

Submission:

NDIS Review – Children in out of home care

The Centre for Excellence in Child and Family Welfare (the Centre) welcomes the opportunity to provide a submission to the NDIS Review for consideration by the Federal Government

The Centre is the peak body for child and family services in Victoria. For over 100 years we have advocated for the rights of children and young people to be heard, to be safe, to access education and to remain connected to family, community, and culture. We represent over 150 community service organisations, students and individuals throughout Victoria working across the continuum of child and family services, from prevention and early intervention to the provision of out-of-home care (OOHC). Many of our members work directly with children and young people with disabilities who have been placed in care or are at risk of being so.

Introduction

Our member organisations work closely with children, young people and families who present with multiple, co-occurring needs, including children and young people experiencing diagnosed and undiagnosed disability. These families often experience intergenerational disadvantage and poverty, unemployment, housing insecurity, drug and alcohol related issues and family violence.

When family circumstances become unsafe for the child, or there is evidence that a child needs to be removed from the family, the child may be placed in foster, kinship or residential care. In Victoria, at any one time there are around 10,300 children and young people living in OOHC, with around 2,000 of these aged from newborn to five years.¹ Residential care is provided for children when kinship or foster care is not an option. Children with disability who are placed on OOHC *may have experienced trauma, abuse and/or neglect in the family home and they typically have multiple, intersecting, complex needs.*²

This cohort is a particularly high-risk group. It is important to understand not only the experiences of children and young people with disabilities in the care system but also how the NDIS (the Scheme), staff, carers, and the broader child and family services sector can better support children and young people with disabilities living in OOHC settings.

¹ See <https://www.vic.gov.au/about-out-home-care>

² Commission for Children and Young People (CCYP) (2021) Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Violence and abuse of people with disability at home. P. 9. <https://ccyp.vic.gov.au/assets/Submissions/Submission-to-Disability-Royal-Commission-Violence-and-abuse-at-home.pdf>

Challenges of the NDIS as experienced by our members

Prevalence

The exact number of children and young people in OOHC settings with a disability is unknown mainly due to incomplete data collection, varying definitions of disability across jurisdictions and differences in how data relating to disability is captured in systems. The most recent Australian Institute of Health and Welfare figures indicate that in Victoria at 30 June 2021, around 13.1 per cent of children in OOHC were recorded as having a disability, 68.8 per cent were recorded as having no disability, and 18.1 per cent were recorded as 'not stated'.³ Nationally, around 18.9 per cent of children in OOHC are reported to have a disability while the 'not stated' category represents more than one third of children in care (37.1 per cent).⁴ This means there are around 17,167 children and young people nationally whose disability status is either not known or has not been recorded ('not stated'). Visibility of children and young people with disability in OOHC matters. If they are not reflected in the data, their needs are easy to overlook.

In 2020, the Commission for Children and Young People (CCYP) in Victoria reported that of the 166 young people living in care whose files the CCYP examined, 67 per cent had a disability. This number is also likely to be an underestimation of the true figure, as children and young people with disabilities in care face many barriers when intersecting with the disability support sector, including the complexities of assessment and report requirements, inaccessible language, poor inter-departmental and inter-sectoral collaboration. Many of these challenges and barriers are due to lack of consistent care and to breakdowns of the care arrangement. Investment in sourcing quality data and understanding of the experiences of young people with disability living in OOHC is critical to understanding the service and support needs of this cohort and addressing the barriers to access and participation in the NDIS.

The CCYP file review confirms what our members have experienced in relation to the high proportion of children and young people with disability in the care system, particularly in residential care. Our members who provide residential care report that the residential care system is becoming a de facto disability home provider, something these residential care homes are not set up to be. For children and young people with disability who have also often experienced trauma to be placed in a residential home with several other children and young people who have their own significant trauma histories, behavioural challenges and high needs, is not always in the best interests of these children. We hear from members that children with a disability can be bullied in these home settings or may themselves be the aggressor through their challenging behaviours. There is considerable pressure on staff who are not equipped with the specialist knowledge to manage specific disability needs or confident in navigating the NDIS system on behalf of the children in their care.

In addition to an underestimation of prevalence, there is also limited understanding of the full extent and impact of the disabilities children in care live with. Many have psychosocial disabilities that can go undetected and diagnosed, especially when there is inconsistency of care, repeated care

³ Australian Institute of Health and Welfare (2021) Child Protection Australia 2020–2021, Table S5.8. Children in out-of-home care by disability status and state or territory.

⁴ Ibid.

arrangement breakdowns, and other challenges for the young person in care to overcome. This makes it complex and difficult to estimate the number of children and young people in care who might need support under the NDIS and be eligible to receive support under the Scheme.

First Nations children and young people are overrepresented in the OOHC system. Data indicates that First Nations children aged 0–14 years are more than twice as likely as non-Indigenous children to have a disability (15.2% compared with 6.6%).⁵ While the exact proportion of First Nations children and young people with disability in the OOHC system is unknown, it is estimated to be high.⁶

The Evaluation and Research team at the NDIS currently partners with academic institutions and research bodies 'to drive and shape the national and international research agenda and develop insights that improve outcomes for people with disability'. The Centre believes this team could also partner with federal and state governments to develop more accurate, complete and consistent data around the number of children with disability in foster, kinship and residential care nationally and in each jurisdiction.

There also needs to be much better inter-sectoral and inter-departmental collaboration to provide much needed specialised supports for children and young people with disabilities in OOHC and stronger connections between the Commonwealth and state-run child protection agencies to ensure children and young people in care have equitable access to the NDIS.

Intersectionality of mental health & trauma

Children and young people living in care experience high rates of complex mental and physical health challenges.⁷ The intersection between trauma, mental health and disability is not well understood. Our members report that the NDIS only recognises a small part of the intersection between trauma, mental health and disability. Service systems, like the NDIS, must also recognise the capacity the eligibility process has to retraumatise children and young people in OOHC seeking to access help.

Almost every child in OOHC has by definition experienced some form of trauma in their childhood given they have been removed from their birth families often for reasons to do with *exposure to parental violence, drug use, mental illness, physical abuse, sexual abuse, or the risk of such abuse*.⁸

The 2019 CCYP inquiry into OOHC, in which around 204 young people with lived experience of the OOHC system participated, found that children with complex trauma, behavioural problems, and intellectual disabilities lacked access to specialised services. In addition, it was found that many residential care staff members lack the specialised training necessary to provide complex care to children and young people with disabilities. A 2014 VAGO inquiry into residential care services for children found that children and young people with disabilities were more likely to enter short-term

⁵ Australian Bureau of Statistics (2017) 4433.0.55.005 - Aboriginal and Torres Strait Islander People with a Disability, 2012.

⁶ CCYP. P. 5.

⁷ The Royal Australian & New Zealand College of Psychiatrists (2021) The mental health needs of children in care or at risk of entering care. Position statement 59. <https://www.ranzcp.org/news-policy/policy-and-advocacy/position-statements/the-mental-health-needs-of-children-in-care>

⁸ Victorian Auditor General's Office (2014) Residential care services for children. VAGO. P. 2.

contingency (i.e. unfunded) placements than other children and young people with complex needs, including violence or aggression.⁹

Psychosocial disability and the impact of trauma relating to early adversity and intergenerational trauma affect many children in OOHC.¹⁰ It can be challenging for professionals to distinguish between the impacts of the disability and trauma, creating barriers around secure funding for supports. The Berry Street submission to the NDIS Review notes that NDIS definitions and scope for disability 'largely fail to account for the comorbidity of trauma and diagnosed disability', reflecting the experiences of other member organisations seeking to mitigate the impacts of children whose disability has been compounded by trauma. Older children and young people who are no longer eligible for the Early Childhood Education Intervention, which recognises developmental delay and the impact of trauma, are less likely to experience trauma-informed support when transitioning to the NDIS at the age of seven.¹¹

The capacity of the NDIS workforce should be expanded and strengthened to make sure all workers are trauma-informed, holistic in practice, and empowering. Disability-specific knowledge is critical, as is specific knowledge of how to provide specialised care to children and young people.

The Centre asks the NDIS Review to consider the impacts of NDIS assessments on children and young people with disability and limited informal supports to prevent further traumatising children. Provision of independent advocates could support children and young people in OOHC to take part in planning and decision-making concerning their healthcare needs. Training and education could help build the capacity of the NDIS workforce so that it has a high level of competency in dealing with the complexities of mental health and disability, with a focus on trauma and trauma-informed practice, as well as the intersection between trauma, mental health and disability.

Early intervention and sustainability of care

Many of our members work in prevention and early intervention, with a strong focus on linking children, young people and families into the necessary supports that can meet often complex needs. NDIS supports can play an important role in keeping children, young people and their families together and preventing children from entering the OOHC system. The informal supports provided by parents, carers and families are vitally important for children and young people living with a disability.¹² For children in the OOHC system, the repercussions of inadequate assessments, NDIS plan funding allocation, lack of early intervention and provision of supports can result in placement breakdown, children and young people experiencing multiple moves, carers burning out, and future placements being made more difficult.

Our members possess specific knowledge that can assist the NDIS to understand risks to the sustainability of care for NDIS participants. Currently input from professionals, such as those working

⁹ Ibid. p. 31.

¹⁰ Ibid.

¹¹ Berry Street (2023) Submission on the interface between the NDIS and Out-of-Home Care.

¹² NDIS (2023) Sustaining informal supports. <https://www.ndis.gov.au/about-us/operational-guidelines/including-specific-types-supports-plans-operational-guideline/including-specific-types-supports-plans-operational-guideline-sustaining-informal-supports>

in family services, are not considered adequately by the scheme, creating a gap in participant and carer supports. These worker's assessments should be regarded as expert assessments in the eyes of the NDIS. The presence of such support workers should demonstrate the need for the NDIS to invest in early intervention supports to increase carers' capacities, keeping children and young people's needs at the forefront of all decisions made.

In reference to 7.11 of the NDIS Act, '[supports] required as a direct result of a child's disability' should be extended. It is the Centre's view that the Act should consider internal and external factors, not directly linked to the child or young person's impairment, that may impact on a carer's capacity to provide informal supports for a child or young person's disability. Practitioners in community services hold valuable knowledge +in relation to these factors. The NDIS needs to formally acknowledge the expertise of these practitioners, in the same way the NDIS has preferred types of evidence for specific impairments.

A clear framework is needed so the NDIS can recognise that some carers experience complexity beyond the impairment(s) of the children and young people they care for. Such recognition would allow for a holistic system that provides supports to the whole family and all caregivers, strengthening the sustainability of carers.

Our member organisations suggest that Support Coordinators should always be included in the supports offered for participants in OOHHC, with adequate funding provided in the plan to include training and capacity building for carers. Carer impact statements should be formally recognised as evidence and be considered carefully in NDIS preplanning, planning and plan review processes. Carers' perspectives are unique and should be valued during the planning process.

The Centre asks the NDIS Review to consider how the NDIS might make better use of the knowledge and experience of support workers external to the NDIS whose assessments of the child or young person's needs are based on the evidence they have collected. There also needs to be better supports for caregivers to reduce the risk of relinquishment of a child with a disability with Support Coordination being included in the supports offered for carers with adequate funding provided in the plan. Funding for respite care for parents could mean the difference between family preservation and relinquishment while respite care for foster and kinship carers could mean the difference between a stable placement for a child and placement breakdowns with resultant associated trauma and the possibility of entering residential care.

Care leavers

Access to safe and secure accommodation is a critical consideration in preparing any young person in care for independent living. For a young person with a disability in OOHHC, the need for a planned and appropriate transition is even more critical. Planning for life after care for young people with a disability, who may not have the skills for independent living, needs to begin much sooner than is currently the case. Service providers need to be able to support the young person well before they turn 18 years of age through a planned transition into Supported Independent Living or Supported Disability Accommodation. If funding for housing options is not available until the young person

turns 18, this makes it difficult for service providers to effectively manage leaving care planning and access into supported accommodation successfully.¹³ For many, the transition to independent living

can be a period of significant uncertainty, impacting on a young person's mental health and potentially creating additional trauma. A young person with a disability leaving care faces additional challenges, not the least of which, is potentially grappling with the impact of their disability on their capacity for employment and independent living, and the need to navigate the NDIS in the absence of a carer family or advocacy support.¹⁴

In addition to the NDIS recognising the need for a longer lead-in time to transitioning a young person from care to accessible, safe and available accommodation, service providers could also be supported to identify and access the range of post leaving care options and supports available to young people with a disability leaving care.

Systemic change

The NDIS, its terminology and systems can be challenging to navigate. The task of accessing the Scheme is made more difficult for individuals who care for children and young people in OOHC, since it requires integrating the intricate procedures and context of the OOHC and Child Protection systems with those of the NDIS.

The NDIS's systemic complexities and procedural terminology are key barriers to providing children, young people, families and carers with the supports they require. Carers try their best to navigate this complicated system, taking the child to various appointments to complete assessments, finding the right provider for them and their needs.

There are systemic barriers that exist, preventing children and young people in or entering OOHC systems from accessing the Scheme. An unintended consequence of soft referral points into the NDIS (child protection, support workers, broader community service system) could encourage or discourage possible participants from accessing the Scheme. Our members' experience overwhelmingly indicates that many workers do not fully understand the NDIS because of its complexities and inaccessible use of language.

The Scheme has a responsibility to ensure that children and young people with a disability living in OOHC are not disadvantaged due to a caregiver's lack of access to resources and familiarity with the service system. Current information suggests that children and young people in OOHC settings are disadvantaged when accessing the Scheme. Plans are underused, suggesting that there have been challenges sourcing appropriate supports and fully utilising the assistance offered by the Scheme.

The Centre asks the NDIS Review to consider simplification of language and the system itself, removing hard-to-understand medicalised and NDIS-specific language to ensure equitable access to

¹³ Association of Children's Welfare Agencies (ACWA) (2021) 'Falling through the gaps?' Delivering the best possible outcomes for vulnerable children and young people with disability.

¹⁴ Ibid. P. 66.

the NDIS for children and young people with a disability in OOHC compared with their peers who are not in OOHC.

Conclusion

The Centre welcomes changes to the NDIS system that will enable children and young people with disability in OOHC to receive the necessary services and supports to meet their immediate and future needs. This includes simplification of the system and language, provision of Support Coordinators to assist caregivers in navigating the system, ensuring NDIS workers are trauma-informed, encouraging the NDIS to recognise the unique and complex needs of children and young people with disability who have been placed in care, and fund respite for carers – and parents – of children with disability to the requisite level of need. Our members stress the need for earlier and more coordinated support for families who are at risk of relinquishing their child into state care. *[P]arents in difficult situations need support that is timely, easy to access, flexible and gives them the capacity to continue to care for children with disabilities that can be complex and challenging.*¹⁵ For parents and carers alike, access to NDIS funded respite could enable children to remain in stable home settings.

Our members also highlight the importance of centring the experiences and voices of young people in OOHC in their health and wellbeing, ensuring the NDIS takes these into account when creating care plans for this particularly vulnerable cohort.

Suggestions for consideration by the NDIS Review

1. Work with State and Federal government to systematically collect data relating to the number of children and young people with disabilities in OOHC.
2. Strengthen the connections between the Commonwealth and state-run child protection agencies to ensure children and young people in care have equitable access to the NDIS.
3. Strengthen NDIS understanding of the particular challenges associated with the care system – such as constant changes in care arrangements or in case managers, the significant levels of childhood adversity experienced by children and young people in care, and workers and carers who lack disability specific expertise.
4. Provide training and resources to build the capacity of the NDIS workforce, with a focus on trauma and trauma-informed practice, as well as the intersection between trauma, mental health and disability.
5. Provide independent advocates so children and young people in OOHC are encouraged to take part in planning and decision-making concerning their healthcare needs.
6. Support workers assessments and knowledge to be formally recognised by the NDIS.
7. Include Support Coordination in the supports offered for caregivers, with adequate funding provided in the NDIS plan.

¹⁵ Victorian Equal Opportunity and Human Rights Commission. (2012) Desperate measures: The relinquishment of children with disability into state care in Victoria. VEOHRC. P. 4.

8. Formally recognise carer impact statements in the preplanning, planning and review processes.
9. Remove barriers of hard-to-understand medicalised and NDIS-specific language to ensure equitable access to the NDIS for children and young people with a disability in OOHC.
10. Support strong collaboration between OOHC providers and disability support agencies to facilitate understanding and navigation of the system, pursue diagnoses, develop appropriate support plans and increase positive outcomes for young people in care.
11. Listen to the views and wishes of children and young people with disability in OOHC wherever possible and incorporate in care plans.

Appendix A: Three case studies

Case study 1

This case study example was provided by a small regional service provider in Victoria.

Of the children in the homes of this regional residential care provider, most have a diagnosed disability even though the home itself is not a disability unit. These include Foetal Alcohol Syndrome, Autism Spectrum Disorder and intellectual disabilities. Some children with a suspected disability have not yet been assessed to confirm a diagnosis.

These are some of the challenges identified by this member organisation:

1. Difficulty in finding NDIS services that are robust enough to work with their young people given the complexity of the children's needs
2. The time it takes to have a young person in the home assessed for NDIS supports
3. NDIS lack of understanding or lack of accounting for trauma, which is a significant factor in the lives of these young people
4. NDIS workers are not trained to work effectively with young people who have complex behaviours and/or trauma backgrounds
5. Child protection workers not knowing how to navigate the NDIS
6. Lack of specialist services available in the region, particularly paediatricians
7. Difficulty in finding services that will 'stay the course' with a young person who is not engaging
8. Lack of residential care homes to cater for several young people living together with complex and often significant disabilities, meaning some young people with disability are highly vulnerable to bullying and violence
9. Staff needing a lot of support to manage the specific needs of some young people with disability and the violence towards staff and young people that can occur through mismatched placements.

Case study 2

This case study was provided by Uniting VicTas, a large service provider supporting children and families located in Victoria and Tasmania.

Rory* is a ten-year-old male living in a Uniting RP3-funded residential care home. Rory is a person with significant disability, who has non-verbal communication and requires 24-hour support to meet his personal care needs. Prior to entering Uniting's care, Rory had not resided in OoHC, although he had spent some time in specialised disability respite services. After receiving Rory's referral from Child Protection, Uniting strongly advocated for 24-hour NDIS support workers to support Rory within the residential home and emphasised the importance of these staff having supported Rory before. This was granted by Child Protection and Rory has seemingly adjusted well to living in the residential home and is well supported by both NDIS staff and Uniting staff. However, as evidenced below, there is clear need for specialised youth disability services comprised of multidisciplinary teams trained in both trauma-informed care, youth work and disability.

The impact of living in a residential care home without specialised disability support and alongside young people with trauma histories and potentially high-risk behaviours poses less than ideal outcomes and increased vulnerability for Rory. Prior to Rory's placement, the residential care home was settled with four young people, who had resided there for a significant period of time. Due to the need to place Rory quickly, two young people were moved to another placement to allow capacity. For the young people remaining in the home, there is an expectation placed upon them to hold space, with empathy and compassion for their co-resident, while they are there to heal.

Uniting faced pressure to place Rory due to the limited options available for young people with disabilities who need urgent access to residential care. This pressure for placement presented several complexities for staff, Rory and young people in the residential care home. Uniting was concerned about being able to adequately support Rory within the residential care home setting as support staff have no specialised training in disability support. In response, DFFH offered training to staff. Whilst commended by Uniting, this training represents a significant time commitment for staff and places extra pressures on management to fill shifts and support other young people when staff are in training.

For staff working in the home, there is reported difficulty in identifying what is a behaviour and what is a symptom of a lack of appropriate disability support. Furthermore, there has been confusion as to the overlap between the NDIS support worker and Uniting support worker duties when it comes to Rory's care. This has placed extra pressure on both staff and management to unpack these complexities whilst still providing care to other young people.

Case study 3

This case study was provided by Anglicare Victoria (Anglicare), a large service provider supporting children and families in communities across metropolitan and regional Victoria, which has partnered with Yooralla, a specialist disability service, in a pilot to better support the needs of young people with disability in residential care.

At the start of the year-long pilot, Anglicare's data showed that 35 per cent per cent of their children and young people in care (residential and home-based) had a diagnosed disability.

- Of this 35 per cent, only 49 per cent of children and young people had an NDIS plan and were using supports
- 12 per cent had an NDIS plan but were not using supports
- 30 per cent needed an NDIS plan but did not have one.

The pilot commenced in January 2022 with Yooralla providing NDIS service navigation and support (0.8 EFT) and behaviour support (0.4EFT).

In just over a year, there is already evidence of the significant difference that a specialist disability service, working in partnership with child and family services practitioners, can make to the lives of children with disability in care.

A key benefit from the partnership was the difference made to young people's access to appropriate NDIS supports, including for children whose earlier NDIS applications had been rejected or whose plan funding and components had proved insufficient to sustainably support them in their current residential care living arrangements. Having Yooralla's expertise with clinical assessments, interpreting the technical language of the NDIS and navigating the complex processes has made an enormous difference to getting young people the support they need. With some young people, these supports were able to stabilise their placements, avoiding what had previously appeared to be imminent placement breakdowns and the potential need for contingency placements.

Another benefit has been the discernible changes in the behaviours of young people following Yooralla's assistance with implementation of behavioural support strategies and getting appropriate support services for care teams. Changes include a reduction in children's antisocial behaviours, increased capacity to communicate, and better engagement with staff and the broader community.

Children and young people also benefited from Yooralla's expertise in pursuing concrete diagnoses. The pilot highlighted the complexity of the overlap that can occur between trauma, mental health issues and a disability such as ASD, and the critical importance of being able to have disability expertise of the kind provided by Yooralla to expedite assessments and diagnoses so that the necessary NDIS support plans could be put in place for the young person.

The pilot has also shown the difference that can be made when staff are able to access existing NDIS plans. Constant changes in care arrangements for children and young people, changes in child protection case managers, and changes in court orders in relation to guardianship, make it very difficult for workers and carers to find and access NDIS plans. In addition to assisting residential care program staff to locate and access young people's existing NDIS plans, Yooralla also assisted

care teams to avoid funding in plans being reduced (due to it not being utilised), and to successfully seek increases in plan funding for some young people. The Yooralla/Anglicare Victoria partnership has proved critical in filling this key gap in Child Protection/Out-of-Home-Care system capacity.