



Submission to the Social Development Committee Inquiry into NDIS participants with complex needs living in inappropriate accommodation

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Introduction

As South Australia's Commissioner for Children and Young People, my mandate under the *Children and Young People (Oversight and Advocacy Bodies) Act 2016* is to advocate at a systemic level for the rights, interests and wellbeing of all children and young people in South Australia.

I welcome the opportunity to provide a submission to the Inquiry into the impacts of the National Disability Insurance Scheme (NDIS) on South Australians living with disability who have complex needs and are, or are at risk of, living in inappropriate accommodation for long periods.

This submission focuses on a particular group of NDIS participants in South Australia whose voices are not usually heard: children and young people with complex needs who are unable, or are at risk of being unable, to live in the family home.

Since the full rollout of the NDIS in South Australia in June 2019, children and young people aged 0 to 18 years old have consistently made up more than half of all NDIS participants in the state.ⁱ Compared to other states and territories, South Australia has the highest NDIS participation rates of children across all three NDIS age groups 18 years and under.ⁱⁱ

The developmental and service needs of children and young people who are NDIS participants are different to those of adult participants. As such, the rights and experiences of children and young people in relation to this Inquiry's terms of reference require particular consideration and tailored responses.

Most children and young people with complex disability needs who are unable, or at risk of being unable, to live at home have never been the subject of the child protection system. Where a child lives outside of the family home in these circumstances, the child's parents generally retain guardianship and parental responsibility.

These arrangements, commonly referred to as voluntary out of home care (VOOHC), are often crisis-driven and a 'last resort', generally occurring amid a breakdown of family support, relationships or resources, or where there is a lack of appropriate services available.

I acknowledge there have been some positive steps over recent years towards recognising and supporting this vulnerable group of children and their families. In 2019, the Disability Reform Council committed to provide 'stable and supported arrangements' for children with disability 'who are unable to live at home' and 'improve the service experience' for families.ⁱⁱⁱ

This commitment has been formalised in a Memorandum of Understanding, whereby the National Disability Insurance Agency funds 24/7 staffing, support coordination and disability supports for this group of children while the state (represented by the Department of Human Services and Department for Child Protection) provides funding for board and lodging, facilitates access to mainstream services, as well as early intervention and prevention supports to reduce the need for families requiring these arrangements in the future.

This agreement is positive insofar as it recognises that the family home is the best place for a child, and the need to ensure adequate supports are available to keep children at home. At the same time, it acknowledges that there are some cases where out-of-home care arrangements are likely to still be required.

Despite this progress, significant concerns remain regarding the isolation, invisibility and lack of safeguarding and oversight of this group of children and their families. Parents, service providers and other advocacy bodies have contacted my office to raise concerns about systemic gaps in relation to children and families in this situation.

Where a child's complex needs and behaviours escalate to the point where living at home is no longer safe or tenable, no one appears to know what to do, where they can turn or whose responsibility it is to ensure that these children have quality and stable environments and that their families are supported. This appears to be the case even for families who have a high level of advocacy support, are well-informed and connected with skilled support teams.

The NDIS After Hours Crisis Referral Service (AHCRC), which is designed to support participants who are experiencing a crisis or breakdown in support, is only available to NDIS participants aged 18 and over. In the absence of real crisis-point intervention services, hospital tends to become the only option.

As concerns most recently raised by the federal Minister for the NDIS reveal, it is well-known that hospital environments are inappropriate places for adults with complex disability needs, let alone for children. Indeed, the impacts on fundamental human rights can be even more far-reaching and traumatic for children and young people who are still developing.

Evidence overwhelmingly shows that quality, safe and stable housing is key to a range of positive life outcomes.^{iv} On the contrary, inappropriate and unstable accommodation has significant impacts on the health, wellbeing and safety of people of all ages and abilities.

It is critical that the particular impacts of inappropriate accommodation on the rights of children and young people with complex support needs are acknowledged and addressed. This includes the impacts on their social and emotional development, their relationships, wellbeing and social connections, and their engagement in play, education and the community, not to mention their ability to access – and ultimately benefit from – therapeutic and behavioural support and other appropriate supports.

This submission identifies gaps in policies, services and systems specific to children with disability. In doing so, it highlights the need for a holistic response that ensures all children with complex needs have places to live, learn and play where they can develop socially and emotionally and where they are safe, healthy, confident, empowered and connected to others and their community.

Specifically, it is recommended that the Committee:

- 1. Consider the unique experiences and developmental needs of children and young people with complex needs who are unable, or at risk of being unable, to live in the family home, with particular regard to their:**
 - a. Rights, participation, safety and social and emotional development.**

- b. Access to and engagement with education.
 - c. Key transitions from childhood through adolescence to adulthood.
 - d. Complex behavioural support needs and mental health needs.
2. Consider the particular impacts of the following on children and young people with complex needs who are NDIS participants and their families:
- a. The conflict between what is 'parental responsibility' and what is a 'reasonable and necessary' NDIS-funded disability support.
 - b. Planning processes and lengthy review processes that do not account for child and adolescent development.
 - c. Thin markets and long wait lists for key NDIS-funded supports and mainstream services.
 - d. The interface between NDIS and mainstream services and the lack of safeguarding mechanisms for children and young people with disability.
 - e. Workforce consistency, skills and knowledge.
 - f. Shortage of safe and available housing stock.

I hope that the concerns, insights and recommendations throughout this submission are able to inform a systemic response that prevents South Australian children with the most complex needs from falling through the gaps.

The quotes throughout this submission are from children and young people with disabilities who participated in my targeted listening project during 2020 and 2021. The findings of this project are presented in more detail in my 2022 *From Checkbox to Commitment* report, which I encourage the Committee to consider alongside this submission.^v

The *From Checkbox to Commitment* report highlights the diverse needs, personalities, resources and experiences of children and young people with disability that we can only seek to understand and accommodate by engaging with them and their support networks and listening to what they have to say.

If you would like to discuss anything further, please do not hesitate to contact my office.

Yours sincerely,



Helen Connolly

Commissioner for Children and Young People South Australia

Background: The rights of children and young people with disability

As a signatory to the United Nations Convention on the Rights of the Child (the UNCRC) and the United Nations Convention on the Rights of Persons with Disability (the UNCRPD), Australia acknowledges and commits to give effect to the full range of rights of children and young people with disability.

These rights are embedded in South Australia's *Disability Inclusion Act 2018* (the Act), which sets out the right of children with disability 'to a full life in conditions that ensure the child's dignity, promote self-reliance and facilitate the child's active and full participation in family, cultural and social life'.

Other principles specific to children with disability in the Act include listening to children's views, ensuring decisions affecting children are child-centred and account for children's developmental needs, and providing developmentally appropriate opportunities for children to participate in decision-making.

Despite these legislative protections and principles, experience shows that rights related to 'voice' and 'choice' are often overlooked in favour of a focus on child safety and protection. While this is the case for all children regardless of disability, children with disability face a number of additional barriers that limit their participation, including:

- A culture of ableism and low expectations that presumes children with disability do not want to or are unable to engage in decision-making.
- A lack of opportunity, due to an absence of processes, activities and events specifically designed to include children with disability.
- Inaccessible communication methods or the absence of necessary and appropriate tools and support to engage children and young people with complex needs.
- A lack of skills, training, support and resources available to practitioners and carers through which children can be understood.

These barriers can be self-perpetuating and children with complex needs are even more vulnerable, as a lack of opportunity excludes children from opportunities to develop the skills, experience and confidence they need to participate in the future.

Context in South Australia: Children with complex needs who require or may require accommodation outside the family home

Across Australia, it is estimated that there are approximately 160 to 220 children and young people with disability who require accommodation outside of the family home. As at 30 June 2022, there were 34 children and young people in South Australia in the Exceptional Needs Unit (ENU) Voluntary Out of Home Care stream through the Department of Human Services, in collaboration with the NDIS. A further 20 children were part of the Early Intervention and Prevention stream.

Although South Australian children make up a high proportion (15 to 20%) of this national estimate, the actual number of children is relatively small. Therefore, we should be able to provide the multi-agency, child-focused and family-centred responses that are required to meet the needs of these children and their families.

Of the 54 children across both streams, the most common recorded disability is autism, and most children also live with intellectual disability. A smaller number have Fetal Alcohol Spectrum Disorders (FASD) or cerebral palsy. The youngest child is 8 years old and the significant majority are male, with a smaller number of young females and 2 non-binary children.

Many of these children are living with complex mental health needs as well as complex behavioural and sensory needs, all of which can be compounded by the trauma and confusion of being isolated from their family members and familiar home environment.

These children and families are diverse in terms of parental involvement and capacity, as well as socio-economic and cultural backgrounds. In many cases, there is significant 'family complexity' as well as 'individual complexity'.

Some families have multiple children with disabilities and complex behaviours, and most are isolated from the community, with low levels of attendance and engagement in education. More than half of these children are known to be from single-parent households (most commonly single mothers), and many have siblings who have been identified at risk of harm due to the impacts of disability.

Despite often having well-funded NDIS plans, these children become a casualty of 'thin markets', which result in a lack of appropriate services, a lack of workers with the requisite skillset to support the child, and service providers being unable to fill the required roster of supports. A lack of skilled positive behavioural support in particular increases the already high likelihood of disability-related 'behaviours of concern' being criminalised.

Of the 34 children in the VOOHC stream, almost half (16) did have stable accommodation across the last financial year. Among the eighteen children who did not have stable, safe or appropriate accommodation during this period, there were:

- 5 incidents of social admission to hospital.
- 2 incidents of an extended stay in Kurlana Tapa Youth Justice Centre.
- 3 placed in emergency temporary accommodation in Airbnbs or caravan parks.
- 5 incidents of children remaining in respite due to lack of accommodation.
- 6 incidents of children moving between placements due to care concerns.

Insufficient supports, difficulty accessing services or a breakdown in supports can contribute to the need for voluntary out-of-home care arrangements in the first instance. Yet it is incredibly difficult to provide children with high-quality and consistent support in the context of unstable or temporary 'crisis' accommodation.

This cycle of unmet need and uncertainty is not only distressing and traumatic for children, families and workers, but it can also bear significant social and economic costs in the longer-term, including in the youth or adult justice systems.

Recommendations

1. Consider the unique experiences and developmental needs of children and young people with complex needs who are unable, or at risk of being unable, to live in the family home, with particular regard to their:

a. Participation, safety and social and emotional development.

Regardless of disability, it is meaningful participation in everyday activities across home, community and educational environments that drives children's healthy development. Children with complex needs living in (or at risk of living in) VOOHC arrangements generally face significant barriers to being heard, building relationships and developing life skills.

The primary focus of supports for these children tends to be on meeting the child's immediate medical needs and ensuring physical safety. Individual therapies and medical models of support tend to be prioritised over other social and community-based supports (see Recommendation 2b).

Given the complexity of needs among this group of children, such a focus is important and understandable. However, a focus almost exclusively on medical and physical safety can limit a child's holistic social and emotional development.

In the context of rotational care arrangements, the inconsistency of care staff can exacerbate these barriers. Where the role of care staff is generally limited to addressing a child's disability support needs, they generally lack the capacity and resources to address the range of factors that influence a child's development (see Recommendation 2e).

"I feel included when people be human to me – when they treat me like a human."

– 15 year old, female

"Sometimes people might think I struggle with things I don't. And they talk to me differently."

– 11 year old, female

"Sometimes they talk down to me, like I'm a dog."

– 13 year old, male

Whether due to a lack of services or suitable transport options, genuine safety concerns or attitudinal barriers, the result is often that these children and young people are largely confined to where they live and miss out on a range of opportunities that other children take for granted. Stakeholders have provided examples of situations where a child's request to go to the local park or participate in an activity is denied, often without reasons for this being explained to them.

Evidence suggests that increasing participation and reducing social and physical isolation is a key safeguard against maltreatment for both children and adults living with disability.^{vi} Safety for children and young people is more than just physical safety; safety is feeling valued, known, accepted and understood, and having their sensory, emotional, behavioural and physical needs met.

Engagement with children not only improves the design and delivery of the systems and services they use, but also increases children's confidence and skills, sense of belonging and safety. Addressing these barriers and recognising the importance of participatory service models and practices for children and their families must therefore be a key part of system reform.

b. Access to and engagement with education.

A good education is key to lifelong physical and mental health and wellbeing, social inclusion, independence and economic security. Education is not only a human right in itself, but also a fundamental means of realising other human rights.

All children with disability have the right to access and participate in education without discrimination and on the same basis as students without disability. These rights are enshrined in the UNCRC and the UNCRPD, and protected in the *Disability Discrimination Act 1992 (Cth)* and Australia's *Disability Standards for Education 2005*.

Despite this, Australia has one of the lowest educational attainment rates of people with disability when compared to other OECD countries. Formal recommendations and regulations guiding inclusive education remain well ahead of attitudes and practice.

There are variable levels of engagement in education among the 54 children across both the ENU Voluntary Out of Home Care and Early Intervention & Prevention streams. Many children and young people are not attending school in any form. School refusal is also a factor in some cases, while the education status is unknown for others.

Almost half are in full-time education while a smaller group are in part-time education. They often have a teacher working 1 on 1 with them, with limited to no opportunities to engage with other children. This again highlights the need to make available and accessible supports that foster every child's learning, social connections, participation and social and emotional development, no matter how complex their needs.

Children with disability are disproportionately excluded from education from a young age. Even where specialist settings are unable to consistently support a child's high levels of need, the response is often formal and informal exclusion, which can exacerbate disengagement and ultimately detachment from education. Significant barriers to engaging with school remain in the context of unstable accommodation, and in some cases may be exacerbated.

The short-term and long-term social, emotional and financial impacts of missing out on education are significant. Parents and carers pay financially when they are forced to give up paid work in order to meet their child's care and educational needs. Children and young people pay in terms of poorer health outcomes, increased social isolation and, under- or unemployment, all of which influence their ability to participate and contribute to society later in life.

"I have been suspended when it's been the teacher not understanding what I need due to my disability."

– 13 year old, male

“Just because I have autism, shouldn’t mean school should be a too hard place. Teachers just tell me I’m difficult or lazy.”

– 17 year old, female

“I don’t have many friends, so I don’t really feel included.”

– 13 year old, male

c. Key transitions from childhood through adolescence to adulthood.

Our current systems do not appear to adequately plan for and project from childhood through to adulthood. Navigating key transitions across childhood and adolescence to adulthood presents many challenges for all children and young people, regardless of disability.

Children with disability and their families are also navigating whether or how the child’s complex needs will limit their independence and capacity to reach their goals as they become adults. They are generally aware that they need additional supports and are very open to having support, yet many describe having too few opportunities to participate in activities or engage with their community.

Their thinking and goals for the future reflect how much they value the support provided by those around them. In turn, they want their family and communities to be supported, and want more time to do more activities together with members of their family.

“My mum would like for me to be independent, but she also does a lot for me.”

– 19 year old, female

“I love feeling really independent, ‘cos it will set me up for the long term.”

– 16 year old, female

“When they did it all for me, it didn’t feel good cos I wasn’t independent.”

– 14 year old, male

Most children with complex needs living outside of the family home are at a stage of life where they are not yet an adult but no longer a child. While children exit the MoU arrangements at 18, planning and assessment for Specialist Disability Accommodation (SDA) and Independent Living Support (ILS) may begin at age 16.

Developing independent living skills can create challenges for adults and service providers, where it is necessary to balance risks while also building capacity for young people with disability to have increased independence. It is critical that these young people and families are supported to successfully navigate these key transitions. Beyond ensuring safe and stable accommodation, this support must:

- Ensure children have access to a range of opportunities and activities in the community (and safe transport options) that support their complex disability needs, but also their social and emotional development and their transition to adulthood.
- Improve knowledge and capacity among both NDIS planners and care staff regarding child and adolescent development, and how this differs from adult

participants. As a child and young person's goals and needs will change over time, so too will the appropriate guidance required to navigate key transitions (see Recommendation 2b).

d. Complex behavioural support needs and mental health needs.

A holistic response to this group of children also requires recognition of the interplay between trauma and disability, and the importance of appropriate therapeutic services as well as positive behavioural supports. While the individual experiences of children and families in these situations are incredibly diverse, many children experience significant trauma or have complex mental health needs in addition to their complex disability needs.

As these children are separated from family and home, they are often dealing with confusion, disruption, distress and feelings of abandonment, coming to terms with the reality that their family 'couldn't cope' with them.

Stakeholders have raised concerns about the difficulty accessing psychological support. NDIS only fund disability support, leaving the costs of psychiatry and other medical services to Medicare or to families to pay out of pocket. The Exceptional Needs Unit has started to provide funding for these services out of concern for children's wellbeing, but report that they do not have adequate resources to do so.

While psychologists may fit into NDIS plans for children with autism and behavioural support needs, a lack of available services and long waiting lists are major barriers to children receiving timely and appropriate support (see Recommendation 2c).

Where children with complex disability needs do present to hospitals or other health care settings, stakeholders have raised concerns about the quality of the mental health care provided to them, particularly those with intellectual disability. Some families report that their child is denied mental health care because their 'behaviours of concern' are deemed 'disability-related' rather than mental health-related.

Many children who are unable to live at home due to complex disability support needs are likely to have behaviours that require access to specialist behaviour support providers, registered behaviour support practitioners and providers who use regulated restrictive practices (implementing providers) and meet the requirements in the *NDIS (Restrictive Practices and Behaviour Support) Rules 2018*.

There are thin markets for a range of services, but particularly gaps for positive behaviour support (see Recommendation 2c). The lack of this vital support is detrimental and can contribute to disengagement from education, family breakdown and in some cases lead to Youth Justice involvement.

In the absence of appropriate alternative accommodation support and other supports, behaviours can be triggered and exacerbated and there is currently an over-reliance on the justice system to bridge the gap.

Disability-related behaviours already place young people at increased risk of criminalisation, with people with disability over-represented in both the youth and adult justice systems.^{vii} Criminalising already vulnerable young people with complex needs

perpetuates a cycle of disadvantage, discrimination and stigma and increases the likely progression from youth justice to the adult justice system.

Responses must address these support gaps and seek to reduce exposure to the justice system, which has been shown to further traumatise children, limiting their chances of becoming healthy, safe and responsible adults.

2. Consider the particular impacts of the following on children and young people with complex needs who are NDIS participants and their families:

a. The conflict between what is ‘parental responsibility’ and what is a ‘reasonable and necessary’ NDIS-funded disability support.

Building the capacity of parents and families of children with disability living in the family home is vital. Yet many families experience NDIS planning processes for child participants as a ‘conflict dynamic’ between what is a funded disability support and what is ‘parental responsibility’.

The support available to a child who is a NDIS participant is only as good as the support available to those around them. Where systems fail to consider the needs of a child participant’s family members or carers and where there is an over-reliance on informal supports, the ultimate impact is crisis interventions and ‘relinquishment’ of the participant.^{viii}

As per Section 34(e) of the *National Disability Insurance Scheme Act 2013*, the funding or provision of ‘reasonable and necessary’ support takes account of what ‘is reasonable to expect families, carers, informal networks and the community to provide’. When decisions are made related to the funding of support for child participants, the NDIS Rules also acknowledge the need to consider the wellbeing of the participant’s family and carers as well as the child’s wellbeing.

However, in reality, the literal interpretation of sub-section 34(e) often means a refusal of funds for supports that is deemed a ‘normal parental responsibility’. As children become teenagers, it can become easier to meet the threshold with the argument that a teenager without disability would have certain level of independence. However, it is particularly difficult to make case for supports for younger children. Given that the youngest children entering the VOOHC stream are 8 and 9 years old, these issues require consideration.

We have been told that parents in this situation are advised that the level of support they provide falls within ‘parental responsibility’ despite the fact they are providing levels of care and supervision well beyond what a parent would ‘normally’. Indeed, many parents are forced to reduce their working hours or give up paid work entirely in order to take on full time care coordination for their child.

Carers of children have reported significant barriers accessing services that provide a ‘respite effect’. These services support families to continue to care for their children at home and are therefore critical in terms of preventing the need for OOHHC arrangements.

However, they are often denied on the basis that they are ‘for the carer’ rather than the person with disability.

The 2019 review of the NDIS Act (the Tune Review) highlighted these barriers, and also found that if a request was for ‘short-term accommodation’ or additional paid care supports in the home, this support would be granted, even if the ‘respite effect’ was similar.^{ix} It is concerning that outcomes appear to be depend on the level of information and support available to the family to advocate and use the ‘correct terms’ in their requests for support.

Families provide vital informal supports and are the experts on what their child needs. It is critical that they are well-supported, informed and that their input is valued and acted upon, particularly given the high proportion of single parents (often single mothers) with multiple children and multiple disabilities in this situation.

Stakeholders have also raised concerns that some parents are cut off from their carer support payments once their child is living outside of the family home. This is despite the reality that their significant caring role continues, with an expectation from service providers that parents will be available at any time to provide direct care, pay out of pocket expenses for supports, complete paperwork or follow up on other advocacy or care tasks.

Evidence provided to the Disability Royal Commission has highlighted the impacts, particularly for those living in regional areas, where the NDIS does not pay for family members who are carers. While a reliance on informal supports may be considered an opportunity to save costs in the short term, the reality is that inadequate support increases the likelihood of crisis situations and the need for more services, ultimately leading to greater costs in the long term.

b. Planning processes and lengthy review processes that do not account for child and adolescent development.

The NDIS has been designed to provide participants with supports that are tailored to their individual needs and allow greater choice and control in how they live their lives. This focus on participants as individuals is generally positive. However, when the focus is almost exclusively on the individual and their disability needs in the case of children, there is a tendency to consider children and young people as isolated from their families, environment and community.

Current approaches to NDIS planning and decision-making do not appear to consider the range of factors that influence a child’s development across childhood, adolescence and the transition to adulthood. There is a tendency to prioritise individual and medicalised therapy at the expense of other social and community-based supports that drive children’s development and wellbeing.

There is an expectation that mainstream services will provide these services where they do not meet the ‘reasonable and necessary’ threshold for NDIS funding. However, families are not necessarily referred to another system or followed up on (see recommendation

2d). Even in cases where they are referred to mainstream services, some children's support needs are too complex for these services to safely accommodate them.

NDIS planning processes and provision of supports are premised on child participants having significant informal support networks and parents and guardians who can adequately support and advocate for their child. In reality, despite their best efforts, many parents and families are struggling without the information and support required to advocate for their child.

During my direct engagement and consultations with young people with disability, they sometimes spoke about mentors or paid supports assisting them to access the community. However, very few appear to have an active role in developing, reviewing, or utilising their NDIS plans.

Lengthy review processes impede a crisis response and compound distress, uncertainty and disruption for families who lack the information, support and access to services required to fully implement their child's plan.

There is work underway on alternate dispute resolutions in light of the high number of NDIS cases being referred to Administrative Appeals Tribunal for review. This office is of the view that there would be reduced demand for such reviews if there were greater efforts to:

- Meaningfully include participants and their families in the planning process, and ensure they have the information and other support needed to implement their plans.
- Ensure the NDIA provides participants with reasons for decisions.
- Improve the knowledge and skills of NDIS planners in understanding child and adolescent development.

c. Thin markets and long waiting lists for key NDIS-funded supports and mainstream services.

The children who are the focus of this submission generally have very well-funded NDIS plans. However, the capacity to implement and use these plans to their full potential is limited by thin markets and long waiting lists that make it difficult to find consistent providers with the skills to work with children with multiple complexities.

As noted in the Department of Human Services Submission to this Inquiry, both Kudos and Novita have waitlists of over 12 months for NDIS-funded allied health supports, and there are significant shortages of behaviour support practitioners, allied health professionals and psychologists in South Australia.^x For families living in regional areas, services are even thinner on the ground.

This limits the degree of 'choice and control' afforded to participants and their families and leads to delays in assessment and access to other supports that may reduce the need for accommodation outside the family home in the future. In some cases, this can result in children coming to the attention of the Department for Child Protection who would not normally do so if services were available.

The issue of ‘thin markets’ has been raised consistently by service providers, NDIS participants of all ages and their families and advocates across several reviews of the NDIS. It is very likely to receive attention in the upcoming federal review. There is a real need to identify specific gaps in service availability for children and young people with disability as distinct from adult participants.

d. The interface between NDIS and mainstream services and the lack of safeguarding mechanisms for children and young people with disability.

Children and young people with disability have contact with many services and systems, from health, education and sports and recreation to child protection, homelessness and justice systems.

Key issues remain at the interface between the NDIS and mainstream services, which become particularly evident during crisis situations where state-funded mainstream services often become a provider of last resort.

Section 34(f) of the *NDIS Act 2013* provides that NDIS will fund a support if it is ‘not appropriately funded or provided through general systems of service delivery’. NDIS plans only mention NDIS-funded services. Where a child is not eligible for support through NDIS because it is deemed a state government responsibility, they are generally not referred to another system. Rather, it is left to the participant to source this other support, even where the lack of support impacts on the effectiveness of the NDIS services.

There is a need for greater clarity regarding the roles and responsibilities of different sectors to deliver supports to all people with disability, but particularly children with complex needs. Families need information and support to be connected with right services, whether or not they are funded by the NDIS. Ultimately, where children are falling through the service system gaps, the likelihood that circumstances will escalate to a crisis point increases.

While the South Australian government has resourced the Adult Safeguarding Unit in recognition of the gaps in oversight of adults living with disability, there appears to be no recognition that the same safeguarding gaps exist for children with disability. Currently, there is no oversight of places where children with disability live, learn, earn and play. Further, eligibility for both Specialist Disability Accommodation and the NDIS after-hours crisis referral service is limited to NDIS participants aged over 18.

Beyond ensuring access to services, oversight and safeguarding mechanisms for children with disability are also key to ensuring safe environments both for children to live in and for staff to work in.

e. Workforce consistency, skills and knowledge.

Many children who are living outside the family home are living with full-time rotational carers. Stakeholders have raised significant concerns about the quality of care provided

by a workforce that is characterised by high workloads, high levels of casualisation and significant gaps in experience, skills, training, and knowledge.

Young people are often provided with limited knowledge about major staff movements, including when new staff are starting or when long-term staff are leaving. The inconsistency inherent in rotational care arrangements can leave young people feeling destabilised or distressed by changes that are not explained to them.

There has been significant policy attention and investment in formalising safeguarding in response to high-level incidents of violence, abuse, neglect and exploitation. The more subtle but still potentially harmful ‘everyday harms’ or ‘misrecognition’ between young people with disability and their support workers – being disrespected or ignored – tend to receive less attention.^{xi}

Information relating to children for workers in the disability sector is predominantly compliance-focused (eg. screening workers). It is critical that staff are also supported with practical guidance that promote practices and culture that recognise the importance of children’s rights, participation, social and emotional development and relationships.

f. Shortage of safe and available housing stock.

Across Australia, there is a dire shortage of available, affordable and safe housing stock. This lack of appropriate housing makes it impossible to deliver on the necessary accommodation and funded support for NDIS participants of any age, let alone those designed specifically for children and young people with complex needs.

After Victoria and New South Wales, South Australia is the third highest jurisdiction for children requiring accommodation outside the family home. In the absence of appropriate housing supply, children are being placed in Airbnbs and caravan parks and may be forced to move between unstable placements multiple times a year.

This group of children and young people are generally invisible to policymakers and service providers – they are assumed to be at home in the care of their parents. While parents and support coordinators who are aware of these issues are informing responses at a grassroots level, no one is designing housing with children and young people with complex disability support needs in mind.

NDIS participants aged under 18 are generally not eligible for Specialist Disability Accommodation (SDA), although exceptions are occasionally made for 16 year olds. However, even if children and young people were eligible, supply remains a major issue and there is a thin market for robust SDA.

While there is no simple solution to housing supply issues, the needs and experiences of children and young people require specific consideration and tailored responses to ensure their safety and healthy development.

- ⁱ NDIS, NDIS Quarterly Report to disability ministers, Q4 2021-22. 30 June 2022. Table J.20 Participant profile per quarter (participants not in SIL) by age group – South Australia, P. 524. Available at <https://www.ndis.gov.au/media/4615/download?attachment>.
- ⁱⁱ NDIS, NDIS Quarterly Report to disability ministers, Q4 2021-22. 30 June 2022. Table N.23 Participation rates by age at 30 June 2022, p. 789. Available at <https://www.ndis.gov.au/media/4615/download?attachment>.
- ⁱⁱⁱ Meeting of the COAG Disability Reform Council, 28 June 2019. Communique. Available at https://www.dss.gov.au/sites/default/files/documents/07_2019/communique-drc-28-june-2019.pdf.
- ^{iv} Australian Housing and Urban Research Institute, 2022. Housing First: An evidence review of implementation, effectiveness and outcomes. Available at <https://www.ahuri.edu.au/sites/default/files/documents/2022-08/AHURI-Prof-Services-Housing-First-An-evidence-review-of-implementation-effectiveness-and-outcomes.pdf>.
- ^v Connolly, Helen. Commissioner for Children and Young People South Australia, 2022. *From Checkbox to Commitment: What children and young people with disability said about identity, inclusion and independence*. Available at <https://www.ccyp.com.au/wp-content/uploads/2022/05/Screen-From-Checkbox-to-Commitment-Report.pdf>.
- ^{vi} Robinson, Sally & Anne Graham, 2021. Feeling safe, avoiding harm: Safety priorities of children and young people with disability and high support needs. *Journal of Intellectual Disabilities*, 35 (4), 583-602.
- ^{vii} Government of South Australia, Department of Human Services. 2020. Disability Screening Assessment Project Report: Identification of Population Needs at the Adelaide Youth Training Centre (Kurlana Tapa). Available at https://dhs.sa.gov.au/_data/assets/pdf_file/0003/93927/Disability-Screening-Assessment-Project-Report-2020.pdf.
- ^{viii} Commonwealth of Australia 2020, Parliament of Australia. NDIS Planning Final Report. Chapter 4: Informal supports and the role of families. Available at https://www.gph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/NDISPlanning/Final_Report.
- ^{ix} David Tune AO PSM, December 2019. Review of the National Disability Insurance Scheme Act 2013. Available at https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf
- ^x Parliament of South Australia, Official Hansard Report. 4 July 2022. Department of Human Services Submission to the Social Development Committee: NDIS SA participants with complex needs living in or at risk of living in inappropriate accommodation for long periods, p. 7.
- ^{xi} Robinson, S, Fisher, K., Graham, A., Ikäheimo, H., Johnson, K. & Rozengarten, T. 2022. Recasting 'harm' in support: Misrecognition between people with intellectual disability and paid workers, *Disability & Society*, 1-22. Available at <https://www.tandfonline.com/doi/full/10.1080/09687599.2022.2029357>.