

**Submission to the Royal Commission into Violence, Abuse, Neglect and
Exploitation of People with Disability**

***‘We should not be punished for having a
disability.’ Recommendations for reforms to Child
Protection, Family Services and Disability Systems
from Parents with a Disability***

A submission to the Disability Royal Commission from Family Inclusion
Network Australia with input from Positive Powerful Parents Self Advocacy
Group.

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1. Background to This Report

This report has been created for groups associated with the Family Inclusion Network Australia (FINA) including FIN Townsville, FIN Southeast Queensland, FIN Victoria, FIN Western Australia; Positive Powerful Parents Self Advocacy Group (PPP); Family Inclusion Strategies in the Hunter (FISH); the Reily Foundation in South Australia; and, parent co-researchers involved with the University of Sydney with assistance from Dr Kate Fitt and Dr Christina David of RMIT University. The purpose of this report is to highlight key problems and share ideas from parents and their supporters with the Disability Royal Commission about what might work to better support parents with a disability and their children in contact with child protection and welfare systems. FINA and PPP gathered feedback from their members and associated groups and gave reports documenting key issues with these systems and recommendations for reform, based on their lived experience, to Drs Fitt and David to analyse and to help write this report. This report relies heavily on direct quotes from the consultations to ensure the voice of parents and their supporters remain at the centre of the discussion of what is needed to make services systems fairer and more supportive and safer for parents with disability. All quotes included in this report are formatted in italics.

The feedback reports from the organisations did not identify which comments were from parents or supporters however we are aware that the majority of respondents are parents living with disability and the majority of quotes are from parents with disabilities that include physical, neuro-developmental and intellectual disability. Many of these parents are experienced in making public response about the issues faced by parents in the child protection context.

Whilst this report focusses on recommendations for change to reduce discrimination, systemic violence across the Child Protection system, and to promote rights based and family centred reforms, it recognises that the issues do not begin nor end with that system. The types of neglect, violence, abuse or exploitation outlined in this report and to which we are responding are difficult for others to understand and respond to because they are pervasive, systemic, and are often invisible to those who are not impacted.

Who We Are:

Positive Powerful Parents

Positive Powerful Parents is a self-advocacy group established in Victoria in 2012 and is run by and for Parents with Intellectual Disability. PPP strongly believes that every parent with intellectual disability has their own unique way of parenting and the voice of parents with disability needs to be heard and actioned.

Family Inclusion Network Australia

The Family Inclusion Network of Australia is a collective of family inclusion groups throughout Australia that promote family inclusive child protection practice and the rights of children to experience family inclusion. It first began in Australia in 2006 and formed a national network in 2010. The groups share common principles but are operated differently in each location. Some receive funding support from government and /or philanthropic sources and others rely wholly on volunteers. All support the notion of supporting a parent led or co-led organisation that aims to support parents and families caught up in child protection systems.

FIN groups that contributed to this report:

FIN Townsville: <https://fin-qldsv.org.au>

FIN Southeast Queensland: <https://finseq.org.au>

FIN Victoria: <https://www.finvic.org.au>

FIN Western Australia: <https://www.finwa.org.au>

Member organisations of FINA that also contributed to this report:

Family Inclusion Strategies Hunter

FISH promotes family inclusion and family inclusive initiatives including peer parent and family advocacy and support. FISH provides parent advocacy at an individual /group/community and systems level. Our objectives and a broader description of FISH activities are at: www.finclusionh.org

The Reily Foundation

The Reily Foundation supports parents, families, and carers to navigate the child protection system through targeted education, therapeutic support, and advocacy. We provide therapeutic tools to help parents to work with the Department for Child Protection in

addressing parenting concerns and building protective capacity within the initial investigation phase and beyond: <https://thereily.foundation/>

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List of Acronyms Used in This Report

ASD: Autism Spectrum Disorder

CP: Child Protection

CPS: Child Protective Services

CSO: Community Service Organisation

DRC: Disability Royal Commission

DCP: Department of Child Protection

PPP: Positive Powerful Parents

FINA: Family Inclusion Network Australia

FISH: Family Inclusion Strategies Hunter

NDIA: National Disability Insurance Agency

NDIS: National Disability Insurance Scheme

3. Plain English Summary of This Report

The Disability Royal Commission (DRC) wants to look at how services should change to make sure people with disability can be safe.

- Dr Kate Fitt and Dr Christina David helped parents and their supporters from Family Inclusion Network Australia (FINA) and Positive Powerful Parents (PPP) write this report.
- 30 people from FINA groups and PPP helped give ideas and 21 of them were parents with a disability.

There are a lot of ideas from parents about how to make services fairer, safer, and better in this report. The ideas from the parents and their supporters have been put into five main groups for the Disability Royal Commission:

3.1. Justice: (Listen to parents and treat them fairly)

- Help parents with disability keep their children
- Stop discrimination: stop treating parents badly because they have a disability
- Listen to what parents have to say
- Make sure what workers write down about parents is true
- Parents should have an advocate

3.2. Supports:

- Make sure workers always ask parents what help they need.
- Give help that is right for the parent.

The right help looks like:

- Services or programs that help parents look after children at home.
- Support for parents who have had their children removed to get their children back.
- Services and workers that know how to work with parents with a disability.
- Changes to the NDIS so that it can help parents build parenting skills and fund specialised workers to help with children at home and in the community.
- Funding for parents with a disability that can be used quickly to get the help they need to keep their children.
- Parent education programs that are accessible. For example, training at home, using easy English and training for a longer period of time.

3.3. Strength based approaches:

- Workers should treat parents with respect
- Workers should look at what parents can do.
- Workers should listen to parents.

3.4. Value children's relationships:

- Help children stay connected to their parents, family, friends and support networks

3.5. Workforce skills, knowledge and capability

- Workers need training about how to work with and help parents with any type of disability, especially intellectual disability.
- Workers need training to stop discrimination and understand family's rights.

3.6. Recommendations

These ideas have been turned into four recommendations that we hope the Disability Royal Commission will think about. Any changes to services and laws should be developed with parents with lived experience of disability and child protection:

3.6.1. Independent non-legal advocacy:

- Include parents with disability and an advocate in decisions about the children.
- Talk to parents with disability about how to make services better.

All parents with disability should have an independent advocate if they want one. Advocates help parents to:

- know about their rights

- understand the child protection system
- understand what child protection want parents to do to keep their children safe
- know about the types of help a parent needs
- support parents to get the help they need
- help a parent speak with child protection and other services about keeping their children safe.

3.6.2. Review of complaint systems:

- Make sure there are proper reviews of child protection and other services when things go wrong. Involve parents in these reviews.
- Change laws and policies (the rules for child protection workers and parents) that make it hard or unfair for parents with disability.
- Review complaints systems to make sure it is fair for families. This includes child protection complaints, or organisations like the ombudsmen or appeal tribunals.
- Stop systems which allow workers to document and use the wrong information to take children away. Change laws and policies so these problems can be fixed.

3.6.3. Fund parents with disability:

- Tell the NDIA that parenting is a good goal to put in an NDIS plan and that it needs to be funded.
- Make sure all parents can access a flexible funding package and an independent coordinator so parents can get the type of services that would work best for them and their children. This should happen early when the mother is pregnant.

3.6.4. Recreate the Healthy Start Network:

- There needs to be a service where workers can get good information and ideas about working with parents with disability when they need it. This should include having experts about working with parents with a disability and parent peer mentors.

4. Key Areas for Reform in Child Protection and Welfare Systems

The injustices and experiences of parents with a disability in child protection systems across English speaking countries is well documented within research (Albert & Powell, 2021; Collings, Spencer, et al., 2018; LaLiberte et al., 2017; Macintyre & Stewart, 2012; McConnell et al., 2021; McConnell & Björg Sigurjónsdóttir, 2010; McGhee & Hunter, 2011; Tarleton, 2008) and is worse for parents with multiple characteristics for which discrimination is common such as First Nations' parents with disability (Collings, Dew, et al., 2018).

What is not well-documented are the suggestions of parents with a disability and their supporters of the types of programs, strategies, attitudes, and behaviours society needs to develop to create a safer society for all of us. As such, this submission is informed by the lived experience and insights of parents with disability and their supporters to respond to the final Disability Royal Commission question that asks for recommendations for change.

This report is based on a set of documents (referred to as the consultations in this report) created by representatives of Positive Powerful Parents (PPP) and Family Inclusion Network Australia (FINA). The consultations were with parents with disabilities and their supporters and focussed on suggestions to make the child protection system safer and more inclusive for these families. The analysis of consultations highlighted deficit-based approaches to disability and identified that parents and their supporters believe the best way to reduce systemic violence, abuse, neglect and exploitation of parents with a disability in the child protection system is to work towards providing stronger proactive supports and a fair go. The message from parents and their supporters is that they hope for a system that is fair, non-discriminatory and respectful. All recommendations made suggested flexible, well-resourced and fit for purpose supports provided in a respectful and timely manner that engages with parents and families as partners who may have some difficulties but who also have strengths. The recommendations are informed by a recognition that children's rights to safety, family, and trusted relationships should be privileged even when parents and children are not living together, and that upholding children's rights and parents' rights are not mutually exclusive.

The overarching theme of justice pervaded the consultations. In this research justice is understood in Australian colloquial terms of ‘a fair go’ and of equity and respect. This understanding fits within scholarly understanding of structural injustice or structural violence “as a moral wrong resulting from unintended consequences of institutional and individual action in the pursuit of other interests” and that (Burnett et al., 2018, p. 57) to achieve structural justice a “moral responsibility” and “action-orientation” is required (Burnett et al., 2018, p. 57)..

Perceptions of how a fair go might be achieved are demonstrated throughout the sub-themes of justice within systemic processes, the provision of supports, strength-based approaches, valuing children’s relationships and ensuring professionals have adequate knowledge of how to work respectfully with people with disability.

4.1 Justice within systemic processes

The feedback from parents highlighted experiences of systemic injustice at all levels of the child protection system, characterised by a power imbalance and discrimination on the basis of disability and resulting in the unequal and unfair treatment of parents within this system and legal framework. Key messages from parents relating to justice in systemic processes are the need to reduce discrimination against parents with disability, increase respect for the rights of parents and their children, and reduce unfair and inhumane outcomes that result from inadequate and misleading collection, checking and storage of evidence used against parents. Key areas for reform, in order of frequency of reporting in the consultations, included: discrimination and bias reduction; rights; advocacy; and, issues relating to incorrect reporting and evidence.

4.1.1 Address discrimination and bias

The consultations identified systemic discrimination of parents with disability with disability either seen as synonymous with deficit and ‘inherently risky to children’ or ignored in assessments as a factor to be considered in order to provides the right support. The following quote demonstrates this discriminatory paradox:

We had two different kinds of experiences – one, the disability with a negative frame was all that CP workers saw. Disability seen as abusive and neglectful, and a deficit focus brought. The second way didn’t seem to “see” the disability at all.

As shown in the following quotes, these sentiments were repeated throughout the consultations and also highlight that accessing disability supports which should reduce child protection interest can instead exacerbate the response from child protection:

- *We should not be punished for having a disability.*
- *There is an underlying belief or assumption in the CP system that parents with intellectual disabilities can't parent and that disability is inherently risky to children. This is both a belief and a bias. This needs to be flipped and ask instead what supports are needed to help parents succeed.*
- *Conflicted about NDIS funding, on the one hand it is helpful to have, but they also feel it is used against them by DCP.*
- *If a parent with disability has a baby this is seen by CP as a form of abuse and neglect in itself. This is wrong and incredibly damaging for children and families. Having a disability is not child abuse.*
- *Ensure that all workers have regular discrimination training, case study-based professional development, bringing in guest speakers with lived experience for training sessions (i.e., a mother with ASD who has been able to raise all of her children independently compared to a mother with ASD who has had their child removed at birth.*

4.1.2 Rights

While some parents referred to human rights concepts such as the United Nations conventions or the right to be treated as an equal and valued citizen, more common were comments that indicated to the researchers that respecting parents with disability and their children's human rights remain a current issue. These types of comments were used by parents to justify reform suggestions noted throughout this document. For example:

- *CP should be aware of the UN Convention and follow it.*
- *Parents with disabilities are treated like second-class citizens by child safety.*
- *Child safety judged me, discriminated against me; had 'pet names' for me.*
- *I was ordered to terminate my pregnancy. I was given no support afterward.*
- *After the birth of her youngest child the Department ordered her to have a Mirena.*
- *I was not allowed to speak in my traditional language with my children or teach them my culture.*

- *In my own case I felt that I was interrogated in that initial meeting, having been given no information as to CPS concerns. I had to think and respond on the spot and felt that my interaction was evidence used against me.*
- *Was not allowed to breastfeed as they accused me of using drugs—which I never did. My drug test was negative.*
- *Was voicing her right to take the time to read documents before signing. She was then pressed by her CSO worker who asked if she was prepared to read in the court papers that she was refusing the referral.*
- *They need to remember how lonely it feels to have child protection. Lots of workers judging and stuff, but it feels like no one sees you, knows you, or cares about you.*

4.1.3 Advocacy

Suggestions for change included practices from macro to micro levels that should already occur in an effort to ensure intervention into a child’s life is based on a fair and meticulous process such as: including parents in decision making processes; including parents in service system or program development; checking the history of potential carers; only using evidence that has been verified, without bias and which is not exaggerated; giving parents the right to check information about them before it goes to court; ensuring that fair and informed decisions are made which includes having insight into power imbalances and false or misleading allegations; professional collaboration and evidence checking; and a non-discriminatory evidence based approach. It is in these cases that independent non-legal advocacy was suggested to assist in a timely and informed manner.

- *If you are not at the table, you are on the menu.*
- *All parents should have access to an independent non-legal advocate. It shouldn’t matter where you live or what part of the child protection process you are in. (Even when the case has been closed).*
- *Provide a peer parent advocate as a part of the team, someone who can take a step deeper and relate to the parent and provide emotional support.*
- *Allowing friends/families to accompany them to meetings or appointments and let the friends/families to assist them and help them talk, would be helpful.*
- *Staff should be trained to understand coercive control and how they are often used in a battle. You need to learn to be curious rather than judgemental.*

- *Remember some children have good grandparents and some have bad grandparents. Some of us had manipulative parents and when we became parents the grandparents are listened to. Nobody checks if they use family violence like manipulating services to write bad, negative, things about us. They talk about coercive control from men, but not from grandparents or foster carers. It is too hard to fight this by yourself when you have an intellectual disability.*

Communication was highlighted as important and relevant to a parent's capacity to function within and navigate the system. Many parents also need support and advocacy to communicate and be properly heard. The following list are examples of suggestions to improve communication:

- *..... birth families can be updated by foster families with photos of the child, information on what they're up to and how they're progressing, and encouragement from CPS for carers to take part in this.*
- *Ensure that families are kept aware of the process at every step and interval including 6-week check-ups*
- *Families should also be provided with minutes of all meetings.*
- *List abbreviations that child protection uses.*
- *Regular meetings should be held - monthly or two monthly until the final trimester and increased frequency to a fortnightly minimum within the last month of pregnancy - allow enough time for families to ask questions and seek the help that they require, at a place that is mutually agreed as being safe and convenient for all involved.*
- *They must understand how to simplify the message and make it more relatable to birth parents.*
- *Throughout the process active communication and transparency should be happening between the parents and all services - this includes upcoming dates, meetings, discussions, and evaluations, as well as having regular meetings with the parent throughout the pregnancy and post-birth process.*
- *Would be helpful to have alternate ways to understand information, eg videos.*

4.1.4 *Solve problems with evidence collection and use*

The need for advocacy and effective systems of review is compounded by the tendency of some workers to work on assumptions rather than evidence and inaccurate and incomplete documentation and reporting. An example is incorrect case notes and reports which are in turn taken as 'fact' and subsequently influence key legal decisions.

Workers have to remember that substantiation doesn't mean it's proven. It's just that a worker thinks there is a problem - but that worker might think just having a disability is a problem and so it's called substantiated. This isn't fair and it tricks the magistrate into seeing problems that aren't there.

The following quotes add further insight into the issues associated with the creation of the case against parents based on incomplete or inaccurate information:

- *Child Protection workers should tell the truth.*
- *There needs to be better ways to check that child protection are writing true information. I want to say they lie, but maybe some of them just don't know how to work out what is real.*
- *CP should have actual evidence of what the risk a parent is and not use a possible risk of harm ... Example: ... it was assumed the parents might put the children at risk of harm and abuse by others but there was no evidence of this.*
- *Verify information given - look at evidence given to prove allegations are false.*
- *CP should say sorry for mistakes made.*
- *Parents should be given the opportunity to suggest correction to incorrect information in court documents well before court. If incorrect information, from the parent's perspective, is still contained in the court documents at the court hearing, the parent should have the opportunity to tell the court. If this is found to be the case, the documents should be appropriately edited so that the record for the future is correct.*

4.2 Support

Parents and supporters described a complex child protection and welfare services system that is difficult to navigate and which often does not offer the personalised and timely supports families need. They identified a key need for improved and more tailored supports for parents and families engaging with these systems in the community and at home. Priority areas for

support were system navigation, supports in the community, supports in home, improvements to the NDIS, flexible funding and long term supports.

4.2.1 Navigating Systems

When parents and their supporters refer to the system, they are referring to all services and supports that affect the family. This may include child protection, child and family services, maternal and child health, allied health services, schools, legal supports and more. The following quotes highlight parents' and their supporters' need for a system that is easier to navigate and function within, that includes the provision of timely supports that respond to their unique circumstance, and which improves how supports within and beyond the child protections system are provided.

- *System navigation urgently required for families*
- *System navigation is a big problem. Many parents may be able to access NDIS supports to care for children but this needs to be flexible and timely. Some people described situations where family contact was being supported by NDIS provider while also having a CP funded supervisor present – this is duplication and damaging, too much surveillance and not enough support. Surveillance is not support. Parents with disability and their kids need flexible support and help – not supervision.*
- *System is very hard to navigate. It is incredibly difficult to get psychiatric help and counselling help. It can take years.*
- *The waiting time for the NDIS and the whole system is stuffed up. It takes too long to get approval for changes and the system is really confusing and you don't know what answer to give.*

4.2.2 Supports in the community

Parents outlined characteristics of workers and services that they had found useful and positive. These included those which offered timely, personal, and family focused support. Following are examples from parents of supportive services in the community with which they had had positive experiences:

- *Supports/Ideas for Improved Practice*
 - liked the last CSO-good with her and her kids*
 - NDIS-lovely support*

-Community mental health group-positive connections and activities

-SW [social worker] at the hospital/offers ongoing support

Further to this, parents highlighted the importance of and need for co-ordinated services and community resources which would enable wrap-around supports such as a circle of support around the family, not just the child. For example:

- *Services should build a circle of support for the mother - not just support the child and dump the mother.*
- *There are not enough supports in place (in the community) to keep families together, this should be a priority.*

The consultations also highlighted that many services were not equipped to support parents with disabilities. The following is an example of a homelessness service which excluded a family on the basis of the parent's disability.

- *I was initially referred to existing services for parents at risk of homelessness, but when it was discovered at the interview point that I had a disability it was inferred that because I wanted to have my support team on the premises, I was an unsuitable candidate. Further, I was told that if I was in danger of having my baby removed, it was also an unsuitable placement for me. This then made me doubly vulnerable to having my baby removed from birth because of homelessness and my disability.*

It was also noted that at times, accessing services presented a dilemma for parents as it was used against them by child protection which held the potential to be both biased and lacking an evidence-based approach to decision making:

- *In my own case, formal supports were considered by the worker to be too many supports and it was stated that a child should only have one or perhaps two attachment figures, intimating that my child would be confused by too many people being involved, yet embracing many people being involved if they were informal supports. That same child, once she was born, was placed in fulltime childcare at 6 weeks of age but there was no acknowledgement that she must have formed attachment to early learning educators. There was also a distinct lack of understanding that the formal supports were there for me, not my baby.*

The issue of services acting as surveillance was also raised. Some parents expressed concern that some services were there to surveil them, rather than support them and their children. The example of a parent and baby unit was raised with one parent highlighting their benefit whilst another called for them to be ‘banned’. These conflicting views are likely based on different experiences with such services where the first parent was excluded from the service and the second had accessed the service. For example:

- *Before a new-born is removed, birth parents should be given the opportunity to parent in an environment where 24/7 supports are available, and skills can be taught. In this environment, there should be specialized disability supports available where necessary and the parent should be able to continue using their usual supports.*

Conversely:

- *Mother and baby units should be banned. They don't work for parents with disabilities and they are biased. They do what child protection tell them to do. Their reports are not checked for bias and exaggeration.*

Related to the above were requests for services to address the shortfall in education, training and support options for parents and families. For example:

- *There is no appropriate parent education to support parents with intellectual disability before and after the birth of children that is accessible or in plain or easy read English.*
- *Parents are not given education or skill development to get their children back. Example: often a magistrate will put in the orders that parents enrol in education such as parenting courses, but there is very little to nothing available if you do not have your child at home with you or even if you do have your child.*
- *Instead of just training the mother, family and friends should do the training with her so everyone is doing the same thing and there's more good help.*
- *Acknowledge that any parent training or education for a parent with intellectual disability will require a longer period of time.*

The following table includes examples of community-based services and practices that were found to be helpful or recommended to be made available (non-italicised are paraphrased):

Table 1: Suggested community supports and helpful practices	
Legal and procedural support	<ul style="list-style-type: none"> • Support in everyday services such as doctors and hospitals to assist in understanding documents and forms • <i>Specialised child protection legal support</i> • <i>Independent non-legal advocate</i> • <i>Peer, family and disability advocates</i> • Plain language explanations of child protection and legal processes e.g. <i>Steps To Speaking Up</i> • Support to challenge legal decisions in the child protection context similar to the Bridge of Hope Innocence Initiative operating in the criminal justice area.
Parent education	<ul style="list-style-type: none"> • <i>Education or skill development to help get children back.</i> • <i>Courses and peer support workshops</i> • Specific programs e.g. <i>Conversations at the dinner table; Circle of Security – disability version; Australian Institute of Social Relations - Restorative Relationships</i> • <i>Financial counselling</i> • <i>Lactation support provided for birth parents affected by separation</i> • <i>Developmental Educators</i> • <i>CPR</i>
Therapeutic	<ul style="list-style-type: none"> • <i>Art therapy</i> • <i>Designated bereavement room/space in birthing places that has supervisory supports available for families in grief/mourning and for families undergoing separation to say goodbyes.</i> • <i>3 monthly checks ups which include access to counsellors/therapists for family.</i> • <i>Lived experience communities</i> • <i>Counsellors and psychologists</i> • <i>Mental Health Social Workers</i> • <i>Grief counsellors and services</i> • <i>Alcohol and drug services</i> • <i>Occupational Therapists</i>
Wrap-around and flexible support	<ul style="list-style-type: none"> • <i>A comprehensive professional support team for families - including independent social workers, counsellors/grief counsellors, and access to therapists</i> • <i>Specialist disability coordinator</i> • <i>Funding pools to support families and children eg: childcare and NDIS</i> • <i>Low-income supports, loans, foodbanks, vouchers, baby and children supplies, etc.</i> • <i>Increased access to NDIS specific resources such as Support Co-ordinators who have worked with CPS clients in the past, or Disability Agencies</i>

	<ul style="list-style-type: none"> • <i>Homelessness/ housing support for parents with disability</i> • <i>Public transport</i> • Financial assistance to cover costs associated with access such as transport, food, activities, nappies and wipes • Flexible funding that allows for parent input about choice of service and choice of support workers to assist in the home and in the community • <i>Playgroups</i>
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4.2.3 *Supports in home*

The focus of suggestions for in home support was on flexible, responsive and practical assistance. It was suggested that this support should be provided before reporting to child protection services which indicates that mandatory reporting may lead to a legalistic rather than practical response to parents. Included in this is the recognition that the parent and informal networks of support require assistance:

- *Give us a fair go to raise our children at home with supports and help*
- *Wanted to be supported to raise her children at home: supported before reported*
- *CP should help parents get support in the home*
- *Get help with addressing issues eg: cooking, cleaning, shopping. And, you should be able to choose the home helpers like they do in the NDIS.*
- *Parents should have access to someone to give you help when you need it and how you need it.*
- *Practical support – the Dept is focusing on admin or ‘their frameworks’ and big meetings and legal processes – when what would help would be practical things like money for a new phone that got smashed when the young person was angry, money to help with public transport to ensure the young person gets to work or school.*
- *Support the supporters - e.g.: if a grandparent, friend or other is helping out, workout how to help keep them helping out - support them*
- *Respect and value should be given to all support networks*

4.2.4 NDIS, flexible funding and service provision

It was suggested that issues of accessing the right support at the right time could be addressed with the use of flexible funding. There are many parents with disability who cannot access support through the NDIS and others who find that the NDIS is not adequately flexible for those who can. For example, *“Flexible funding where families have a say about the services they can access - a system like the NDIS.”* Parents felt this would enhance their choice and control regarding funding and services with positive flow on outcomes for their families.

Suggestions also included the need for a support co-ordinator, similar to those in the NDIS, be made available to families who needed additional support to co-ordinate services. This person would have relevant expertise and knowledge of the service system:

A person with a disability with an NDIS plan is allocated funding for a Support Co-ordinator where it is considered they need help to find and co-ordinate supports; it would be helpful if such a resource were available within the CPS system or independently – one person with their finger on the pulse of multiple resources.

Key suggestions to address access to supports included the need to restructure criteria and processes involved in parents accessing personalised and flexible funding. This indicates the need to consider the competition or gate keeping that occurs across organisation, state and federal boundaries. For example:

Restructure the funding criteria at child protection, the flexible funding used to support parents to keep the children in the home should be easy to access and not in competition between mental health, the NDIS and child protection.

Parents suggested such a service should be managed externally to the child protection and/or disability systems and should include family centred and proactive supports beyond the removal stages of system engagement with child protection. This also indicates early mandatory reporting is not effective in ensuring an adequate response for parents with disability and their children. For example, *“Pre-birth notifications for parents with disability should not go to child protection - they should go to a specialist disability coordinator to get help and training early”*.

There were also suggestions for changes to the NDIS to better support parents with a disability that were able to access this system. This included clarity about the inclusion of parenting being a valued goal and integrating parenting support and training with a “*strengths and capabilities focus.*” Parents also identified problems associated with lengthy wait times for NDIS funded supports and barriers related to the complexity of the NDIS system and services. A further suggestion was the need for closer liaison between the NDIS and child protection systems in order to optimise resources, reduce ‘over surveillance’ and ensure more timely, expert and respectful support:

- *We can and should use existing funding pools to support families and children e.g.: childcare and NDIS can mean families have considerable support if applied flexibly, strategically and collaboratively with people with disability and their advocates /support people in the driving seat.*
- *There needs to be very close liaison between the NDIA and child protection in order to make sure expert, specialist advice is available when required. External to child protection situated in the NDIA.*
- *With NDIS I feel judged by support workers because my children are in care.*

4.3 Strength-based approaches

The consultations called for a shift from deficit to strengths and capabilities based approaches and working *with* rather than *doing things to* parents and families. This would involve a cultural and attitudinal shift in many services and has significant implications for worker development and training.

4.3.1 Focus on respect and strengths

The consultations provided many suggestions to overcome what parents perceived as a misuse of power and highlighted key issues regarding the deficit based and often adversarial nature of engagement between families and child protection and family welfare systems with a focus on the qualitative nature of the working relationship between parents and practitioners. For example, “*If I can change one thing it would be workers having an open mind asking what the parent needs help with and working together to be a better parent.*” However, the analysis revealed parents’ and their supporters’ experience of the child protection and family welfare system as ‘pessimistic’ about the capacity of parents with disability, as demonstrated by the following quote:

The system is very pessimistic about parents with disability – little hope for children. This is misplaced and more hope and optimism about the capability of families is warranted. Parents want a better life and want to be good parents. They need support but they face enormous barriers.

Suggestions for reform identified in the consultation include a shift to strengths-based approaches (as opposed to deficit based) at all stages of engagement, reforms to assessment, increased capacity for the system and workers to ‘listen’ to parents, and improvements to how information is explained and given to parents. This shift would include increased patience with parents and an acknowledgement of the way parents process information under extreme pressure, as well as the fear and distrust informed by previous experiences. For example:

Be patient, sometimes parents have a reason not to trust the department. As a manager if you only see the worst in people and can't change your view, retire.

The overwhelming message from the consultations is that professionals need to work with parents in a respectful manner, develop strategies to better include parents, offer supports earlier, and begin with and maintain a focus on strengths of parents and their families. Parents and supporters asked for workers who “*don't talk down to them, show them respect, include them, talk to them with words they understand, offer clarification*”. They also stressed the importance of workers partnering and working *with* them rather than just doing things *to* them, as the following quotes demonstrate:

- *Parents need workers who will partner with them and help them – not assess and do things to them.*

And:

- *Better training for maternal child and health nurses - who are bullies, judgemental and rude. Work on engagement skills. The 'big stick approach' is not ok. Having an intellectual disability doesn't mean that a 'big stick' approach is ok.*
- *Learn how to negotiate and communicate more effectively. Difference is not defiance or a sign of lack of insight.*
- *It is scary being a new parent and asking for help or having a different opinion to the worker (this includes child protection, teacher, MCHN [Maternal and Child Health Nurse], doctors etc) can lead to the worker acting defensively or aggressively.*

Conversely:

- *Midwives at hospital were helpful- were very comforting and reassuring, explained things well, showed clients how to do things instead of just telling.*

4.3.2 Assessment

The assessment phase is where there are opportunities to engage positively with parents and establish a positive working relationship between the parent and the worker and system.

Parents advised that assessment should be conducted in a comfortable environment informed by a strengths-based and relational approach rather than clinical diagnostic models which have been described as ‘outdated’ and not accurately reflecting individual parents’ capacities and abilities, as demonstrated below:

- *Assessments shouldn't be done in strange offices. It should be done where the people are comfortable.*
- *CPS and other services should be genuinely looking at what strengths (NOT difficulties) the parent has and drawing upon those to work with birth parents instead of severe – moderate – minimally impacted system model. Within the autistic community, for example, there has been a movement to remove outdated labels of severe, moderate, and low in terms of social functionality, because it is now scientifically recognized that neurodiversity manifests uniquely in everyone. In other words, the label given and the assumptions that could be made from the label or assessments may paint a picture of the parent's ability to parent that is not necessarily accurate.*

The need to consider the situation of the parent from a broader perspective was also noted:

- *Parents separated from their children often are on Job Seeker payment with ‘mutual obligations’ - not all parents with a disability receive a Disability Support Pension. They are expected to drop everything for both Centrelink and CPS – it would be helpful if there was more understanding and flexibility around expectations.*

Parents also noted that while training to work with parents with disability is vital, it is important that the entire lived experience of the unique parent be considered and responded to. Issues of trauma, grief, loss, and family violence were noted as reminder that human

emotion common to many should not be viewed as a deficit as demonstrated in the following quotes:

- *Acknowledge and respect that there may be denial and shock, anger, spite and resentment, despair, hopelessness, numbness, depression, or shame, all reasonable responses given the circumstances.*
- *Ensure that all caseworkers receive professional development training in understanding grief as a process and that removal is a grief process for all involved.*
- *All workers, carers and support services working in the out of home care system need to be trauma informed and trauma trained, all children in the system are traumatised, just being removed is enough.*
- *Ensuring that appropriate information and training are undertaken by workers towards understanding what trauma is, and how to approach someone going through the trauma. Giving families and parents access to counsellors and trauma therapists from initial meetings.*
- *When the worker informs the family about the removal of their child(ren), there should be an acknowledgement of trauma, and that families would grieve this loss in a similar way to if the child had died.*
- *Healing from domestic violence – how do we (protective parent and young people) heal from what the dad put us through? Violence is our only trigger – but that damage is now our barrier too.*

4.4 Valuing children's relationships

The purpose of all suggestions for service system improvement from parents and their supporters is to ensure that parents and children can maintain a meaningful long-term relationship. However, at times, this purpose appears to be lost from view in how legal, protective, and welfare systems and processes operate. Despite human rights conventions that support the child's rights to their family, parents' right to receive support to parent and to avoid arbitrary and/or inhumane treatment of both, the experiences of parents and their supporters indicates the supports to uphold and promote these rights is frequently inadequate. This includes lack of good support to help children, parents, extended family and carers (where relationships have been established) to maintain relationships when children are living in out of home care or return home, as demonstrated in the quotes below:

- *Children's hearts are broken because they are not living with their mums.*

- *Parents with intellectual disability are not given education and support to have meaningful relationships with their children who are in out of home care as they grow older.*
- *Help parents to maintain relationships with children and to keep working on issues so that when children turn 18 and come home there is a relationship and better understanding of how to support a young adult; six weeks before they leave care is not helpful.*
- *Child Protection needs to remember that children need their families and start supporting and helping parents with a disability.*

A further request is for workers to recognise the myriad of processes and practices that work to damage the child's relationship with the parent. For example:

- *Would not let mum give Christmas gifts to her children.*
- *Cannot celebrate each child's birthday and does not get to see them on her birthday/does not get them on Mother's Day.*
- *The carers celebrate ... the child's removal date as opposed to his actual birthday.*
- *Cannot attend any special activities at the school.*
- *Always supervised access is making a child feel the parent was unsafe.*
- *CP should fix issues with the supervision at access.*

A variety of relationships, such as with school peers and carers that are important to children, was also recognised. For example, it was noted that workers should not come to schools in recognisable government cars and embarrass children in front of their friends:

CSOs have to be sensitive to children and not show up in kinship cars and flash their badges at school because this has led to bullying of her children.

Parents and supporters also noted the importance of maintaining relationships with carers and their extended families:

- *You do not want it to be the way it is, but it is kind of nice having grandparents [carer's parents] in her children's and her life – her grandparents are deceased.*

- *I think it's also good if carers have bonds/relationships with a child even when they return home. My youngest still has a good friendship with one of her foster carers.*

4.5 Workforce skills, knowledge, and capability

The dominant request throughout the consultations in relation to workers was for those within the child protection system and other associated systems such as nurses, doctors and schools to have the capability, through learning and development activities, to work positively and productively with parents with a disability and their children. Two key requests for training of professionals were to better understand the complex intersecting needs of parents with a disability in a positive light and to understand discrimination and bias. The consultations identified in many cases inadequate understanding of disability in the child protection workforce with this knowledge gap contributing to bias, discrimination, and poor practice. An underlying theme in these suggestions is that practitioners should learn from people with expertise, including parents with lived experience in co-led and co-designed initiatives. The call for workers to develop specialised knowledge included the following suggestions from parents and supporters:

- *Workers and students need to be educated on what biases are and how they may impact their decisions and regularly revisit what biases they have in regard to various disabilities and the lenses they are looking through when working with families. For example, the interpretation made of my every action or response was skewed by preconceived ideas about my disability.*
- *Re-start the Healthy Start Network again to make sure that workers and others have information and advice about parents with disabilities when they need it.*
- *One idea was that as soon as caseworkers become aware that a parent may have a disability they could be mandated to seek advice (to help them work with and support the parent as they lack this specialised knowledge and expertise) and ensure the person has an advocate. There may be an example of this in the police force where officers are required to ring a hotline for advice when they think they are dealing with someone with a disability.*
- *Those managing the co-design process need to value genuine engagement. For example:*
 - *Invite parents with disabilities into the team*

- *Encourage advocates of parents with disability (especially advocates who themselves have a disability) to training events, and seminars and reimburse them for their time.*

5. Recommendations to Achieve Justice in the Systems

The analysis of the consultation reports identified many important recommendations to reduce parents' with disability's experience of systemic neglect, violence, abuse or exploitation within Australia's child protection systems. Many of the suggestions cover multiple areas. For example, access to justice may include access to an independent advocate and to be supported by practitioners that have access to up-to-date information about disability which in turn will reduce bias and discrimination. However, for these strategies to work and effective reform to be achieved, understanding of the effects of a range of legislation and policy is also required. For example, rules of evidence and laws and practices relating to assessment of parents with a disability including the use of hearsay allegations made by others are currently unfair. Such examples create a power imbalance and breach a parent's and children's rights to avoid cruel and inhumane treatment, prevent arbitrary intervention into family life, and maintain a right to a fair trial.

There is nothing in what the parents and their supporters have suggested that doesn't already exist in some format throughout the western world. The suggestions made by parents reflect contemporary research findings regarding good practice. For example, Ward (2010, p. 40), identified the following services as important in supporting parents with intellectual disability through different parenting stages:

- *“identification of their intellectual disability*
- *access to appropriate ante-natal support*
- *assessment of support needs*
- *help to acquire the skills and knowledge needed the right to ongoing support*
- *parenting groups*
- *help to engage with other agencies*
- *multi-agency working advocacy support during child protection or court proceedings.”*

It is inhumane to know that supports exist, but you are ineligible or deemed unworthy of such support due to disability status, perceptions from child protection or other services, living in the wrong post code, not deemed a ‘political priority’, or because services are unaffordable and inaccessible therefore out of reach. It is acknowledged that creating a whole of system reform of the child protection and associated systems to better accommodate all vulnerable parents and their children is an enormous task. However, if such a task is never begun in earnest it will never be achieved.

This section includes discussion of example initiatives that could potentially be adapted or expanded to reduce the negative experiences associated with child protection involvement in family life where a parent has a disability. These initiatives are: provide independent non-legal advocacy, review of systems of complaint and policy and legislation that act as a barrier for parents and their children, the extension or adaption of the NDIS, and recreate the Healthy Start Network.

5.1. Recommendation 1: Provide Independent non-legal advocacy

Independent non-legal advocacy can act as an instantaneous quality control mechanism (Daly et al., 2017). As noted by Tobis et al (2020) in their international review of parent advocacy programs, there are several forms of parent advocacy that could be provided within child protection systems. However, the initiatives that exist depend on the will of government (Featherstone et al., 2011) or philanthropic funds and often only receive short term funding or are reliant on volunteers (Fitt et al., 2021; Maylea et al., 2021). Current programs are also geographically limited. Of the 100 programs reviewed by Tobis and colleagues those that included an interdisciplinary approach and included a parent-peer, a social worker or similar independent non-legal advocate and a lawyer appeared to effectively cover the suggestions made by parents and their supporters in this study. That is: persons that understand the parent and system without judging, who help to put the parent voice forward, who consider both the child’s and parent’s rights, who help to identify and locate supports appropriate to the family, and who provide legal support are available in one location (Gerber et al., 2019; The Detroit Center for Family Advocacy, 2013; Tobis et al., 2020). There are also many possible ways to integrate peer parent and family advocacy as can be seen in the examples provided by FISH and FIN Western Australia. Some of these include peer training, peer court support and a peer support telephone line.

These programs do not necessarily specialise in providing supports to parents with disability. However, Victoria Legal Aid manages the Independent Family Advocacy and Support service and includes parents with a disability as a priority group (Maylea et al., 2021). There are also networks of specialist disability advocates who could be consulted on how to reduce discriminatory treatment through the provision of advocacy for this group of parents.

Further, parents and their supporters in this study made note that advocacy support was required at different points in their parenting journey and engagement with child protection services. Advocacy support is needed from pre-birth notifications to post permanent child removal to ensure parents' are adequately represented and to ensure the children's right to know their parents and extended family was upheld. The issue, however, is that few Australian programs include both advocacy and peer support, and are universally available before, during and after statutory legal intervention. The exception to this seems to be parent support initiatives that act as resourceful friends as exemplified by FIN Townsville (Thorpe & Ramsden, 2014), or in the activities described on the websites of FISH (www.finclusionh.org) or FIN WA (<https://www.finwa.org.au>).

5.2 Recommendation 2: Review of systems of review and complaints

Throughout this study parents and supporters noted the need for effective and safe systems of review. Parents with disability experience difficulty when trying to access supports or to achieve justice (a fair go). Making complaints or requesting reviews from child protection services (or other bodies such as courts, civil and administrative tribunals or ombudsmen) was noted to be difficult or sometimes futile. The difficulties experienced are often a result of law or policy in place.

For example:

No point in putting in complaints as they go back to the CSO/TL.

Or

A real oversight body is required.

And

Families should be made aware that they can request information through the Freedom of Information Act. If a family does so it should not negatively impact the relationship with CPS.

Parents and their supporters suggest that systemic abuse of parents and their children continues unabated despite the systems in place. While legal systems, commissioners, ombudsmen, civil and administrative tribunals and internal review processes are intended to prevent arbitrary intervention into family life, ensure children's safety and bring accountability to the system, it is noted by parents and their supporters that these systemic responses are not working as intended and cannot work if parents as a key stakeholder are continually silenced. This is an issue of epistemic injustice. While advocacy was suggested for immediate short-term and family level systems improvement, macro-level strategies are also required.

Examples of systemic issues include eligibility criteria that prevents parents with disability accessing mainstream services, how rules of evidence are applied in courts, or how the Victorian Child Youth and Families Act 2005 limits the ability of magistrates to order access with children more than four times a year. It is state and federal governments that create accessible options and ensure accountability for fair and informed practice throughout child protection and other systems. Positive structural reform will require identifying and responding to the places where problems begin and acknowledge that the individual interacts with many systems simultaneously.

Currently, there is little research that explores these issues in depth and from the experience of families as only, approximately, three academic articles are published per year about parents' experience of the child protection system (Tilbury & Ramsay, 2018). These research initiatives are not generally inclusive of parents with a disability (Albert & Powell, 2021) and do not draw connection between multiple systems, laws and policies and what happens in the family home. Without more extensive research, drawing on the lived experiences of parents with disabilities and their families, the government is limited in its ability to execute innovative and important reforms. More systematic and in-depth research and review of the complex interactions between all community and statutory systems and families is required.

Any review should start with child protection but include disability services, community services, schools, maternal and health services, housing, drug and alcohol, Courts, Centrelink and many other services that interact with the family and have an influence on outcomes for the family. To do this effectively, any such review should place the perspective of the family's lived experience at the centre of the evaluation of laws, programs and systems.

Further, the suggestions made by parents and their supporters indicate that thorough research and review that can lead to legislative reform is required in regards to powers held by the noted bodies or systems and how processes operate in regard to:

- evidence creation, collection, storage and usage
- systemic bias (McConnell et al., 2021) including confirmation bias (Keddell, 2019) that occurs with referrals across systems, and issues of group think (Kaba et al., 2016)
- unintended outcomes of various pieces of legislation and policy relating to areas such as the rules of evidence, freedom of information, gate keeping and service eligibility criteria and complaint and review systems.

5.3 Recommendation 3: Ensure Flexible Funding for all Parents with Disability and Improve the NDIS

The parents in this study viewed parenting as a significant life role that should be afforded by government, and in programs such as the NDIS, the same value and attention as employment or community participation. Throughout this study the need for flexible, well-resourced parenting supports provided in a respectful and timely manner was evident. The NDIS provides a good example of what can be achieved when government is able to achieve bi-partisan support to address wicked problems and to uphold the human rights of its citizens. Difficulties associated with the implementation of the NDIS are noted and include siloed approaches between the three levels of governments and disability and child protection sectors and the failure of the NDIA to consider parenting as a valued goal for people with disability. The key principles of the scheme, however, reflect many of the suggestions made by parents in this study. That is, the provision of supports that are responsive to the person's needs and goals, is participant led, flexible, where the individual holds purchasing power to acquire supports that will empower them to achieve life goals in a respectful manner and to participate positively within society. Issues of service navigation can be managed when help is needed, there is acknowledgement that different people with the same condition have differing needs and may require different supports and resources, and participants are valued as equals in the process.

The NDIS is available for many (but not all) parents with disability, however, currently there is considerable variation in what will or will not be funded by the NDIS. The lack of clarity

about which service will fund parenting and family support leads to considerable difficulty and waste for parents with a disability. For example:

Child Protection, Orange Door, family services, schools and the NDIS need to stop arguing about who should help. The amount of money they spent on arguing could have paid for a support worker in my house for a lot of hours.

Parents and their supporters made suggestion that the NDIS should be altered to better support all parents with a disability and/or an alternative flexible funding options should be established with a preference that any alternative system is not managed by the child protection system. In developing options for all parents with disability, program development should:

- Ensure that parenting is recognised and valued as a personal goal.
- Include parents who have a disability but are ineligible for NDIS funding.
- Ensure that systems outside of child protection are monitoring and acquiring the supports actually required by the family and are fit for all families including parents with a disability.
- Empower parents to acquire the supports they need rather than the supports they are told to have.
- Ensure that services within the child protection system work with disability supports in a collaborative manner.
- Have a role in determining if the service to be accessed such a parenting assessment, parent education and support programs are fit for purpose for the individual parents and their networks of support.
- Value and support the natural network of the family where one exists or help to create a circle of support.
- Work with current options in society to pool resources such as pooling childcare, NDIS and other in-home supports options thus increasing resources while reducing duplication of services.
- Allow for greater matching of staff with parents, for example with the use of platforms such as Mable or Hireup.
- Provide a mechanism to assist governments to monitor the interfaces between sectors such as disability, health, child protection and education.

- Provide a mechanism to assist government to monitor how fit for all families current child, family, health, disability, education and associated services are.

5.4 Recommendation 4: Recreate the Healthy Start Network

A frequent suggestion was for strategies to compel professionals to access up to date, evidence-based, non-discriminatory information and strategies. It was felt that practitioners need access to this type of support at the time a parent with disability is placed on the professional's case load. Fitt (2019) also found that even when training about working with parents with disability was available, practitioners did not attend scheduled training and did not seek information about parents with disability until they had a parent with disability on their case load. At the time of Fitt's study, practitioners required access to expertise in a flexible manner. Mentioned in the consultations was the national Healthy Start Network.

The Healthy Start Network is no longer operational because of lack of funding. When operating, the Healthy Start network included over 60 learning hubs throughout Australia with 100 convenors developing activities to support professionals to support families where the parent has an intellectual disability. The network included phone support for practitioners and the development of specialist evidence-based resources, with a website, newsletters and training opportunities. The involvement of two key centres, the Parenting Research Centre based in Melbourne and the University of Sydney ensured a quality, national, practical response to parents and their practitioners was achievable (Fitt, 2019; McConnell et al., 2009). It is recommended that a similar network be redeveloped and co-designed with families and their supporters. The centres could be extended beyond the original Healthy Start Network model to offer peer workers and be guided by advisory boards including people with lived experience of disability, parenting, and engagement with child protection and welfare systems.

6. Conclusion

The views and voices of parents and their supporters captured in the consultation documents and presented in this submission are broad and include suggestions for action from the micro individual level to macro whole of government, structural, and cultural reforms. The recommendations outlined above relating to independent advocacy, systematically addressing epistemic injustice, flexible funding packages and support co-ordination, and recreating the

Healthy Start Network, are informed by these consultations and identify key areas for reform. All service, policy or legislative reform should be co-designed with parents with lived experience of disability and the child protection system and parents with lived experience should be included at all levels of decision making with the appropriate supports to enable conditions for meaningful participation.

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