four to six months I've been trying to get connected. Lack of communication, people changing roles results in a

lack of continuity of care. There isn't that overarching person who says, "Right. This person's case load, this is the person you need to be contacting." There's none of that there. (Tamara, mother)

A hospital-based social worker spoke of a connection with the local FRS, which was facilitated by an FRS worker regularly attending the hospital and meeting with the social worker to discuss potential FRS clients' needs. She valued the ease with which she was able to link clients to FRS support before they were discharged from hospital, and the sustained connection that the FRS is able to maintain with clients in a way that other services cannot. She was comforted by the fact that she might be able to refer clients to the FRS for practical support in the first instance, which might encourage the client to contact the FRS at a later stage if they felt they needed additional support:

So, if I've got somebody coming in who is also being discharged this afternoon, I can do that referral and we can have those people spoken to before they actually leave. (Non-FRS practitioner)

Another service provider said that she refers families to the FRS when they are unwilling to engage with face-to-face services. She appreciated the responsiveness of the FRS staff, commenting that they let her know how the engagement with the client has gone and who the client has been referred to, but also when they have struggled to get in contact with the client. Stakeholders valued the range of supports that the FRS could provide, including practical support, such as accompanying families to Centrelink, sometimes in the context of extremely distressing events such as stillbirths.

The capacity of the FRS to offer brokerage funding contributes to its flexibility of service delivery, and was identified by many mothers and FRS workers as an effective way of supporting and engaging families quickly. An early positive experience for people as they first engage with the FRS can build trust and a longer relationship, which workers viewed as important for families who are reluctant to work with services because of fears of discrimination and poor treatment. This is a common experience for many families with disability.

Another strength of FRS identified by workers, and also by women using the services, was their universal nature, meaning that clients can seek support or advice for a range of issues and be connected with a large number of organisations. From different vantage points, mothers and FRS workers were both particularly positive about the co-location of FRS in schools and in shopping centres. For mothers, the convenience of co-location was mentioned, and their comfort in using FRS co-located at a shopping centre for making phone calls, using internet and changing babies' nappies was seen during the research. FRS workers spoke about the increased ease with which they could build working relationships and encourage women and children into informal conversation and, through this, identify opportunities for warm referral.

As the next vignette illustrates, the different kinds of practical support FRS workers provided to their clients was also highlighted during the interviews with mothers.

The universal, non-stigmatising nature of FRS service provision can also allow for early intervention when the involvement of statutory child protection agencies in crisis situations is a risk:

We always say “We’re not a crisis service” but I can guarantee we work in crisis because ... if [a] family walks in the door and they’ve got no food and no nappies ... some services would make a child protection report. For us it was like, okay, well if we can buy the family nappies and food and get them somewhere safe to sleep tonight there doesn’t need to be a report to Community Services because there’s no risk to report. So I think for us one of the benefits is we can minimise the risk immediately so that it limits the number of reports going to the helpline and families don’t need FACS [Family and Community Services]. (FRS practitioner)

Stakeholders across a range of domains noted that a further strength of the FRS model was that it allows staff to assess families’ needs holistically, which was regarded as critical to enable services to uncover any intersection between their experiences of disability and DFV.

They look at the family and the children in [the] context [of their everyday lives and relationships]. So, they’re more likely to pick up this disability, and what are the needs around that, and they’ll think about that holistically. They’ll be looking at all of those needs and then by the way, through their engagement, they’ve actually recognised there’s a family violence issue here. (State policymaker)

Thirteen-year-old Jason and his mum Maryanne were a close family who spoke to the researchers together. They were both referred to FRS by their local general practitioner (GP). FRS have supported them for more than two years with their different sets of needs.

Maryanne received support for herself through FRS to make reports to police and obtain an AVO against a partner. This was a significantly troubling time and she felt glad she had someone to help her when she needed it. FRS also connected her with counselling through the Victims of Crime program:

It was good having someone who listened to me and someone who could give me tips on how to talk with [my son] Jason about how he's going and other tricky issues. (Maryanne, mother)

FRS have supported both Maryanne and Jason through engagements with FACS (now the Department of Communities and Justice), meetings with Jason's primary school and transitions to high school, including negotiating learning supports. Supports for Jason have included:

- being referred to the autism service provider Aspect Australia, where they are currently receiving support coordination and are on a waiting list to be connected with a speech pathologist and occupational therapist (Jason is unsure about the value of a speech therapist)
- being linked with an organisation that organised a laptop for Jason to use at school
- connection to supported youth clubs.

When asked how life has changed since engaging with FRS, Maryanne said it is very different, she feels much more supported and she feels good knowing if she needs help that FRS are just a phone call away. Maryanne felt Jason was better supported at school and had social support for fun, recreation and building friendships.

The main gap Maryanne and Jason experienced was at the time of Jason's diagnosis with autism spectrum disorder. Maryanne felt there was not enough support for her in how to access funding to get help for Jason and their additional needs.

Mothers talked about the range of ways they felt supported by FRS. Several commented that the support they received from their FRS worker was greater than that from their experience with any other services. "They're more supportive than anyone, than any of the other services ... Well, they're always there when you need them. They're heaps more flexible." (Maryanne, mother)

This was particularly true for one mother, who needed immediate support when she first engaged FRS. Chloe and her family were homeless, and her FRS worker understood the urgency of finding the family somewhere to live. Chloe said she felt supported because her worker kept in constant contact with her until her needs were met. Chloe also talked about the importance of sitting with mothers and doing the work with them, as giving a brochure to people and expecting them to connect with another service is unrealistic due to the overwhelming and challenging situation they are in. They

need workers to act on their behalf:

Whereas people in situations, sensitive situations like this, don't understand how the hell they've ended up in that situation to begin with, or if or why or how, so therefore it's no good passing them a brochure and sending them on their way, there's no point in doing that at all ... it's more hands-on and sitting there and making the phone calls with us, or putting us in that connection or getting us to that place, rather than just handing us a brochure and sending us on our way. (Chloe, mother)

Other mothers also talked about how their FRS workers supported them in a way that enabled them to enact change to improve their lives for themselves and their children. This empowerment was about walking alongside the woman and giving them the agency to make changes for themselves. For example, one mother spoke about knowing her workers were there for her, that she was not alone, and knowing this,

coupled with the referrals to the court advocacy service, gave her the strength to take action against her violent ex-partner who had been harassing her.

FRS workers reported that they tended to work directly with parents, during school hours, and children and young people mostly did not talk about FRS directly. They were more likely to notice the impact of FRS assistance, for example, being connected to another service. The children and young people who knew and talked in interviews about FRS focused on the relationship with workers and the support they were providing. For instance, Caitlin identified that “the lady from here” [FRS] was helping her with using services. Similarly, Robert talked about the help that the FRS worker had provided his family in helping him to access Centrelink payments.

In this context, it was easy for the perspectives and ideas of children to slip from view. In our study, both mothers and practitioners were justifiably and necessarily focused on the needs of children, and very concerned about their safety and wellbeing. Children themselves were generally welcoming of additional support, particularly when it was framed through a positive lens. However, there was very little focus about how FRS might accommodate the priorities and perspectives of the children themselves, and find out directly from them about how support might assist their family.

## Effects of the National Disability Insurance Scheme

The NDIS was in the roll-out phase at the time of the research, and the engagement of families with the NDIS was a significant and repeated concern. Service providers made frequent reference to how individuals’ ability to navigate the NDIS system varies, with some apparently managing well and others not. On balance, however, it appeared that many of the families with disability accessing support through FRS were struggling to access and navigate NDIS support. Families faced difficulties in navigating the application process: many plans had been declined for poorly explained or unjustified reasons, and the appeals process was not well known. Those families who did get a plan could only benefit

from it if services were available in the area, which was not always the case.

Access to the NDIS was raised frequently by mothers, predominantly as a source of stress, and an area where they relied heavily on FRS for support. FRS workers had supported families to apply (and reapply) for the NDIS and to access supports through the NDIS, had explained NDIS systems and processes, and referred clients to services to further assist them with the NDIS. FRS workers spoke frequently about their concerns about limits to their own knowledge and skills in this area, and that they felt ill-equipped to support families in the detail of navigating the NDIS.

We try and fill the gaps, even if we can only do [a bit]. It has a huge impact on the families, because they’ll say, “Well, I’ve got this NDIS funding now and I still don’t have the supports I need for little Mary.” (FRS practitioner)

Several families in this study were in the process of obtaining diagnoses for their children in order for them to be eligible for NDIS funding. For children seven years and older, a formal diagnosis and assessment of disability is required in order to be eligible for funding under the NDIS. Many of the children in this study had been diagnosed with conditions relating to behaviour (ADHD, oppositional defiant disorder [ODD], ASD and so on). Some workers were concerned about the link between behaviour and trauma, and the potential for labelling children’s behaviour as part of a disability when it may be a reaction to trauma:

It will be quite interesting to know when the doctors are diagnosing children, are they actually diagnosing the right way. Especially—they go automatically are they ADHD or ODD, and they’re on the spectrum ... Yeah, but have you taken any consideration that he’s witnessed his mother being flogged around for eight years? (FRS practitioner)

Mothers were appreciative of the support from FRS to navigate the NDIS, and spoke about how overwhelming they found the process:

I don’t understand it. One of the workers explained it to me ... what was going to happen and where the money went to, and who was going to be the person doing it all, which was good that I had them for support to come with



me as well. Then to tell me what was going to happen with the money and who I could use it on, and then who I could actually take my child to, because I didn't know any places around here that I could take her to. They actually said, "Well, this will be a good place for you to take him for physio and speech therapy and all type of stuff." (Sharon, mother)

The need for support workers specifically to assist mothers with their NDIS queries and processes was important for many families. For some, their FRS worker filled this role, and once the FRS service concluded, if other services were not actively involved the mother was left to try and manage all aspects of the NDIS themselves. For many of the mothers, this proved very stressful. A number of mothers expressed the view that they still needed continued support due to the complexity of their lives. This was well expressed by one mother, who talked about the challenges in dealing with the multiple sets of providers on her own:

I'm still trying to get access to services through NDIS. They were supposed to ring me back last week and I still haven't heard from them. I found that we were connected with [FRS worker] through that program, and then we were disconnected from it, because they didn't think there was anything more that they could do. Once we were disconnected, the issues are all still sitting there. (Tamara, mother)

Some stakeholders referred to a perceived inconsistency in the funding amounts awarded to different individuals under the NDIS, with one FRS caseworker commenting that FRS sometimes had to fund services that should have been funded under the NDIS. Some FRS staff described having to intervene on families' behalf in order to secure NDIS funding:

I went through a process of accessing NDIS funding, supported mum and advocated at the NDIA office locally for it to be escalated, because they'd lost the application about three times. I actually went to the NDIS planning appointment, and I talked a lot about our 12-week period, and the need for, say, something like, coordination of supports to carry that over intensively to get the family to then have that support after us as well. (FRS practitioner)

Another FRS worker referred to the lack of Aboriginal-specific case management services to assist Aboriginal families where the child or mother has disability to access NDIS: "There's still massive gaps, massive."

One of the key issues that mothers and FRS workers raised when discussing NDIS was that the services approved for funding often did not meet the families' needs. For instance, one mother drew on two examples from her family to demonstrate the difficulties of using NDIS to support what participants actually need funding for. Her daughter required monthly medical appointments several hours' drive away, and while the family struggled to pay for the cost of the petrol to get there, this cost was ineligible for funding. The other example was related to her own situation. This mother has a significant physical disability and requires equipment to get around. She applied to use some of her NDIS funds to purchase a scooter to increase her mobility, but this was denied. She spent \$1500 of her funding getting assessed for the scooter, and when it was denied she was left no choice but to purchase a non-motorised wheelchair, which was not appropriate to her needs or preferences.

Other participants raised similar challenges, commenting that the services they had access to prior to the NDIS are no longer funded under the new scheme or that services their children refuse are included in their funding package instead of preferred services that would be more useful to the child and family. For example, one mother explained that the services they are eligible for (psychological services) are not useful to the family as her daughter does not want the service:

My daughter was getting picked up every day from school. Sometimes, dropped at school. Going with workers. Now, that's all stopped. She refuses to go to psychology, to a psychologist. (Sharon, mother)

Besides families not being able to access the services they need through the NDIS, some clients commented on the lengthy delays in gaining access to their funds once approved. One mother, Chloe, described the process of trying to get the quote assessed as "a nightmare". She used the example of needing orthotics for her daughter. The time delay in getting the funds was very difficult for her daughter because she was



in pain, and the family did not have the money to pay for the orthotics outright.

Even when families secured funding, the lack of support and advice about purchasing decisions under the NDIS was raised by FRS workers as challenging and difficult for many families who struggled to identify the range of services that might be available to support them. A lack of clarity about which services would accept NDIS funding was also raised as a challenge, particularly when FRS services were seeking to use funds more creatively in regional areas where there were limited specialist services.

## Positive practices

In this section, we discuss practices that in large part are not innovative, but are good and positive practice. Individually, they are perhaps not noteworthy. However, for women and children who have complex personal circumstances, such as the families in this study, the combinations of good practice described below are not always in operation in the services they use.

FRS workers shared a range of practices that constitute fundamental good practice principles, such as building trust and showing respect to all clients; following through on promises made (e.g. returning calls as promised); making efforts to meet families face to face; and allowing clients the time and space to engage when they are ready.

In addition, a number of positive practices were identified that built trust and confidence in the families and supported helpful outcomes. These were focused around timeliness and scaffolded planning; personalised support; flexibility; building and sustaining local sector relationships; improving service coordination; and building cultural safety with Aboriginal families. These are discussed in more detail below.

## Timeliness and scaffolded planning

Families referred to FRS were provided with an initial response within 48 hours. In all four sites, the teams worked to bring

in new clients quickly. They used brokerage funds to meet urgent needs to prevent people falling into crisis, especially around issues that presented a potential child protection issue (e.g. when families had no food or nappies). Once these urgent needs were met, they focused on addressing longer-term planning with families.

They assisted both me and Tim when we were really in need. They sort of got us on our feet. They gave us vouchers. They even had a little backpack ready for our son to start school this year when he went to preschool. That was a big help. I mean, lunchboxes and things like that. (Jasmine, mother)

## Personalised support

The active support provided through FRS to find solutions to sometimes complex problems was raised by most of the mothers as a feature of the services they appreciated. This support was often completed in stages, with an initial crisis point addressed and further planning developed in consultation with families. Many workers spoke about warm referral, and how they did not leave families to make cold calls to services for support. They spoke about working “behind the scenes” to ensure that appropriate support in the services referred to would be available, and that referrals were working.

Until families are engaged with the services that we’ve referred them to, we hold them open, so we hold them open for a very long time, often waiting, when we’ve got plenty of new referrals coming through, but we don’t close until they’re engaged. That’s why sometimes there’s behind-the-scenes work that’s got to be carried out because otherwise they’d never be engaged. (FRS practitioner)

While families were waiting for services to become available, FRS workers followed a policy of staying in contact and keeping them updated, and continuing to provide as much interim support as they could with brokerage funds and short-term options.

## Flexibility

The flexibility built into the design of the FRS program supported positive practice for mothers and children with disability, in several ways. The universal nature of the service provision meant that no diagnosis, or even identification of disability was required in order for support to be provided, and this was a positive feature. For women who did not identify as people with disability, this meant that there was no barrier to either perceived suitability of the program or eligibility.

The holistic approach to assessment and focus on assessing the needs of the family in the context of their everyday lives also encouraged responsiveness to families' circumstances relating to disability and other parts of their lives.

I think we listen and they get heard. A lot of the issue is that you ring up certain services, it's a "press one button for this, press that", and so that creates and adds frustration, whereas with us, well, FRS in general, it's a face-to-face meeting, usually, and they do get to tell their story. (FRS practitioner)

For most women, support through FRS was provided according to need, rather than calendar. While there were efforts to keep families moving through the program, people were not exited until their referrals were secured. Several mentioned the ability to return if needs change.

## Building and sustaining local service sector relationships

Work that FRS both led and contributed to in their local communities to build and sustain local service sector relationships was important for ensuring that the referral pathways worked. Some of this practice was interpersonal, between individual workers across agencies in different sectors, and some occurred at interagency levels (such as communities of practice). Other initiatives were structural, such as:

- co-location of services, including the FRS in Schools model (described below), a collaborative arrangement between FRS and the maternity unit in the local hospital,

and Centrelink and child protection workers being based in FRS offices

- outreach activities by FRS workers to schools, playgroups and courts
- integrated service provision (e.g. a residential men's behaviour change program for DFV perpetrators that provides multiple services, including disability support).

An FRS worker spoke about an initiative whereby a FACS child protection worker had been based in an FRS office part-time. It was important that this was voluntary and additional to general FRS service. He felt that the arrangement was particularly beneficial because it allowed for collaborative work and information sharing:

... when you've got someone sitting there you can talk to rather than having to send an email and wait until they bother to reply, which sometimes doesn't happen. (FRS practitioner)

Another collaborative practice FRS staff found valuable was having a Centrelink worker based in an FRS office to provide advice to them and families who came in by appointment about how families could best make use of Centrelink benefits. Despite the arrangement's limited time frame (just two hours a week), it was regarded as worthwhile for families and workers.

A midwife employed by an Aboriginal Medical Service spoke of good collaboration between local non-government organisations, noting that some offer transport to enable mothers to attend "mums & bubs" groups. She also spoke of the importance of community-based services that deliver services where clients live rather than requiring them to travel significant distances, highlighting the importance of the NSW Health Substance Use in Pregnancy program that supports women in the community.

## Improving service coordination

A number of service providers outlined strategies for building trust and respect with other organisations to improve service coordination in order to better support clients. It was facilitated in one case by weekly interagency meetings where service providers discussed how clients in maternity and antenatal care could be supported. Building trust with other organisations was also about workers in each service acknowledging their service's limitations and attempting to work collaboratively to meet need. Building trust with other organisations was also about being accountable to them and following up on referrals.

Another suggestion for building trust between FRS and statutory child protection services was arranging secondments between the two, so that child protection workers could spend time in FRS to help build worker knowledge and skills. This initiative was undertaken some years prior in one of the FRS sites, and was an asset to the local service sector.

The FRS in Schools initiative involves having an FRS worker based in a school one day a week, to improve local service coordination. The aim of the model is to keep attendance above 85 percent for schools that are identified as having low attendance, low socio-economic status and a range of other factors. Referrals come from multiple agencies and self-referrals; self-referrals can also involve referral of a family member. In one school where this model operates, the Aboriginal Education Officer introduces the FRS worker to the family at the school, who then works with the family. Being based at the school has helped the students and families get to know her:

She's sitting in at school one day a week, her face is quite familiar. Our young people will just come to [FRS worker] and just tell her their problems. [FRS worker] will then relay the message back to their case manager. [FRS worker]'s like the friendly face that's just here all the time. (Non-FRS practitioner)

The approach is viewed very positively by staff and stakeholders:

They're working holistically with the family. They're seeing the child in the setting of the school. They're seeing the

setting of the family, the family unit, and they may be picking up on issues around family violence, that the school aren't seeing. The schools see the result of the behaviour. (FRS manager)

An FRS worker described how they have a very positive relationship with the local office of FACS, the statutory child protection agency. She said that many of the referrals FRS get are for families who are not allocated to FACS caseworkers at the weekly allocation meetings. These are families where children may be "at risk" but the child protection system lacks capacity to respond and the only service they may get would be from FRS.

The next vignette shows an example of FRS enabling support to be provided from different agencies in ways that support women and children.

Someone at Lori's son's school suggested she talk with FRS about what assistance could be provided. From then on Lori felt a lot more supported, and FRS were able to link Lori up with supports for both herself and her 13-year old son.

FRS have helped Lori become connected to many services:

- A DFV support for women and children provided emergency refuge support and temporary accommodation.
- A community housing organisation provided Lori with advocacy in accessing secure housing for her and her family and helped her communicate with the FACS (now DCJ) Housing office.
- A family support agency was able to refer her to the Court Advocacy Service. This service was instrumental in helping Lori in gathering evidence to apply for an AVO against a previous partner.
- A GP who specialises in trauma provided trauma support. This GP has also connected Lori with physiotherapists, nutritionists and pain management supports.

A psychologist helped Lori work through emotional struggles and supported Lori to build her self-esteem and sense of self-efficacy.

FRS have also been supporting Lori's son to work through issues relating to his father's domestic violence.

## Building cultural safety with Aboriginal families

One FRS was an Aboriginal-targeted service, which meant that the service is committed to providing culturally safe and responsive support to Aboriginal clients, and specifically ensuring that Aboriginal workers are available to clients. An FRS worker spoke about the importance of building relationships with Aboriginal families before referring them to other services. Given the histories and ongoing practices of punitive child protection responses to Aboriginal families, FRS workers also spent time emphasising to families that use of FRS is voluntary, and that FRS are not part of the statutory child protection system. Another consideration that FRS staff identified as important to their work was recognising that Aboriginal families include not just mum, dad and kids, but also uncles, aunts, cousins and more. The FRS worker also reported that their usual practice is supported or warm referrals when working with Aboriginal families, to ensure that the services are connected with families and are culturally safe.

An FRS manager described a cultural inclusion project that was developed to work with Aboriginal children and young people with disability. It focused on using culture to engage them in services:

What it does is it helps us engage our kids into our services through culture. So, we talk to them about respect for their parents, respect for women and all that type of stuff. It

helps for us then when we have to put mainstream services in that they've started to build that relationship with us, but they've also started to build resilience in themselves to be able to engage in those services. (FRS manager)

## Challenges in meeting needs

A number of challenges in meeting the needs of families when mothers or children have disability were identified. These centred around the disconnect between DFV and disability policy and service delivery; sector and inter-sector capacity at organisational and practitioner level (e.g. cross-referral capacity or the confidence of workers to have difficult conversations with women with disability); gaps in services and systems; and integration and coordination.

### The disconnect between DFV and disability policy and service delivery

Despite the research evidence that highlights the very high prevalence of DFV where disability is present (Frawley et al., 2015) and the growth of policy in this space, the two are still rarely connected in ways that facilitate implementation of high-level policy goals by services. Stakeholders acknowledged the national- and state-level plans and strategies designed to address DFV and the development of the NDIS, but noted that these two streams of policy were considered separately, with little recognition of the links between the two. One

stakeholder reflected on the significant developments in the DFV space in recent years, while noting that disability did not appear to factor in these developments:

I'm not sure whether ... it's reached that horizon yet around building a literacy around the risk of family violence to kids with a disability or kids who are in a family where there's a disability present. (Commonwealth policymaker)

From a service delivery perspective, stakeholders also identified lack of crossover between disability supports and services and an awareness or consideration of DFV:

I think there's a lot of services who say they specialise in disability or specialise in other areas, mental health or whatever, don't always have really solid family and domestic violence understanding and responses, if any. (State policymaker)

This is also true of services and policy relating to perpetrators: a Commonwealth policymaker interview participant noted that the *National Outcome Standards on Perpetrator Interventions* (Commonwealth of Australia, 2015) does not adequately recognise disability, and another participant referred to their experience working with perpetrators and reported that they never considered the intersection with disability:

I can't think of any in my memory, where disability has been a factor, that I've been aware of. That doesn't mean it hasn't been a factor, but I certainly haven't been aware of it. (FRS manager)

## Sector and inter-sector capacity

The interviews with staff and stakeholders identified that while FRS workers are skilled and confident in working with women and children in terms of DFV, they lack confidence, knowledge and awareness about disability, particularly intellectual disability. Although there were examples of skilled practitioners working in each of the sites, these were individuals with a personal background or interest. Most of those interviewed in FRS and other DFV service provision and policy sectors needed to pause for thought when considering how early intervention violence prevention and disability intersect, which is telling in regard to the ongoing separation and exclusivity of the two policy frames.

Service providers reported being aware of or recognising the signs that might indicate DFV but, for many, disability was a grey area, particularly intellectual disability and psychosocial disability. This appears to be attributable to providers' narrow views of disability and their confusion around the distinctions between mental illness and disability, and trauma and disability—although it is unlikely that a diagnostic approach would be helpful in determining the type of support provided, certainly through DFV services. This confusion was described by a non-FRS service provider who spoke of the difficulties in determining whether someone had intellectual disability from birth, an acquired disability/brain injury/trauma-related disability or drug-induced disability/delay:

It can be really difficult to ascertain whether it's a disability, as such, or if it's a combination of drug use, being hit on the head too many times, and ongoing trauma ... That's what you can see with some of the mothers, just ongoing surviving violence and all the other pressures that motherhood and having a violent partner brings. It can be really difficult to ascertain whether it's a disability or environmental. (Non-FRS practitioner)

Some felt that mentioning disability to clients was an awkward topic to broach, with one non-FRS service provider describing her reluctance to do so:

We see a range of domestic violence. But ... I don't know that people would say they had a disability ... There's a lot of addiction issues here in town ... Look, it's a tricky one, isn't it ... I'm well aware of the issues, but it's not something I'd say to someone. (Non-FRS practitioner)

This was echoed by an FRS manager who was aware that more work was needed to assist FRS staff to initiate conversations with clients who may not identify as having disability:

From a worker's perspective if they're not skilled in having those conversations they're fearful that the conversation may offend or they're fearful that the family may disengage from the service. (FRS manager)

From a service delivery perspective, another reported challenge is that clients are often reluctant to disclose both disability and their experiences of DFV. This may be because



they do not identify as a person with disability, or as a victim of DFV, or it may be because of fear of consequences, lack of trust or other reasons. All of these are substantive and common barriers to disclosure, and it is a strong indicator that many people's needs are not being met if receipt of support is dependent on voluntary disclosure to FRS staff or other services. Supporting this, FRS staff believed that a significant proportion of their clients have disability and have experienced DFV, and suspected that this was even higher among the families who were reluctant to seek or accept support from services.

In some cases, FRS staff have been able to support clients to identify and respond to their experiences as violence:

She couldn't understand what was happening with domestic violence. So, it was just trying to break it down until they realise what was going on, and by talking to the partner about it, because he had a disability as well. (FRS practitioner)

The impact of failures to consider the presence of disability and DFV is illustrated in the following vignette.



A senior FRS caseworker recounted the story of a young mother who had approached FRS for support with her two young children, because she had just left an abusive relationship and was homeless. Technically, FRS should not have provided support because she was classified as “an open child protection case”. However, the FRS worker recognised that she had an intellectual disability and that she was not going to be able to fulfil the requirements to maintain her temporary accommodation (TA) as a single mother with two young children, limited finances, no transport and poor literacy. For the TA to be extended from week to week, the caseworker said that the young mother was required to inspect five properties per day.

I was quite distressed about the fact that her caseworker at FACS had not only not identified this [her intellectual disability] but was putting her and her children at further risk because they were setting her up to fail, she couldn't complete the TA requirement. (FRS practitioner)

The FRS caseworker contacted the young woman's FACS caseworker, but, she reported, no action was taken. The FRS caseworker described being distressed by how the support system had failed the young mother by not recognising her disability. This lack of recognition and support, she felt, may well have compelled the young mother to return to a violent relationship, or left her homeless, which may have resulted in her children being removed from her care:

Nobody identified this girl had an intellectual disability, and her presentation was so obvious it wasn't funny. Nobody identified her lack of literacy skills, and I'm thinking to myself, you've had this caseworker at Community Services for months, at some point you must have filled in a form in front of her. I could see straightaway with her writing that she wasn't coping. There's just not enough attention paid, and when these gaps are identified, there need to be services or caseworkers, if said parties aren't going to deliver it, that fill these gaps. Because, if they're not filled, they go back to the perpetrator or they're on the street with their kids removed. (FRS practitioner)

Working with a contact at a large non-government organisation, the FRS worker put an application through FACS Housing, provided advocacy and support letters, and secured housing for the young mother and her children.

In addition to the challenges of identifying intimate partner violence or other violence between adults, risks to children are also challenging for services to identify and manage. An FRS worker spoke of the tension of trying to provide support to parents with disability to keep children safe. He noted that the fear of child removal can be an ongoing concern for parents with disability and that within child protection there are two main schools of thought, with one being a “very intolerant, and a very judgemental” assumption that parents with disability cannot bring up their children, the other being a “denial of risk”. He reflected on a situation where a mother with psychosocial disability experienced psychotic episodes. He described her as an “absolutely delightful person, wonderful person, very loving mother” but noted that when she was vulnerable, her child was also vulnerable. The child subsequently suffered injury, which made this stakeholder aware of the importance of balancing respect and risk:

One has to demonstrate absolute respect for, and a commitment to, and support to the parent in those circumstances, but at the same time, that can't be at the expense of failing to be mindful of risks when risks do exist. (FRS practitioner)

He felt that advocacy in this sector must demonstrate an absolute commitment to the rights of all concerned, both parents and children.

The connection between FRS and the statutory child protection agency was also a barrier to receiving support for some families. Many families where disability or vulnerabilities are present have (well-founded) fears of child protection agencies and removal of their children. The voluntary nature of FRS is a strength for service accessibility and clarifying distance from statutory child protection, but was also experienced as a frustration by some FRS staff who reported that when families do not take up services this can result in repeated notifications to child protection.

A similar concern applies to court-mandated referrals, which oblige FRS to attempt to engage with families, but allow families the choice to engage or not. This is an unusual circumstance for court-mandated referrals: they are generally to the child protection agency, which can also mandate engagement

from families. Because families referred by courts to FRS do not have to take up services, this is also experienced as a frustration by some FRS staff.

The family focus of FRS, which is in most cases a relationship between FRS staff and parents, could also be a limitation. FRS staff talked about how they sighted the child/ren for child safety reasons, but then often had limited opportunity to work with them to develop linkages and goals that responded to their priorities for safety and support.

Practitioners spoke of the complexity of needs of clients who use FRS and emphasised the need for “upskilling” and disability “literacy building” to enable staff to work more effectively with clients with disability, but stressed that this required resourcing.

System-level challenges for women with disability who have experienced DFV were also discussed, primarily by practitioners but also by some mothers. A number of state policy stakeholders in the DFV and disability fields reported that crisis responses often present both physical and online access barriers for women with disability. One state policy stakeholder noted that many women with disability cannot flee their homes to escape violence if they cannot find accessible accommodation or “appropriately modified private rental”, or cannot afford a two-bedroom home to accommodate a live-in carer. “Safe at home” programs such as NSW’s Staying Home Leaving Violence can present challenges for women with disability, particularly if the perpetrator is also their carer, as the woman cannot remain at home independently (NSW Department of Community and Justice, 2019).

## Gaps in services and systems

Challenges with referral pathways were raised by many stakeholders, affecting how effectively FRS could work for clients when there was a lack of local resources or services to refer clients to. This is not exclusive to FRS, but was noted in this research as a feature of service provision that had significant impact. As one mother noted:

She did a lot of work in six weeks. Trying to do a lot of referrals, but no referrals come back ... She was ringing

me, “Keep your phone on because you’ll probably get [calls]”. All the time when I come in, “Did you hear from them or anything?” She’s straight onto it. They don’t get back to her and they don’t get back to me. You know what I mean. They try really hard here. (Claire, mother)

Stakeholders identified a lack of services in some areas, particularly in more regional or rural locations. Services that are needed but not always available include appropriate and safe accommodation, including emergency accommodation, for women and children experiencing DFV; bereavement support services; housing; public transport; Aboriginal-specific services; in-home care services; therapy services (particularly for children with disability); and respite services.

Alongside the lack of available services, long waiting times for limited available services was raised by many mothers and FRS workers, particularly for assessments for children and for therapies for both children and mothers. Cost was a huge issue for families, with assessment for eligibility for the NDIS costing up to \$1500—money that most of the families simply did not have. Some FRS workers found creative ways around this, finding small funding pools and service streams—several of which had closed during the course of the research. Many of the families were placed on long waiting lists for assessment by providers who generally did not know the children. It was also noted by several FRS practitioners that some services are unaware of FRS, affecting cross-referral of families with disability who might benefit from the more flexible support.

FRS service providers spoke with frustration about the inability to focus on early intervention because of service gaps and skills shortages in the area and the delays that families faced in receiving timely support from the services they were referred to. They also spoke of the limited capacity of early intervention services to provide support to families where children are at risk of harm, and that there is no response until risks have escalated and intensive support is needed:

We’re having to send them through that system to get to an intensive case management service. It defeats the purpose. It’s not what we’re here to do as early intervention services in the area. We’re meant to all prevent that escalation. (FRS practitioner)

In rural and regional areas, long waiting lists and slow intake processes for some services, if they are available at all, compounded these challenges.

Mothers were very aware of the strain on financial and practical resources for services to adequately meet the needs of their families, and commented on issues like services not having the budget to be able to help them with immediate supports such as vouchers or food relief. The lack of resources for services also extended to the capacity of staff to meet the demands for support, as one mother commented:

All I remember is that all the agencies just passed us around. It was the same reply, “We don’t have funding for that. We don’t have enough time to talk to you. We have limited resources.” It was all the same story. I heard it from so many agencies. I was thinking, “How am I supposed to get any help in this climate of welfare?” (Annette, mother)

## Integration and coordination

Practitioners spoke of the challenge of delivering services to clients when there was no way to track their movement through the service system or to share information in a timely manner.

The client may book in at an antenatal clinic. They may go to their GP. They may see 20 or 30 people antenatally and while they’re in hospital and there’s nothing really for their unique pathway to be followed. (Non-FRS practitioner)

This links to the lack of coordination and integration between services to meet families’ needs. This fragmentation was related to how services are funded and the fact that few are funded to work with clients on a long-term basis.

# Discussion

The focus of this research on service delivery underlines the points at which systemic gaps are most affecting families in their day to day lives, and the potential points of intervention to improve practice. The strengths of the FRS model, as with early intervention and referral services in other jurisdictions (Dyson et al., 2017; Tayton et al., 2014), are in their flexible and accessible ways of working, the priority given to families' immediate needs and those needs that families identify as most important, and the sustained efforts made by staff to connect and maintain connections with other services. The risks of this model for families is that FRS themselves cannot provide long-term specialist support, and many families need that. Nor can they offer specialist mental health, disability or DFV support, which many families also need. The benefits are that a relationship with FRS will enable families to connect with those specialist services, at least in areas where they are available, and provide additional support in navigating service systems.

Our research indicates that the focus of FRS service delivery is on adults more than children, and that the priorities of children in improving social connectedness and building relationships were not directly supported by FRS. There may be a role for FRS in providing more specific support to children and young people, and this would require specific resources including, in some areas, training and workforce support. In its roles of ensuring service access and referral, it is appropriate that FRS work with adults because, in general, obliging children and young people to take an active part in finding support services is neither valued by them nor equitable. However, given the known vulnerabilities of children and young people with disability, it is important that services for families can provide support to children as well as adults.

FRS's focus is on family needs and priorities, rather than on mobilising strict eligibility criteria or delivering standardised service models or programs. This is a productive foundation on which to build positive practice because it aligns with the social model of disability, in which the support needed to fully participate in life is a more important point of intervention than diagnosis or disability category (Shakespeare, 2013). There were concerns expressed, for example, from service providers that they cannot ascertain if a client has a mental

health condition, an acquired brain injury or an ongoing traumatic reaction from experiencing violence. Yet these categories are far less important than the support needs arising from the lived experience of disability, which should be the focus of service delivery; the skills required by staff to meet these needs; and, therefore, the training and capacity-building needs of organisations. These are skills to do with communication, trauma-informed care, cultural safety, and recognition of past and ongoing stigma and discrimination, as well as adaptive, responsive, strengths-based interactions.

Families with multiple intersecting support needs, especially when DFV or child safety is present or at high risk of being present, require both support from specialist services, and case coordination and referral services such as those provided by FRS. Safety and risk assessments are of critical importance, as are staff with specialist expertise in supporting adults and children who have experienced violence and who have disability (Dyson et al., 2017; Healey, Humphries, & Howe, 2013). These skills and capabilities are not held by most staff in early intervention and family support services. Instead, staff in these organisations require expertise and confidence in communicating with families, and in ensuring referrals to specialist services as needed. This also requires that specialist services to which early intervention services can refer are in place and accessible. The capacity of the sector to respond effectively to families with disability depends on the training and support of the workforce, and on organisational capacity, resources and networks.

The challenges in supporting families with disability who are at risk of violence can be significant, and this is recognised by the service providers and stakeholders who participated in this research. While it is encouraging that this is recognised, it also presents a challenge for early intervention support to these families. When many FRS workers themselves acknowledged a level of discomfort and lack of confidence in talking about and addressing issues facing families where children, or especially mothers, have disability, this is particularly problematic. It is unlikely that poor practice will be called out when colleagues witnessing it do not feel confident in how to offer constructive advice and positive practice alternatives.

A core concern of this project is the capacity of FRS and other universal services to work effectively for families in meeting support needs related to disability and violence prevention. Several stakeholders felt that FRS have the ability to straddle a disconnected service system, but that they were not resourced to provide case management support, which requires relationship building. Others were less confident in the ability of FRS staff to recognise and respond to disability-related needs in women and children, and said that it was critical that staff were all appropriately trained to improve their capacity and confidence.

While there are FRS program guidelines in place, such as a program standard about disability (NSW Health, 2014, p. 27), none of the FRS sites in this research had conducted training or systematically implemented the practice standard. Their responses to women and children with disability were reliant on the skills that individual workers brought into the organisations—for example where they had strong backgrounds or interests that improved practice. Where they did not, that particular FRS site was not strong in supporting women and children with disability. This practice needs to be systematised and resourced. This is particularly important because the assessment approach is holistic, focused on collecting the person's story, building a picture of their need and responding to it—not filling out forms. This means that workers need to have the skills to have conversations that explore how disability affects women's and children's experiences of navigating safety and harm, and their priorities for support.

The stigma of disability, and of DFV, can present barriers to seeking support for families who need it. This stigma can result in feelings of shame and isolation, and can also have significant material effects as it is known to manifest in service responses that are punitive and harmful. Families with disability and those where violence is present are often at risk of statutory child protection intervention, and even where child protection services are supportive and enhance safety, families may avoid them because of shame and fear (Cripps & Habibis, 2019; Humphreys & Healey, 2017). The role of FRS in providing early intervention child protection support is highly valued, and the introduction of secondary and tertiary services, such as the child protection caseworker

pilot and referrals from the Children's Court, could jeopardise this. However, the threshold separating early intervention child protection from intensive interventions is uncertain and often contested (valentine & Katz, 2015), and service providers' experiences of collaboration between FRS and statutory services appear to be positive. Sustained research, such as longitudinal studies, on families' experiences of these collaborations would be valuable.

Well-documented gaps and challenges in family support and disability services are compounded when families are living with current or past experiences of violence (Maher et al., 2018; Mikton et al., 2014). To address this, the investment of resources is needed in DFV service systems to improve responsiveness to disability, and in disability services to improve responsiveness to DFV. It is important that these resources go beyond funding for short-term programs or service enhancements, particularly as access to service coordination over time was emphasised by stakeholders and parents in this research, as it has been in previous research (Breckenridge & Huppert, 2010; Dyson et al., 2017; Humphreys & Healey, 2017; Maher et al., 2018). Without such investment, individual workers are forced to rely on the quality of their own professional networks, as services change and cannot keep online information updated.

It is also important that the purpose and limits of the NDIS as a mechanism to meet families' needs are not lost as a result of service delivery gaps. In a context of unmet need, there is a risk that early intervention DFV services such as FRS will invest efforts in ensuring a child or mother applies for an NDIS package for therapeutic interventions, even though this may not meet their most important needs. The NDIS is not designed to be a crisis response (Dickinson & Carey, 2017), and should not become an inappropriately applied crisis-funding mechanism because it is the only feasible source of funding for families. The short-term incentive (access to much-needed funding, particularly for children) may have long-term unintended consequences. A diagnosis of disability is a significant consideration, and for young children experiencing trauma, a complex one. A diagnosis will follow children through their school lives and beyond, and a diagnosis made in haste or by a practitioner lacking skills in understanding the effects of trauma on children may ill



fit children's long-term needs and aspirations (Crnic, Neece, McIntyre, Blacher, & Baker, 2017). There may be short-term advantages to a diagnosis of disability, because a diagnosis may have implications for service eligibility. However, if the support needs of children are caused by their traumatised responses to experiences of violence, a diagnosis of disability may result in the failure to provide the support that is needed. It is critically important that support is available to meet children's immediate needs after a crisis, that this support is not contingent on a diagnosis, and that long-term support is provided to meet disability or other needs.

Notwithstanding this, this study shows that barriers to effective and efficient use of the NDIS clearly need to be addressed for families with disability facing DFV. This includes potential learning from the elements of the FRS program that are helpful and supportive for families with disability, particularly supported referral, flexibility in service provision, access to brokerage funds and continuity of support. These findings extend the conclusions of recent research with insights of women with disability who outlined their experiences of seeking justice and security after violence, and the pathways and obstacles they encountered (Maher et al., 2018). That research concluded that there is an urgent need to improve responses for women with disability who have experienced violence, including access to specialised violence services and to disability services that can facilitate access to those specialised services. This research extends those findings into an important new space concerning children with disability in families where there is a risk of DFV.

## Implications for policy and practice

In this report, our team has identified a range of positive practices and points to improve well-known blockages in service systems. The practices themselves are not especially surprising. Multiple people told us that there is nothing magical or different about supporting women and children with disability. However, we have also identified points that were not so well known about why blockages were happening, and how people were working to reconcile them. This is new information, useful in thinking about how to progress practices across disciplinary boundaries.

A framework for training and capacity building (Table 4) is suggested here to support the development of positive practice in frontline service workers and organisations providing support to women and children with disability who experience DFV. It should aim to:

- shift culture at organisational and sector levels by taking a diversity approach to disability and impairment
- skill workers and organisations to feel confident and able to respond to the needs of families with disability who are at risk of violence
- build a bank of positive practice that is locally tailored and responsive to women's and children's needs and preferences
- inform program development to bridge the existing gaps between violence and disability.

**Table 4:** Proposed framework for building capacity and positive practice

Domain	Activity
Shifting culture	Build knowledge and understanding about disability as a part of human diversity (not a risk factor or diagnostic criterion)
Skilling workers and organisations	Build skill in recognising and responding to the needs and preferences of women and children with disability Establish helpful/constructive referral pathways and processes that work for people who might need more/different support Build organisational capacity
Building positive practice	Build confidence in workers in having difficult conversations with individual women and children, colleagues and other service providers Build a body of knowledge about alternatives to standard practice that are helpful and useful: <ul style="list-style-type: none"> <li>• for mothers</li> <li>• for children</li> </ul> Develop and sustain local referral pathways and processes for people who need more/different support
Informing policy	Ensure policies include a focus on program and workforce development that specifically prioritises meeting the needs of women and children with disability who are experiencing/recovering from DFV

A key finding from this research is the importance to mothers and children of providers understanding disability as part of the complexity of families, and not taking an overly diagnostic approach. It should not make any difference to a service whether someone has an intellectual disability or an acquired brain injury: to provide effective assistance, they need to know how to provide functional support and information that is responsive to people's receptive and expressive abilities. This involves the core skills of being clear in communication, breaking down information, not relying heavily on written material (such as providing written referral information without checking it is understood), providing more time than usual, giving more frequent reminders about appointments than usual and similar supportive practices as needed.

The positive practice with children with disability identified in our study is an opportunity to enter into early intervention family violence support using a child- and disability-focused approach. Children with disability were almost completely absent as a target group for support in existing family violence initiatives reviewed in this project. While children interviewed for the research were generally welcoming of additional support provided through FRS, they had little experience of contributing their perspectives and ideas about what might help their families. As FRS are redesigned into Family Connect and Support (NSW Government, 2019), clear opportunities can be seen in the child-safety emphasis of the Their Futures Matter reform program to promote

opportunities to prioritise both the needs and preferences of children with disability.

Where the effects of disability are beyond the limit of what early intervention services responding to DFV can support, workers and services need to know how to refer effectively, and in ways that are done consultatively and collaboratively with families. The need to ensure that there is adequate information available to families about the types of services and programs that are available is challenging in a context in which funding for programs is time-limited or restricted to specific jurisdictions, and when information is not available in accessible formats. This problem is common across violence and violence prevention services (Tayton et al., 2014).

The need to build confidence and skill in individual workers is clear from this study. Alongside this sits the need to generate whole-of-organisation capacity to respond to families with disability more effectively, so that services are not reliant on one or two skilled workers. This is needed to ensure that organisations effectively account and plan for the impact of supporting clients with complex lives at different implementation levels, in structural rules and in terms of funding adequacy.

Focused collaboration in the family support and child protection, DFV and disability sectors to build capacity is a priority to support families. Local programs have been

found to be effective at understanding local needs, but would benefit from overarching programs at national and state level to improve continuity in referrals; opportunities for communication and collaboration; education about needs and priorities of women and children; and other effective service delivery models (Frawley et al., 2015; Woodlock, Healey et al., 2014). Actions to support current initiatives can scaffold promising practice into current practice. For example, practical initiatives that recognise and respond to the need to build connection between DFV and disability sectors include providing information, underpinned by the evidence in this research, to enhance training currently delivered in both sectors about responding to violence, abuse and neglect.

To ensure that women and children are successfully referred to other parts of the system, there is a need for training and capacity-building among the mainstream service sector (e.g. housing, child protection, Centrelink) to better recognise and respond when families with disability are experiencing or at risk of DFV.

Improvements are needed to the NDIS guidelines to better recognise the additional requirements for families facing DFV, so that they are able to gain access to funds for support coordination and specialist support coordination where complexity in their family lives is caused by the intersections of disability and DFV. Current limitations in the capacity of the NDIS to support worker training, resource individual capacity-building to build resilience, and fund travel in regional and remote areas need addressing in this context.

# Conclusion

Women and children with disability who have experienced violence have historically not been well served by support systems. This issue is recognised in policies and programs that are designed to redress it. The challenges in making real changes to support systems are significant, and it is important to recognise that current and previous system failures have often occurred despite the goodwill and efforts of researchers, advocates, service providers and policy agencies. Scholarship that draws on intersectionality can provide insights into the nature and intractability of some of these challenges. Intersectionality theory shows that power operates through multiple aspects of social relations, and that the effects of power are experienced cumulatively rather than as the sum of individual identity categories. However, services and systems tend to still be set up along the lines of individual categories and responsibilities, and efforts to integrate these categories often require more resources and take longer to achieve than anticipated.

Despite this, services and people with lived experience have diverse strengths and capabilities, and can draw on resources to meet support needs and ensure the safety of adults and children. The positive practices that are identified in this report are in some respects as familiar as the challenges and failures, but also represent a basis for continued work in improving systems and practice.

The need for national policy to recognise the intersectional nature of DFV and disability and provide pathways for practice is undiminished over time. As new national agreements are in negotiation, the time is ripe to reinvigorate these discussions to ensure that both the national disability and DFV strategies account for embedded intersections and that responsibility for action on violence prevention is not vested in the NDIS.

## Future activity from this research

An immediate practical output from the study that would respond to the needs identified by women, children and providers is the development of a literacy-building resource to assist specialist and mainstream service providers to recognise when mothers and/or children have disability, and to respond effectively. Such a resource could:

- include a brief introduction on the prevalence of DFV among women with disability
- outline the warning signs of DFV (using accessible information like the quiz developed by the Domestic Violence Resource Centre Victoria [n.d.])
- provide suggestions to assist service providers with recognising disability in mothers and children, particularly intellectual disability (for example the information provided by Community Door [n.d.])
- share tips and suggestions for how to respond in ways that respond to the priorities and preferences of mothers and children.

A plain English summary of the research is also a priority output.

The research team will work collaboratively with ANROWS and the women's advisory group in the development of these practice resources.

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## APPENDIX A

# Advertisement



## Invitation to Participate in Research

### Mothers and children with disability using Family Referral Services

Researchers at UNSW Sydney (The University of New South Wales) and the Centre for Children and Young People, Southern Cross University, are looking to interview mothers with disability and mothers of children with who have used some extra support for their family in difficult times. The researchers want to learn about how families with disability can be better supported.

#### Would the research study be a good fit for me?

The study might be a good fit for you if:

- Your or your child has disability
- You needed extra support for your family or have experienced family violence
- You receive support from an organisation that helps families to find the support that they need.

#### What would happen if I took part in the research study?

If you decide to take part we would speak to you and your child on three occasions:

- The first time will be with you and your child.
- The second time will be with just you.
- The third time will be with just your child.

We will ask you about the support you get and how it has helped your family. You and your child can invite a friend or someone you trust to be with you during the interview if that makes you feel more comfortable about talking to us.

#### Will I be paid to take part in the research study?

You will be given a \$30 voucher each time we meet to cover any expenses associated with the research.

#### Who do I contact if I want more information or want to take part in the study?

If you would like more information or are interested in being part of the study, please contact:

Name: [INSERT name of job title]

Email: [INSERT work email address]

Phone: [INSERT work mobile number]

Website: [INSERT website]

# Information and consent form: Plain English—mothers

## Research about Family Referral Services (FRS) that support mothers and children with disability when they need extra support

We are researchers at the University of New South Wales and Southern Cross University. We are doing research on organisations that support mothers and children with disability when they need extra support.

The aim of the research is to find out how good the support is and if it can be improved. The research is being funded by Australia's National Research Organisation for Women's Safety (ANROWS).



I would like to invite you and your child to talk to us 3 times:

- The 1st time will be with you and your child
- The 2nd time will be with just you or with other mothers if you prefer
- The 3rd time will be with just your child

When we talk, I'll ask you about:



- What types of support you are getting
- If the support has helped
- If there is anything you want help with but haven't been able to get help with



Talking to me will take between **30 mins and 1 hour**. I'll ask to record what you say, but if you don't want me to, I can write it down instead. If you speak to me with other mothers, I will need to use the recorder to help me remember what everyone has said. You will get a \$30 voucher per interview as thanks for your participation.



It is your choice to join in an interview. You can say no. It will not change the support you receive, and it will not affect your relationship with FRS (Family Referral Services), the University of New South Wales, ANROWS or any other agency.



You can choose the questions you want to answer in the interview. You can say no if you don't want to answer a question. If you decide to join in an interview, *you can change your mind at any time* and let me know that you don't want to take part.

You can choose to have someone stay with you when we meet if that makes you feel more comfortable about talking to me.



The answers you give will not be shared with anyone else. Your name and personal details will be kept private.



If talking to me makes you feel sad, you can let me know and I will help you find someone to speak to.



You can use the phone numbers and email addresses on the next page to find out more about the research or if you have a question or problem with the research.



If you want to take part, please sign your name on the form that says "I want to take part".



If you want to take part, but do not want to sign your name, I will ask you to say "I agree to take part" when I start the audio recording of the interview.



If you agree to take part, you can leave the interview at any time and sign your name on the form that says "I changed my mind—I don't want to take part anymore".

Thank you,

kylie, Sally and the other researchers

### People to talk to about the research



If you have questions about the research, you can talk to kylie valentine at the University of New South Wales at [k.valentine@unsw.edu.au](mailto:k.valentine@unsw.edu.au) or 02 9385 7800.

If you want to complain or have a problem about the research, please talk with the Human Research Ethics Committee at Relationships Australia— [research@ransw.org.au](mailto:research@ransw.org.au) or 02 8874 8000. Tell them this number: CS03230.

If you feel sad or upset after answering the questions, you can call *beyond blue* on 1300 22 4636 or Lifeline on 131 114 and they will talk with you.







I want to take part in the research

- I am signing this form because I want to join in an interview about organisations that support mothers and children with disability when they need extra support
- I am happy to have my responses recorded
- I understand that if I speak in a group with other young people, the researchers will not be able to destroy the answers I gave
- I understand that talking in the interview will not change the support I get
- I understand that I can leave the interview at any time and ask the researchers to delete the responses I gave
- I understand that I will be given a signed copy of this form to keep

.....

My signature

.....

Write your name here

.....

Date

.....

.....

Signature of someone who saw me  
sign the form

.....

Write their name here

.....

Write how they know you

.....



I changed my mind—I don't want to take part anymore

I am signing this form because I changed my mind. I don't want to take part in the research about organisations that support mothers and children with disability when they need extra support. In changing my mind, I understand that the answers I gave during the discussion will be deleted by the researchers.

.....

My signature

.....

Write your name here

.....

Date

.....

.....

Signature of someone who saw me  
sign the form

.....

Write their name here

.....

Write how they know you

.....

Please return the signed form to:

kylie valentine, Social Policy Research Centre, UNSW Australia, Sydney 2052

APPENDIX C

# Information and consent form: Easy read—children

This can be either viewed on an iPad as a social story or printed out and stapled together as an A5 booklet.

<p>Research about mothers and children with disability when they need extra support Information about interviews</p> 	<p>Would you like to be in our project?</p>  <p>This book is for you to look at to help you decide if you want to be in our project. It's up to you</p>
<p>My name is Ciara. I work at the University of NSW.</p>  <p>My job is to ask people about things that are important to them.</p>	<p>I want to know who you talk to when you need help with different things</p> 
<p>I would like to come and talk to you about who you go to when you need help with different things.</p> 	<p>When we talk I would like to record what you say with my recorder. Then I know I won't forget anything.</p>  <p>You don't have to have it on if you don't want you.</p>

<p>I can keep your story private. When I write my notes and report I can make up a pretend name for you.</p>  <p>That way no one will know that it is your story.</p>	<p>You don't have to say yes. It's ok with us if you don't want to be in this project.</p>  <p>We won't be upset if you say no.</p>
<p>If you start talking to us and then change your mind that's ok too.</p>  <p>If you don't like it you can stop. If it makes you feel bad we can stop.</p>	<p>A family member or a friend can stay with you while we talk if you want</p> 
<p>Do you have any questions? Let me know!</p> 	<p>We'll give our phone number to you and your service provider so you can ring us up if you think of a question later on.</p> 
<p>Thank you for reading this book. Remember you can say yes or no about being in the project.</p> 	

## APPENDIX D

# Information and consent form: Standard English—for children/young people

## Research about Family Referral Services (FRS) that support mothers and children with disability when their families are having a hard time

I am a researcher at the University of New South Wales. I am doing research on organisations that support mothers and children when they need extra support.

The research is trying to find out how good the support is and if it can be improved. The research is being funded by Australia's National Research Organisation for Women's Safety (ANROWS).



I would like to invite you to speak to me on two occasions:

- The 1st time will be with you and your mother.
- The 2nd time will be with just you or with someone sitting in for support if you would like



When we talk, I'll ask about:

- What types of support you are getting
- If the support has helped
- If there is anything you want help with but haven't been able to get help with



Talking to me will take between 30 mins and 1 hour. I'll ask to record what you say, but if you don't want me to, I can write it down instead. You will get a \$30 voucher as thanks.



It is your choice to speak to me or not. You can say no. It will not change the support you receive from FRS and it will not affect your relationship with the University of New South Wales, ANROWS or any other agency.

You can choose the questions you want to answer. You can say no if you don't want to answer a question. It is your choice to tell me as much or as little about your experience/ life as you want.

You can choose to have someone stay with you when we meet if that makes you feel more comfortable about talking to me.



There are lots of ways you can have your say. When we meet, I can show you some ways we can work together so you can have your say about this. You might like to draw, or take photos, or show us what is important to you.



If you want to take part, please sign your name on the form that says "I want to take part". If you want to take part, but do not want to sign your name, I will ask you to say "I agree to take part" when I start the audio recording of the interview.



If you decide to join in an interview, *you can change your mind at any time* and let me know that you don't want to take part.

The answers you give will not be shared with anyone else. Your name and personal details will be kept private.



If the discussion makes you feel sad, you can let me know and I will help you find someone to speak to.



You can use the phone numbers and email addresses on the next page to find out more about the research or if you have a question or problem with the research.



If you want to take part, please sign your name on the form that says "I want to take part".



If you want to take part, but do not want to sign your name, I will ask you to say "I agree to take part" when I start the audio recording of the interview.



If you agree to take part, you can leave the interview at any time and sign your name on the form that says "I changed my mind—I don't want to take part anymore" and we will delete the responses you give during the discussion.

Thank you,

kylie, Sally and the other researchers



### People to talk to about the research



If you have questions about the research, you can talk to kylie valentine at the University of New South Wales at [k.valentine@unsw.edu.au](mailto:k.valentine@unsw.edu.au) or 02 9385 7800.

If you want to complain or have a problem about the research, please talk with the Human Research Ethics Committee at Relationships Australia– [research@ransw.org.au](mailto:research@ransw.org.au) or 02 8874 8000. Tell them this number: CS03230.

If you feel sad or upset after answering the questions, you can call *beyond blue* on 1300 22 4636 or Lifeline on 131 114 and they will talk with you.



I want to take part in the research



I am signing this form because I want to join in a group discussion about organisations that support mothers and children when their families are having a hard time

I am happy to have my responses recorded

I understand that talking in the interview will not change the support I get

I understand that I can leave the interview at any time and ask the researchers to delete the responses I gave

I understand that I will be given a signed copy of this form to keep

.....

My signature

.....

Signature of someone who saw me

sign the form

.....

Write your name here

.....

Write their name here

.....

Date

.....

Write how they know you

.....

.....

I changed my mind—I don't want to take part anymore



I am signing this form because I changed my mind. I don't want to take part in the research about organisations that support mothers and children when their families are having a hard time. In changing my mind, I understand that the answers I gave during the discussion will be deleted by the researchers.

.....  
My signature

.....  
Signature of someone who saw me  
sign the form

.....  
Write your name here

.....  
Write their name here

.....  
Date

.....  
Write how they know you

Please return the signed form to:

kylie valentine, Social Policy Research Centre, UNSW Australia, Sydney 2052

# Information and consent form: Standard English—for stakeholders

## What is the research study about?

You are invited to take part in a research project about building positive practice in early intervention violence support services for families where mothers and/or children have disability. The aim of the research is to provide new knowledge on the impact of early intervention support, with a specific focus on the experiences and voices of women and children with disability. It will address critical gaps in understanding of intervention points at which effective support can be delivered.

You have been invited because you have been identified by your service, the project team or other stakeholders in the sector as representing an organisation with knowledge, expertise or experience about the Family Referral Service or family violence early intervention support to families where disability is a feature. Your organisation's contact details were already known by the project team or another stakeholder with knowledge about this project.

## 1. Who is conducting this research?

The study is being carried out by kylie valentine and B.J. Newton from the Social Policy Research Centre (SPRC), University of New South Wales (UNSW), and Sally Robinson from the Centre for Children and Young People, Southern Cross University.

**Research funder:** This research is being funded by Australia's National Research Organisation for Women's Safety (ANROWS).

## 2. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- read the information carefully (ask questions if necessary)
- sign and return the consent form if you decide to participate in the study
- take a copy of this form with you to keep.

## 3. What does participation in this research require, and are there any risks involved?

If you decide to take part in the research study, you will be asked to participate in either:

- a focus group discussion with other colleagues (approximately 1-2 hours in length), or
- an individual interview with a member of the project team, either by phone or face to face (approximately 30 minutes-1 hour).

The focus of the discussions will be to ask relevant stakeholders to share their views on the facilitators and barriers to supporting families when disability is featured in families. The interview guide can be provided to you in advance.

We don't expect the questions to cause any harm or discomfort. You can withdraw participation at any time, BUT, in the case of the group discussion, your responses cannot be withdrawn because they will be audio recorded with others.

To ensure we collect the responses accurately, we seek your permission to digitally record our discussions using an audio recorder. Focus groups will be audio-recorded. If you would like to participate in an individual interview but do not wish to be audio recorded, a researcher will just take notes.

#### 4. What are the possible benefits to participation?

We hope to use information we get from this research study to contribute to policy and practice in family support and early intervention violence prevention.

#### 5. What will happen to information about me?

The audio recordings will be transcribed and then analysed by the research team. The researchers will use NVivo, a specialised software for large scale data analysis, to code the qualitative data collected as part of the research against a coding framework (based on the research focus areas).

Individual participants' personal details will be kept private and confidential and participants will be personally de-identified in reporting.

By signing the consent form you consent to the research team collecting and using information about you for the research study. Your data will be kept for 5 years after the project's completion. We will store information about you in a non-identifiable format in a secure server at the SPRC at UNSW. Your information will only be used to inform a report on the findings of this research project.

The information you provide is personal information for the purposes of the *Privacy and Personal Information Protection Act 1998* (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

#### 6. How and when will I find out what the results of the research study are?

The research team intend to publish and report the results of the research study in a report that will be submitted to ANROWS and made available publicly on the SPRC and SCU websites.

All information published will be written in a way that will not identify you personally or the organisation or agency you are affiliated with.

If you would like to receive a copy of the results you can let the research team know by adding your email address within the consent form below. We will only use these details to send you the results of the research.



### 7. What if I want to withdraw from the research study?

- If you do consent to participate, you may withdraw at any time. You can do so by completing the "Withdrawal of Consent Form" which is provided at the end of this document. Alternatively, you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with SPRC, UNSW Sydney, SCU or ANROWS.
- If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project. But please note that if you have already participated in a group discussion, your comments along with other participants' will be recorded during the group discussions. Because of the way in which the focus group discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses, but will make sure no one can identify you.

### 8. What should I do if I have further questions about my involvement in the research study?

- If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following members of the research team:

#### Research team contact details

Name	Sally Robinson
Position	Chief Investigator, SCU
Telephone	(02) 6620 3134
Email	<a href="mailto:sally.robinson@scu.edu.au">sally.robinson@scu.edu.au</a>

Name	kylie valentine
Position	Chief Investigator, UNSW
Telephone	02 9385 7825
Email	<a href="mailto:k.valentine@unsw.edu.au">k.valentine@unsw.edu.au</a>

- What if I have a complaint or any concerns about the research study?
- If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

#### Complaints contact

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	<a href="mailto:humanethics@unsw.edu.au">humanethics@unsw.edu.au</a>
HC reference number	HC180342

## Consent form–Participant providing own consent

## Declaration by the participant

I understand I am being asked to provide consent to participate in this research study

I have read the participant information sheet

I understand the purposes, research activities and risks of the research described in the study

I consent to participate in a focus group or individual interview

I understand that the research team will audio-record the discussion, and I agree to be recorded for this purpose

I understand I will not be personally identified

I provide my consent for the information collected about me to be used for the purpose of this research study only

I have had an opportunity to ask questions and I am satisfied with the answers I have received

I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members

I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email address: \_\_\_\_\_

I understand that I will be given a signed copy of this document to keep

## Participant signature

Name of participant (please print)	
Signature of research participant	
Date	

Note: All parties signing the consent section must date their own signature.

## Form for withdrawal of participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with the University of New South Wales, or the Social Policy Research Centre or Department of Social Services. In withdrawing my consent I would like any identifiable information which I have provided for the purpose of this research study withdrawn. I understand that the information collected about me during my participation in the roundtable discussion cannot be withdrawn given the nature of the group discussions that have been recorded.

## Participant signature

Name of participant (please print)	
Signature of research participant	
Date	

The section for withdrawal of participation should be forwarded to:

CI Name:	kylie valentine
Email:	<a href="mailto:k.valentine@unsw.edu.au">k.valentine@unsw.edu.au</a>
Phone:	02 9385 7825
Postal address:	Social Policy Research Centre UNSW Sydney, NSW 2052

## APPENDIX F

# Guide for step one joint interview schedule with mothers and children

1. Tell us about you.
2. Who is important to you?
3. What services do you use? What kinds of supports do you receive?
4. How long have you used these supports for?
5. What kind of help were you looking for before you started using this service?
6. We want to talk to you about FRS and about your views on services, what has been helpful to you and what has been not so helpful.

# Guide for step two individual interviews with mothers

1. Could you tell me more about the supports you were looking for before you started using FRS?
2. Who do you ask when you have questions about a) your family b) what you need in your life, for example, Centrelink Disability Support c) what you can do if things aren't going well or you are in trouble?
3. Who helps you in your daily life?
4. What have services done that you have found helpful in supporting your family?
5. What has not been helpful?
6. What things could help you in your community?
7. Is it ok to need help? Why?
8. Who and what makes you feel safe? Are there times when you do not feel safe?
9. What happens then?
10. How do you feel about changes in your life?
11. What do you find hard about speaking up?
12. What advice would you give someone about speaking up?
13. What do you think you will do/what will change after you stop using the FRS service?

## APPENDIX H

# Guide for step two individual interviews with children

1. Can you tell me about who is in your household/your family?
  - Who helps you when you need help with stuff?
  - Do you help other people in your family?
  - What sort of stuff do you help them with?
  
2. What do you know about the workers who come and give a hand to mum?
  - Do they spend any time with you?
  - Do you know anything about what sort of stuff they help mum with?
  
3. Is there anything you think of that [those ladies/that service] could do that would help your family?
  - [If you could wave a magic wand and make something good happen for your family, what would you make happen?]
  
4. What will help you in the next little while to be happy and safe?



# Interview guide for Family Referral Services providers

1. How do families come into your FRS?
2. What supports/services can/do you provide to active clients?
  - intake
  - casework
  - exit
3. How do you recognise disability? For mums? For kids?
4. How do you respond to disability? For mums? For kids?
5. Regarding your work creating linkages in the community, what is working locally to support collaborative practices?
  - What are the challenges/gaps?
6. More broadly, how well do FRS/early intervention recognise and respond to these families?  
(person-centred, time-focused)
7. What is your opinion on the capacity of your service and other services in the community to support families where disability (diagnosis or lived experience) and violence (or risk of) are present?
  - What's working well?
  - What isn't?
  - Gaps?
  - Child protection developments/concerns
  - Police engagement
8. What improvements do you see are needed?
  - Between services and clients
  - Between services
  - Between services and government/political bodies

## APPENDIX J

# Interview guide for stakeholders

1. What is your understanding of early intervention violence prevention?
  
2. What are some of the key issues affecting the capacity of early intervention violence prevention services in the community to support families where disability (diagnosis or lived experience) and violence (or risk of) are present?
  
3. What underpins effective integrated/collaborative practice to support mothers and children with disability?
  - a. What's working well in the sector(s) with which you are familiar?
  - b. What isn't?
  - c. Gaps?
  - d. What is the quality of intersections with other jurisdictions (e.g. disability services; criminal justice; child protection)?
  
4. Can you comment on the strengths of the Family Referral Services model?
  
5. What innovative practice have you seen in FRS?
  - In service design
  - In service implementation
  - Between services and clients
  - Between services
  - Between services and government/political bodies
  
6. What barriers to effectiveness in the Family Referral Services model can you identify?
  
7. What improvements do you see are needed?
  - In service design
  - In service implementation
  - Between services and clients
  - Between services
  - Between services and government/political bodies

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AUSTRALIA'S NATIONAL RESEARCH  
ORGANISATION FOR WOMEN'S SAFETY

*to Reduce Violence against Women & their Children*

