Association for
Children with a
Disability

“Bigger ears, bigger hearts”

Making the NDIS better for children at-risk and those in out-of-home care

Submission: NDIS Review

August 2023

ACD is the leading disability advocacy organisation for children and families in Victoria. This submission focuses on children at-risk and those in out-of-home care.

Our heartfelt thanks to those that helped inform this work including:

- More than 40 incredible foster carers, kinship carers and permanent carers who are currently raising children who are NDIS participants.
- Birth families who bravely provided insights into what causes or prevents relinquishment decisions.
- Victoria’s network of Family Disability Specialist Practitioners and Children with Complex Disability Support Needs Practitioners.

This submission focuses on children living in home-based settings, either with their family or in home-based care such as kinship care and foster care. We focus on support to keep children out of residential care rather than the experiences of children in residential care.

Missing from our engagement is the voice of children in-care. In addition, while participants in our consultations included a number of Aboriginal carers and workers, and carers caring for Aboriginal children, the consultations did not represent the disproportionate number of Aboriginal children in-care. We commend the submission by the Victorian Commission for Children and Young People as providing deeper insight in these areas.

Recommendations

The **top three recommendations** consistently highlighted by families, carers and workers as a priority for improving outcomes for children at-risk and in out-of-home care are:

- **Expand access to early intervention** for children at-risk and in out-of-home care whose developmental delay or disability is not identified until they are older.

- **Develop a tailored approach and model support package to guide planning** for children at-risk and in out-of-home care, that:
  - heavily invests in strengthening and supplementing family and carer capability
  - prioritises keeping children with their family or in home-based care
  - provides respite and recognition of additional family and carer load
  - includes positive behaviour supports
  - focuses on engagement with early education and school.

- **Priority access and expanded workforce of therapists and support workers skilled at working with children and families with complex support needs**. Innovative purchasing and pricing models are needed.

Addressing access barriers

1. Mandate screening for development delay and disability for children in out-of-home and provide a clear pathway to access the NDIS. Provide priority access to assessment and diagnosis.

2. Operate mobile assessment hubs in regional and remote areas to improve access to screening, assessment and diagnosis for children at-risk and in out-of-home care.

3. Expand access to early intervention for children at-risk and in out-of-home care whose developmental delay or disability is not identified until they are older.

4. Relax primary diagnostic eligibility criteria for getting NDIS support and recognise the disabling nature of trauma, particularly when overlaid with other conditions.

5. Address barriers to NDIS access and planning process for children without identification documentation such as birth certificates.

Planning for complex circumstances

6. Develop a tailored approach and model support package to guide planning for children at-risk and in out-of-home care, that:
   - heavily invests in strengthening and supplementing family and carer capability
   - prioritises keeping children with their family or in home-based care
   - provides respite and recognition of additional family and carer load
   - includes positive behaviour supports
   - focuses on engagement with early education and school.

7. Provide children at-risk and in out-of-home care with access to specialist planners.

8. Undertake plan reviews for every NDIS participant entering care or moving placement, including tailored support to sustain foster, kinship or permanent care placements.

9. Take a family/household approach to planning, with the default position being to have the same planner for each member of the household.

Getting effective support

10. Provide stronger support and guidance to families and carers of children-at risk or in-care to effectively implement NDIS plans and to track progress and outcomes.

11. Prioritise children at-risk and in out-of-home getting access to support.

12. Reward skilled and caring providers for working with children with complex support needs (including behaviours of concern).

13. Market stewardship to increase the number of support workers that can support complex behaviour support needs.

14. Provide travel time for support workers in regional areas who can support complex behaviour.

15. Incentivise services that build family and carer capacity and are delivered in everyday settings.

16. Remove red tape that prevents carers from seeing or implementing plans.

17. Establish a fast-track process for child and family services and the NDIS to troubleshoot barriers to activating or implementing a child or young person's plan.

Positive Victorian initiatives that could be built upon

18. Continue NDIS training for child and family services workforce.

19. Invest in Family services specialist disability practitioners.

20. Retain Children with complex disability support needs program.

21. Expand placements and eligibility for therapeutic foster care.

22. Apply a disability lens to Home Stretch and Better Futures expansion of support for young people in out-of-home care up to age 21.

National initiatives

23. Expand access to Specialist Disability Accommodation to help reduce relinquishment from home-based care settings.

24. Introduce targets to reduce over-representation of children with disability in out-of-home care as part of the upcoming National Action Plan under the National Framework for Protecting Australia's Children.

Addressing access barriers

Many children at-risk or in-care are delayed in having their disability identified, being assessed and connecting with disability related supports. Various challenges include:

- the parent/state guardian/carer not getting the child assessed
- long wait lists and high assessment costs heighten barriers to seeking an assessment
- trauma can interfere with other diagnoses and is often not treated as a disability
- child may have aged out of early childhood approach by the time developmental delay or disability is identified and acted upon
- carers may not have access to required identify and other documentation

Special measures are needed to address this.

Screen children and young people entering out of home care for developmental delay and disability and provide priority access to assessments and diagnosis

There is high prevalence of suspected and undiagnosed disability among children in the child protection system[1]. Covid disruptions have exacerbated this. Currently there is no screening process for children and young people entering the out of home care system despite the disproportionately high rates of disability among this group. High placement turnover can mean children and young people move between a succession of carers.

Although the National Standards for Out of Home Care state that routine health assessments should be undertaken (and the 2011 National Clinical Assessment Framework recommends initial health checks within 30 days of entering OOHC, a comprehensive assessment within three months and for all children to have a health management plan) this is rarely happening.

Just one in 130 participants in a 2022 Victorian study by the Murdoch Children's Research Institute had attended all recommended health services within 12 months of entering foster or kinship care. Just 37% had seen a GP, 17% had visited a paediatrician and less than 10% had seen a dentist, optometrist or audiologist within the recommended timeframes.

Victoria has established Pathway to Good Health (PTGH) which provides an initial health check by a selected GP, priority referrals to multi-disciplinary assessment and a health care management plan. It is operating in limited areas (North and West Metro, Gippsland). Children can be referred to PTHG by child protection and out of home care agencies. It appears this approach has been underfunded and failed to deliver assessments and reviews as intended[2].

Mandatory health screenings for children soon after they enter care is a must to detect any developmental delay or disability, and to create a pathway to support.

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[1] Disability Royal Commission, Research Report: Care Criminalisation of Children with Disability in Child Protection Systems, 2022

[2] McLean K et al, 2019. Health needs and timeliness of assessment of Victorian children entering out-of-home care: An audit of a multidisciplinary assessment clinic. Journal for paediatrics and child health. Available at https://onlinelibrary.wiley.com/doi/10.1111/jpc.14472;

He moved in with us when he was 10 years old. He has profound speech impairment that has never been addressed, despite him being known to child protection since before he was born and having been many years in kinship care. (Permanent carer)

Children and young people with disability often end up in out-of-home come without a diagnosis. So common for those living in residential care not to have been assessed.
(Workforce trainer)

My grandkids have just got onto NDIS. My daughter did nothing for them…If it wasn't for our kinship care they would have fallen through the cracks. It's very complex what they need help with, but they would have got none. (Kinship carer)

Seeing kids who are home schooled or not being schooled, whose parents also have Autism (often undiagnosed). Also seeing women escaping from family violence who have never been able to attend to their child's Autism. (Family Disability Practitioner)

Aide at school suggested there was an issue. Got assessments done, very costly and took out a loan to do it, but felt it was important to get diagnosis. Paediatrician then did final assessment and said he should be on NDIS. (Grandparent carer)

For children and young people who live in out-of-home care, the lack of communication between state-run child protection services and the NDIS means that many young people with a disability go undetected by the system. There is a real barrier to access for this vulnerable cohort of young people, many of whom experience mental health challenges and trauma, inconsistencies in their care, placement breakdowns, and complex conditions that require additional support.
(Centre for Excellence)

Children with disability from culturally and linguistically diverse backgrounds seem to be more prone to not being detected – perhaps because of the shame and stigma, or different views about disability in some communities. (Family Disability Practitioner)

Child has been known to child protection for his 7 years of life, but not yet on NDIS. Aboriginal Health service got paediatrician appointment within 3 months. These kids in-care should have a mandatory assessment by paediatrician when come into care and regular health check. Because over 6, had to get a diagnosis.

Mobile assessment and diagnosis hubs

Although wait lists and high out of pocket costs for assessment and diagnosis are a system wide issue, they have disproportionate impact on children who already experience significant delays in having their disability noticed or acted upon and whose households may be experiencing significant vulnerability.

A practical suggestion, of mobile assessment hubs, to address shortages in regional and remote areas was put forward in one of our community consultations.

> *Had to pay for my grandson's diagnosis privately. The public system wait was going to be two and a half years. (Kinship carer)*
>
> *One of the barriers that I see in the Early Childhood approach is that if the child doesn't already have a diagnosis, they need one prior to turning 6 and the family may not be able to afford this. Then they can't access services any longer. Family services do have access to funding, but it is limited and may not cover the total cost of an assessment. It would be great to see some sort of diagnosis support. (Family Disability Practitioner)*

Extend access to early intervention

We heard from many workers and carers that children are too old to access the Early Childhood Approach, or age out of it, before they can get a diagnosis. There is a need to extend the age of access to early intervention for children at-risk and those in out-of-home care.

> *The 7-year-old in my care was knocked back, because presentations could be explained by trauma. Mostly non-verbal, not going to school, hadn't met many milestones. Not admitted because too old for developmental delay. (Foster carer)*
>
> *Covid disruptions have meant many kids were not picked up by teachers, nurses etc… some have now missed the ECEI entry opportunity. (Family Disability Practitioner)*

Relax primary diagnostic eligibility criteria for getting NDIS support

Many children at-risk and in-care have overlapping conditions often including: autism, ADHD, Foetal Alcohol Spectrum Disorder (FASD), Acquired Brain Injury, trauma and mental health issues.

Trauma is generally not considered a disability and can mask other disabilities. Frequently, pre-existing trauma is a barrier to getting a diagnosis and accessing NDIS supports.

Moving away from diagnostic criteria for entry to the NDIS could help to tackle this barrier.

> *With a traumatic experience of life, it can be hard to understand if, and when it becomes a disability…Difficult to know what is trauma, FASD, Autism, ADHD, attachment disorders? (Foster carer)*
>
> *Children and young people can often present with a range of overlapping conditions: commonly trauma, FASD, ABI, ADHD, autistic. The NDIS is so obsessed with primary diagnosis, they can fall through gaps. (Kinship carer)*
>
> *They say you don't need a diagnosis, but in practice you do. (Permanent carer)*
>
> *So many kids with obvious, but undefined things. They are kept out of the fold.*

Remove documentation barriers

Carers report that a lack of documentation can slow down NDIS access and planning for months at a time. It is relatively common that children in out-of-home care lack documentation such as:

- birth certificates
- the child being known by different names in different documentation.
- children not listed on the carers Medicare card (often still listed with birth parent) which means Medicare rebates cannot be claimed and can prevent appointment bookings being made.

NDIS needs process that allow access and planning to continue while documentation is being sorted out.

Planning for complex circumstances

Children-at-risk or in out-of-home care require an enhanced level of planning and support. Common challenges we heard about included:

- an unrealistic level of family and carer capacity being assumed
- planners that fail to understand or respond to the level of household complexity
- not approving the right supports at the right time to help families stay together or to enable children to remain in home-based care
- not updating plans when children enter care or move placement

There are a range of enablers including:

A tailored approach and model support package to guide planning

NDIS planning needs to take a tailored approach with model support packages that reflect complex circumstances and the critical importance of supporting children to remain with the family or in home-based care.

Assess, build and supplement family and carer capacity

Family and carer capacity has a major impact on the level of informal support and sustainability of care. NDIS partners or planners will often have little visibility of household challenges (e.g. family violence, child protection, alcohol and drugs, others with disability in household etc) unless this is presented to them by the family or carer.

There are assumptions made about families and carers being able to carry out usual parental responsibilities, without specifically assessing this.

> The NDIS needs a systematic way to assess risks to sustainability of care. Complexities relating to a participant's disability should encompass their home environment, the informal supports that may or may not be around them, and care givers should be encouraged to share their experiences with NDIS staff via Carer Statements
> *(Centre for Excellence)*

> NDIS rarely makes provision for families and carers that have very limited capacity. At the heart of the Scheme is the assumption that families and carers provide reasonable supports. A deep contradiction however is that there is little in place to build this capacity.
> *(Workforce trainer)*

> Workers biggest issue is capacity parents/carers. Assumption is families and carers provide informal supports. One of the aims of section 25 is to build capacity of informal supports, yet I hardly ever hear about this being planned for. When does it happen?
> *(Family Disability Practitioner)*

Avoid unrealistic assumptions about support from child and family workers

Advice from Disability Family Practitioners is this when child and family workers attend a NDIS planning meeting, there can be a misguided assumption that they will provide ongoing support. The reality is that most family services programs are short term, often just two or three months.

Prioritise keeping children with their family or in home-based care

At the heart of planning for children at-risk and those in-care needs to be what support is needed to keep this child with their family or in home-based care.

Children with disability are voluntarily relinquished at a much higher rate than children without disability, often because the family cannot get the right disability supports in place to cope and stay safe.

Family disability practitioners noted that nearly all the households they are engaging with have a child or young person with intellectual disability or autism, and have escalated behaviours of concern. We heard that although neurodisability can increase risks to family safety and relinquishment, it is sometimes not treated as complex.

> *Most horrific thing ever was taking him to his (specialist) school one day and telling them I wasn't coming back for him. This triggered an immediate interview with child protection officers who pinned relinquishment of him on my inability to parent…I was trying to get point across that it was not a parenting problem, but a disability issue, he (and we) needed support but couldn't get it. (Parent)*

> *Autism most risky for relinquishment because of behaviours of concern and because families and kids socially excluded.*
> *(Family Disability Practitioner)*

> *He would be better at home because of love and support and constancy – but can't do it on my own….(Parent)*

> *So frustrating because the family was so far down the path. If the plans had been sufficient initially, it could have made a big difference.*
> *(Family Disability Practitioner)*

> *Neurodisability and complex trauma were the most common disabilities seen among children in child protection systems who experience criminalisation…While research shows many criminalised children in child protection systems have a neurodisability, the policies tend to focus on the impact of trauma on children's behaviour, with less attention to how other disabilities might influence children's needs and behaviours. (Disability Royal Commission, Care Criminalisation report)*

I get why people just walk away and say they can't do it anymore. (Family Disability Practitioner)

I would love to see funding for Parent Coaches who can come into the home and help families to manage behaviours and understand how to operate with the impacts of disability. (Family Disability Practitioner)

Feels like NDIS well set up for visible, but not so well for invisible disabilities. (Foster carer)

Sufficient respite care and core support
Frequent access to respite care (every week or fortnight) can make a huge difference to a family and carers ability to cope. Because that NDIS does not use the language of respite, workers and families need to think creatively about how they can ask for supports that will maximise the chance of respite being funded. We also heard that NDIS planners tend to treat the respite care average (of 28 days per annum) more like a cap, but that for families at-risk, skilled practitioners help them advocate for regular respite.

The need to make allowances for extra family and carer load was a strong theme in our consultations.

Protecting carer wellbeing was consistently raised as something that supports ongoing placements in foster care, kinship care and permanent care.

If there was one thing I could change in my life, it would be my child living out of home. I tried everything. I put in a lot of work and effort to keep a family unit. What I begged for, for years, was help in the context of respite, out of home. We, his sisters needed a break. If we could have got this help when he was 7 or 8 … we could have avoided relinquishing him. (Parent)

Respite for carers is critical, but you are made to feel guilty if you request it. (Permanent carer)

I was saying I need help, please help me …. didn't know to ask for respite. (Parent)

Seem to put so much back on parent responsibility and school – but when have child can't access full hours of school … school finishes 1.30 for us every day. (Carer)

Carer burnout is a big thing, with serious consequences. (Disability Family Practitioner)

Can't go to school for more than half a day (because school can't handle him). NDIS won't support in school hours. We've had to take much of our leave from work, cut back hours etc to be there with him. (Kinship Carer)

Getting practical help into the home at higher stress points of the day (such as preparing for school or dinner and bedtime) were identified as effective core supports for households at risk. Good support workers were identified as being able to make a real difference.

The support workers have saved me from placement breakdown (Kinship carer)

We have support workers every day for showering, dressing, accessing the community, to attend scouts and social activates. It works well…but takes long time to get there. Need to look after your support workers, otherwise they won't stay very long. Takes us about 3-4 month to train up support worker, otherwise there is too much violence, and they will leave. We wouldn't be able to remain as carers if it wasn't for our support workers. (Foster carer)

He goes out with his support worker – goes away for weekends or regular fortnightly catch up … Now he wants workers who are aligned with his interests such as talking about cars. (Grandparent carer)

We have support workers for the two oldest kids in our care. The workers have now been with the kids several years and are very well versed in the kids needs and support required. We have struggled in the past to find the right balance of workers, those who would manage the personal care aspects as well as the independence that we are trying to foster in our eldest son. Despite the kid's complex disabilities, we expect the kids to be treated with respect and in an age-appropriate manner. (Permanent carer)

Often requires two to one support to access community: sometimes this is not recognised. (Workforce trainer)

Positive behaviour support needs to be front and centre

Children at-risk and in out-of-home care are at higher risk of experiencing more extreme behaviours of concern (harm to self/others, damaging property, absconding, sexualised behaviours etc).

When well done, behaviour support planning has been identified as a game changing. It seeks to build understanding of the child or young person's behaviours, the household context, identify and address triggers and provide practical guidance and techniques that make a positive difference. It can significantly strengthen capacity of family, carers and other providing informal supports.

Works well when they visit at home, train up family, train up support workers and care team. One very effective practice is putting key instructions on lanyards so that anyone providing care can easily access key information. (Workforce trainer)

Positive behaviour supports should be front and centre of plan and viewed as a critical early investment in family capacity. (Family Disability Practitioner)

Seen big outcomes: growth and change. Reregulate emotion. Helped to maintain placement for the child. (Foster carer)

A focus on engagement in early learning and education

Children and young people living in out-of-home care are at greater risk of much poorer educational engagement, and outcomes than those in the broader community.

This disadvantage is amplified for children with disability in out-of-home care.

Planning needs to focus on supports to secure engagement with early learning and school, including through collaborations under existing programs, such as Victoria's Early Start Kinder and Lookout Education Support Centres.

Specialist planners skilled in children at-risk

Specialist planners ought to be at the frontline of planning with children-at-risk or in-care.

We have heard of instances where a known relinquishment risk triggers additional assistance creating the opportunity for greater flexibility and more immediate assistance beyond usual typical support package amounts.

This needs to be the norm, rather than the exception for children-at-risk

Workers note the challenges of planners and workers getting a full picture of the complexity of the life's children and their family or carer.

For this reason, we recommend that specialist planners undertake the planning, and that for those already in the Scheme, a plan review is triggered when there is involvement with child and family services, or entry into out-of-home care.

Incident reports from schools (hurting other kids at school), support worker agencies (support worker being attacked) are all going to different places. Not gathered on the one place. (Family Disability Practitioner)

A household/family approach to planning

Carers are frequently looking after multiple children disability, but have different planners allocated for each. This dilutes appreciation of household complexities and dynamics, and limits opportunities for mutually reinforcing supports.

> *We had one planner that understood having multiple kids in one household had flow on impacts. The other kids' planners couldn't see interrelationship of complexities in house. (Foster carer)*
>
> *3 kids in-care on NDIS – seen individually rather than as complex of house/family. Not understanding interconnections and interplay between children and households. (Foster carer)*

Automatic plan reviews when a child enters care or changes placement

Support needs may likely vary from placement to placement and needs to be reconsidered when children enter care or move between placements.

> *Many are already on NDIS when they come to us but don't have the support they need. (Family Disability Practitioner)*

Getting effective support

The most common feedback through all the consultations was that even if children at-risk and in-care have NDIS plans with appropriate levels of support it is incredibly difficult for families/carers to implement their plans, to find services who are prepared to work with children with complex behaviour support needs and that help build family capability. Significant market stewardship is needed to ensure those with the most complex needs don't just get a good plan but they can also access effective support.

Quality assistance to understand and implement the plan

There was a strong consensus that that high-quality support for understanding and implementing the plan (regardless of whether this is provided by a complex needs planner or a highly skilled, higher level support coordinator) is critical for households at risk and children in-care.

We heard that the NDIS seems to go through waves of alternatively approving or rejecting requests for Support Coordination, and that many households at risk and carers of children in-care are struggling to coordinate and manage their plans.

Even for those who understand how to navigate the system, it is very labour intensive and requires significant literacy in NDIS systems and markets, and in finding services that are responsive to their circumstances.

Constant crisis means families at-risk and carers need more than standard support coordination: they are often trying to manage a care team while juggling complex family dynamics – it's too much. (Family Disability Practitioner)

Having a support coordinator (level 2 or level 3) – is a godsend. (Family Disability Practitioner)

I usually need to push for it (support coordination and plan management) and I am getting a lot of families that have plans that they must self-manage. (Family Disability Practitioner)

I need to be an NDIS expert … it so much work to know what to ask for and to find all the services. (Foster carer)

I left my job to work on getting supports put in place and settling a long- term foster child. After 2 years we are now in a position where we have flowing supports. We have had 2 plan managers and I can't count how many support coordinators. I sourced all the documentation for plan reviews and now have an incredible plan. I have essentially been a support coordinator for free and have done all the hard work. Complex children need so much time spent on their plans. (Foster carer)

Priority access to supports for children at-risk and in-care

Given their high vulnerability, it is unconscionable that children at-risk or in-care are parked on long waiting lists to receive supports, and that households in crisis or carers are left to ring around multiple providers in the hope of getting support. With many providers preferring to take on easier clients, the market is by and large failing this group.

Special purchasing arrangements with preferred providers that are skilled in working with children and families experiencing complexity and with incentives to prioritise access to these groups are urgently needed.

Practitioners that are skilled and willing to work with complex behaviours

Additional to the challenges of service shortages and long wait lists common to many NDIS participants is finding providers who are willing and capable of working with children and young people with behaviours of concern, and in complex areas such as trauma/FASD interface. We heard that finding the right person is often quite random, and down to good luck.

Innovative pricing or purchasing arrangements can help address this.

Providers pull out after one shift. (Carer)

Can be nightmare to find a suitable provider – mixed quality – many are not setup for high complexities – need those who are skilled, ethical and committed to sticking around. (Carer)

Lack of specialists in FASD. (Carer)

Having so many different people in the children's life can be incredibly problematic. (Carer)

We've had good experiences with mental health OTs. (Carer)

Had 7 OTs in the last year. (Carer)

Support Workers who can work with children with complex behaviour

Likewise, it is hard to find disability support workers who are prepared to work with children with complex behaviour support needs. This is particularly acute in thin markets such as urban growth corridors and regional areas.

Some families and carers spend half their core support on travel time because the only support workers who can work with their children travel more than an hour each way.

When children and families and carers can’t get appropriate support workers, children can end up in emergency respite or being relinquished.

> *Need disability workforce who are trained (like his specialist school) to understand what behaviours of concern are, how to deal with them and create an enviro that is safe for the person, staff, and others. (Parent)*
>
> *We hire the same support workers for all the children, so can get back-to-back sessions, consistent approaches, reduce travel costs etc. (Foster carer)*
>
> *Emergency respite, although it doesn’t in reality exist. This meant in practice he stayed in hotel with two support workers had never met. (Parent)*

Approaches that build family and carer capacity

Carers are eager to be upskilled to support and enable children in their charge. There were mixed experiences, with the most preferred approaches being those that are delivered in, or easily translated to, everyday settings: home, early learning; school, community.

Preferred providers for children at-risk and in out-of-home care ought to be incentivised to deliver in everyday settings, including working in partnership with education providers to support a child’s disability and trauma needs.

> *For the 4 kids the OT is particularly helpful in observing to understand how we can provide the sensory input needed, speech is important to understand how the communication device should be used and modelled at home. Although the therapists are aware we are foster carers we are treated just as anyone else would be. (Foster carer)*
>
> *I’m attending the OT myself and then trying the strategies in our safe space, where I’m his trusted person – its working well. (Carer)*
>
> *I prefer a coaching where therapists help me develop strategies to implement at home. (Carer)*
>
> *Found mobile speech and mobile OTs – they each come to the house every three or so weeks. Plan covers their travel. Makes it so much easier on all of us, plus they get to help us put strategies in place at home. (Grandparent carer)*

Authorise carers to put NDIS plans in to action

A strong concern raised during consultations related to bureaucratic barriers that prevent plans from being used, or decisions that are unable to be made because either:

- the birth parent needs to consent (and can’t or won’t)
- the state is the child’s guardian and departmental staff are slow to respond (in many cases there may effectively be no-one allocated)[3]
- foster parents report they often don’t even get to see the NDIS plan for children in their care.

> *An issue we had was getting the service agreements signed as these still need to be signed by DFFH as both kids are under Secretary Orders but are currently unallocated in terms of case workers, we have had to hope that a team member is able to sign the paperwork and return it in a timely manner. (Foster carer)*
>
> *Initially I was told I wasn’t allowed to see the plan for one of the kids which made no sense since Child Protection had given me complete authority to act on the child’s behalf when it came to NDIS and I had been liaising with the NDIS planner directly to get portal access sorted. Now I have copies of the plans for all 4 kids and portal access for all 4. Although I have portal access I am NOT down as having parental responsibility for the 2 youngest which can make things difficult when needing to ring the NDIS advice line. (Foster carer)*
>
> *I didn’t receive copy of NDIS plan, had to fight DHHS to get it because it’s with them. Plan rolled over without even knowing about it, whereas we wanted extra funding for services. They know nothing about his day-to-day needs. Have to pay for services not billed during last plan period, taking away from funding for this period. (Foster carer)*
>
> *NDIS needs as special team for children in out-of-home care so that the hoops carers have to go through to gain portal access are decreased and planners understand the complexities of foster care and better communication between what is DFFH and what is NDIS responsibility. (Foster carer)*

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[3] Non-verbal young boy in state care can't access $27,000 of his NDIS funding, grandmother says - ABC News

Create a dedicated channel between child and family services and NDIS

Child and family services workers raised the desirability of training for the NDIS workforce in understanding and navigating child and family services and spoke of the need for clear and direct relationships between NDIS and the child and family services sector.

> *Staff working in state services are unable to communicate clearly with the NDIS, meaning this vulnerable group of children are at risk of falling through the cracks. A streamlined approach to information sharing would ensure fewer barriers to decision making and would increase participation for children and young people in the Scheme.*
> *(Centre for Excellence)*
>
> *Would be very helpful if NDIS staff knew about family services system – like banging head up against brick wall trying to get the info needed … some more education on their end, so that they understand services are permitted to ring on behalf of children and families would help.*
> *(Family Disability Practitioner)*
>
> *When we call NDIS, it's like we are no one with no standing …. If ask for Indigenous worker get told you don't get anyone special, don't get treated any differently (Worker)*

Positive Victorian initiatives

The Victorian Government invests in a range of promising initiatives that appear to be yielding strong results. We urge decision makers to look further at these with a view to continuation, and replication in other parts of Australia.

Continue NDIS training for child and family services workforce

The Centre for Excellence in Child and Family Welfare in partnership with ACD delivers training sessions aimed at building the capacity of child and family services workers in Victoria to support families to access and implement NDIS support.

Initially developed in 2018 with ILC funding, the program has continued with support from the Victorian Government (DFFH). Funding lapses mid-2024.

To date more than 3,000 people have completed the training, the overwhelming majority are child and family workers. Around 20% of attendees are kinship and foster carers.

Attendees have consistently rated the course very highly and subsequently reported that it helped them to get children to access the NDIS and to assist families/carers to get more appropriate supports included in their packages.

> *Did the Centre for Excellence training, it lifted my confidence and knowledge even though I already knew a lot!*
> *(Child and Family Services Worker)*

Invest in family services specialist disability practitioners

The Victorian Government (DFFH) funds 34 specialist disability practitioners (2 per region) that are employed by various community organisations delivering child and family services. Funding lapses mid-2024.

Aimed at families involved in child and family services; many are referred by Orange Door (family violence pathway).

Practitioners work directly with families over a short period and provide secondary consults to build the capacity of the broader child and family services workforce. Their scope includes:

- facilitating (and funding) assessment and diagnosis
- facilitating co-ordination of care teams
- supporting access to NDIS
- assisting families to get appropriate NDIS plans in place including through triggering unscheduled reviews for change of circumstances or appeals
- engaging Support Coordination and assisting families to implement plans

Around 900 families (1800 children) are reached each year, and the initiative appears to be having significant impact for those it touches.

Advice from DFFH is that evaluation results (unpublished) are very strong. Families report having better NDIS plans and more services in place. Child and family services staff highly value access to secondary consult support offered. Long wait lists for private and public allied health professionals have been identified as a major program barrier.

Family Disability Practitioners from across the state share insights through a community of practice convened by ACD. The regular connection between the service system and a family-led organisation supports effective referral pathways, including connections to broader advocacy and advice services.

> *My work touches about 200 families each year (most via secondary consult). Getting them the right disability related supports has the practical effect of taking them out of the family services cycle… No families or carers on my caseload have relinquished their child so far. (Family Disability Practitioner)*
>
> *When we work with a family risk, the focus is on rapidly getting supports in place to prevent relinquishment. This often includes NDIS core supports within home, specialist support coordination, regular respite, measures to address behaviours of concern and a focus on building family capacity. (Family Disability Practitioner)*
>
> *I don't think any of them are coming back to The Orange Door once their disability needs are being met. (Family Disability Practitioner)*

Extend the children with complex disability support needs program

The Victorian Government (DFFH) funds a related program staffed with 17 practitioners (one in each region), also housed in child and family service provider organisations. Funding lapses mid-2024.

The aim is to assist households who are at-risk of relinquishment due to complex disability support needs, but where there are no child protection concerns. Around 175 families (350 children) are assisted each year.

DFFH advise the program has strong evaluation (unpublished) results including by:

- promoting sustainability of care for the child in the home and preventing families from breaking down
- supporting continuation of the relationship between children and their families when they are residing outside the home and supporting the goal for the child to return home (where this is appropriate).

Participating agencies report that the program helps meet the gap in integrating family and disability supports to vulnerable families of children with complex disability support needs.

Key program barriers reported by agencies include: thin markets in the disability provider sector; long wait times for health and disability services; inconsistent quality of available disability services and protracted delays in the NDIS process.

Follow the steps to Confident Parenting Program trial

A trial program (running in Barwon and Western Melbourne) commenced in 2021. It provides wraparound family services, early parenting and disability supports to parents with cognitive or intellectual impairment/disability who have children at risk of entry to care.

The program supports parents to provide for the health safety, and development of their children through an intensive home-based case-management response. It features a multi-disciplinary partnership model including community health, child and family health, community organisations and disability support services. It is being independently evaluated by a university to test efficacy and determine whether it is sustaining families and preventing breakdown.

Expand therapeutic foster care

Various Victorian initiatives (TrACK Program and The Circle Program) have placed children with disability and other complex physical and/or emotional needs in therapeutic foster care, where carers are trained and regarded as part of a professional treatment team[4].

Therapeutic foster care can provide an effective and cost-efficient model. Placements have been found to improve emotional regulation, communication and the establishment and maintenance of positive relationships (including social relationships and relationships with carers)[5] [6].

However, there are very few therapeutic foster care placements available and the eligibility criteria is very narrow (for example it is not available in cases of voluntary relinquishment)[7] [8]. There is a strong care to expand access therapeutic foster care and test its potential to divert children with disability from being places in residential care.

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[4] DHHS, 2019. Home based care - therapeutic foster care. Available at https://providers.dffh.vic.gov.au/home-based-care-therapeutic-foster-care-31413 . Centre for Excellence in Child and Family Welfare, 2016. Out-of-home care for children with a disability: A literature review. November 2016. Prepared by the Centre for Excellence in Child and Family Welfare for the *Quality improvement in out-of-home care for children with a disability in Barwon area* project (Unpublished).

[5] McPherson L et al, 2019. Evaluation of the Treatment and Care for Kids Program (TrACK). Southern Cross University and Australian Childhood Foundation. Available at https://bettercarenetwork.org/library/the-continuum-of-care/foster-care/evaluation-of-the-treatment-and-care-for-kids-program-track

[6] Centre for Excellence in Child and Family Welfare, 2016. Out-of-home care for children with a disability: A literature review. November 2016. Prepared by the Centre for Excellence in Child and Family Welfare for the *Quality improvement in out-of-home care for children with a disability in Barwon area* project (Unpublished).

[7] McPherson L et al, 2019. Evaluation of the Treatment and Care for Kids Program (TrACK). Southern Cross University and Australian Childhood Foundation. Available at https://bettercarenetwork.org/library/the-continuum-of-care/foster-care/evaluation-of-the-treatment-and-care-for-kids-program-track

[8] DFFH, 2009. Circle Program Guidelines. Available at https://providers.dffh.vic.gov.au/sites/default/files/2017-08/circle-program-guidelines-may-2009.pdf

Apply a disability lens for Home Stretch and Better Futures

The Victorian Government has extended support for young people in out-of-home care to 21 years old. However, this support does not have a “disability lens” and the challenges young people with disability face often fall between the gaps of the NDIS and state support.

> *Turning 18 is “a mess” (Permanent carer)*
>
> *If not studying or working, there are many hours to fill once they have finished school. These young people are heavily reliant on carers to initiate things at a time when they want to move towards independence. (Permanent carer).*

Opportunities for National initiatives

Expand access to Specialist Disability Accommodation

Accessing Specialist Disability Accommodation (SDA) funding for children could prove an alternative to residential care. There is little housing stock available that suits households with children and young people demonstrating challenging behaviours. There is a lack of ‘robust’ housing in public/social housing, emergency respite and SDA stock. The ‘robust’ category of housing design is intended to reduce the risk of injury for people with complex behaviours and those that live with or visit them and to minimise neighbourhood disturbance.

> *SDA funding approvals for the children is an advancement on the rights of families to have supports provided in a manner that will ensure long term tenure security for their children. It may well encourage other families to consider funding the accommodation their children need and overtime reduce the vulnerabilities they otherwise face. (AFDO 2019)[9].*

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[9] AFDO, 2019. Issues for Children with Disability in Out of Home Care. August 2019. Available at https://www.afdo.org.au/wp-content/uploads/2019/08/AFDO-Children-with-Disability-in-Out-of-Home-Care-August-2019.pdf

Targets to reduce the over-representation of children with disability

The National Framework for Protecting Australia's Children (2021 – 2031) aims to reduce rates of child abuse and neglect, and its intergenerational impacts. It includes a commitment to ensuring that child and family support policies and services are consistently based on reliable evidence, including living experience.

Children with disability, and children in out-of-home care, are separately identified as priority groups under the Framework. The first Action Plan, 2023-2026 commits to developing mechanisms for an efficient interface between the NDIS and child and family services and improved early intervention, information, supports and referral pathways for children with disability. We hope to see practical steps to achieve this reflected in the recommendations of the NDIS Review.

Conspicuously missing from the Action Plan are disability related outcomes measures, and most importantly, targets to reduce the overrepresentation of children with disability in out-of-home care.

Statistics:

Children with disability account for at least 28% of those in out of home care. (This is likely to be an underestimate given many children with disability in-care have not been formally diagnosed.[10]

Around 13,000 children with disability are in-care on any given day.[11]

Intellectual and cognitive disability (autism) are the most prevalent disability types represented.[12]

Children with disability are overrepresented in residential care.[13]

Children with disability are more likely to be subject to voluntary placements,[14] rather than by court order.

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[10] Centre for Excellence in Child and Family Welfare, 2016. Out-of-home care for children with a disability: A literature review. November 2016. Prepared for the *Quality improvement in out-of-home care for children with a disability in Barwon area* project (Unpublished).

[11] AIHW, 2022. Child Protection Australia, 2020 – 21. Available at https://www.aihw.gov.au/reports/child-protection/child-protection-australia-2020-21/contents/out-of-home-care;

[12] Australian Government, 2017. Final Report, Volume 12 – Contemporary out of home care. Royal Commission in Institutional Responses to Child Sexual abuse. Available at https://www.childabuseroyalcommission.gov.au/sites/default/files/final_report_-_volume_12_contemporary_out-of-home_care.pdf

[13] Australian Government, 2017. Final Report, Volume 12 – Contemporary out of home care. Royal Commission in Institutional Responses to Child Sexual abuse. Available at https://www.childabuseroyalcommission.gov.au/sites/default/files/final_report_-_volume_12_contemporary_out-of-home_care.pdf

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