



**Children and Young People
with Disability Australia**

Right services and supports at the right time for children and young people with disability

Children and Young People with Disability Australia Submission – July 2019

Department of Social Services NDIS Thin Markets Project

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Executive Summary

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 – 25 years. CYDA has an extensive national membership of over 5,000 young people with disability, families and caregivers of children and young people with disability, and advocacy and community organisations.

CYDA's purpose is to systemically advocate at the national level for the rights and interests of all children and young people with disability living in Australia.

To address thin markets, where services are not available for people with disability, there needs to be a focus on services for children and young people with disability, in addition to adult services. The service needs of children and young people with disability are different to adults with disability and targeted strategies are required.

This submission is informed by our members and results from a national survey conducted by CYDA in July 2019 of 189 young people with disability, and families and caregivers of children with disability.

Thin markets exist even before children and young people are assessed for their eligibility to the National Disability Insurance Scheme (NDIS). Any actions to address thin markets must consider the pre-eligibility stage. This will require cross-government effort to ensure families have the required information about the NDIS and equitable access to diagnostic assessments and information to prove eligibility the scheme.

During the planning stage, young people with disability, and families and caregivers of children with disability consistently reported challenges with the National Disability Insurance Agency (NDIA), Local Area Coordinators (LACs) and Early Childhood Early Intervention (ECEI) partners. This included their knowledge of the needs of children and young people with disability and their families, lack of family-centred practice, and a push to medicalise the supports in the plan rather than consider the natural environments and supports in the community. The planning stage can also contribute to thin markets due to this mismatch between the goals for the child and young person, and what is included in the plan.

The lack of the right services and supports at the right time for children and young people with disability is a major challenge to the success of NDIS, given what is known about the importance of early intervention for children and young people so they can live enriched lives. Survey participants noted the top challenges in accessing services were not enough services available in the area, the plan not allowing for services needed for the child or young person with disability, and long waiting lists. This was followed by the need for assistance in service navigation and support coordination.

Finally the availability of a highly qualified disability workforce which understands child development, family-centred practice and youth empowerment is a key challenge that needs to be addressed in the Thin Markets Framework. Families are the main caregivers of children and young people with disability, and hence the need for workforce skills development in this area is important. Workforce shortages and staff turnover is a key barrier to accessing the right services at the right time. The health and social assistance industry is the fastest growing industry in Australia and therefore it would be remiss to ignore workforce development in responding to thin markets. Workforce shortages, particularly in rural and remote Australia, need to be urgently addressed, but not at the expense of quality.

Recommendations

Streamline access into NDIS for children and young people with disability

- The NDIA and state and territory governments work together to trial new models of health and diagnostic assessment so children and young people with disability can access the NDIS, with a particular focus on hard to reach cohorts including Aboriginal and Torres Strait Islander children, and children and young people living in families facing poverty and disadvantage
- The NDIA regularly monitor access to the scheme by hard to reach cohorts of children and young people with disability
- Expand and continue to provide funding for information support services targeted at children and young people and their families/caregivers through the Information, Linkages and Capacity Building (ILC) grants

Improve the planning process so the right services and supports are included for children and young people with disability

- Require NDIA, LAC and ECEI workforces to receive training in family-centred practice, child development and youth empowerment
- Develop accessible, evidence-based guidance and information for families of children and young people with disability and for NDIS, LAC and ECEI workforce
- Increase transparency and oversight of NDIA contracted partners so there is a clear process for people to complain and organisations to be held accountable for poor performance

Address thin markets for children and young people with disability

- Provide support coordination for all children and young people with disability
- The NDIA and state and territory governments provide active market stewardship to ensure children and young people with disability receive the right services and supports at the right time
- The NDIA urgently review the provision of equipment and assistive technology and thin markets for these supports
- The Thin Market Framework considers service availability for children and young people with disability as distinct from adult services
- Ensure whole of government responsibility for the NDIS to address interface issues between health, education, justice, child protection and other systems

Build the NDIS workforce of the future

- Develop a cross-government national NDIS workforce strategy to grow a quality, sustainable workforce, targeting areas of workforce shortages.
- Fund a range of workforce development initiatives, co-designed with children and young with disability and their families and advocates, to improve workforce capability and skills

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 – 25 years. CYDA has an extensive national membership of over 5,000 young people with disability, families and caregivers of children and young people with disability, and advocacy and community organisations.

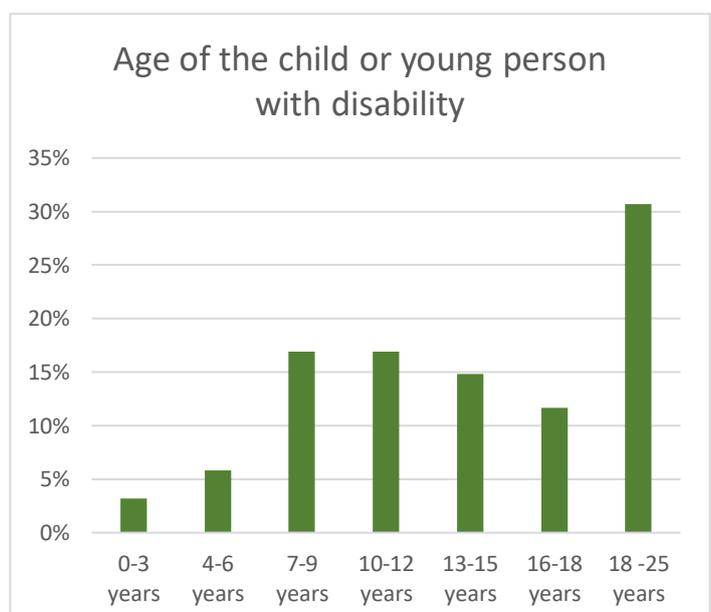
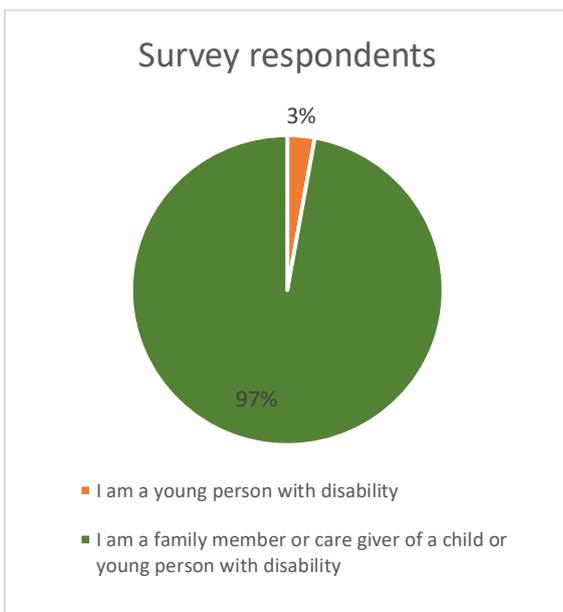
CYDA’s purpose is to systemically advocate at the national level for the rights and interests of all children and young people with disability living in Australia and it undertakes the following to achieve its purpose:

- Listening and responding to the voices and experiences of children and young people with disability.
- Advocating for children and young people with disability for equal opportunities, participation and inclusion in the Australian community.
- Educating national public policy-makers and the broader community about the experiences of children and young people with disability.
- Informing children and young people with disability, their families and care givers about their citizenship rights and entitlements.
- Celebrating the successes and achievements of children and young people with disability.

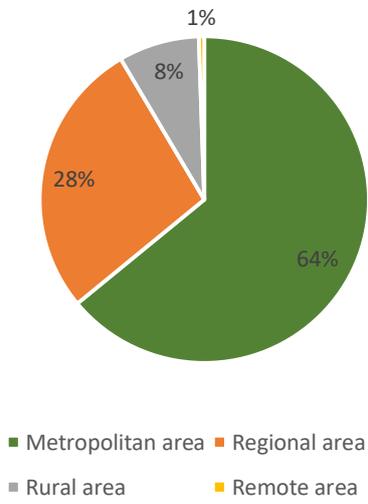
CYDA welcomes this opportunity to provide a submission into the Department of Social Services NDIS Thin Markets Project.

This submission is informed by our members and results from a national survey conducted by CYDA in July 2019 of 189 young people with disability, and families and caregivers of children with disability.

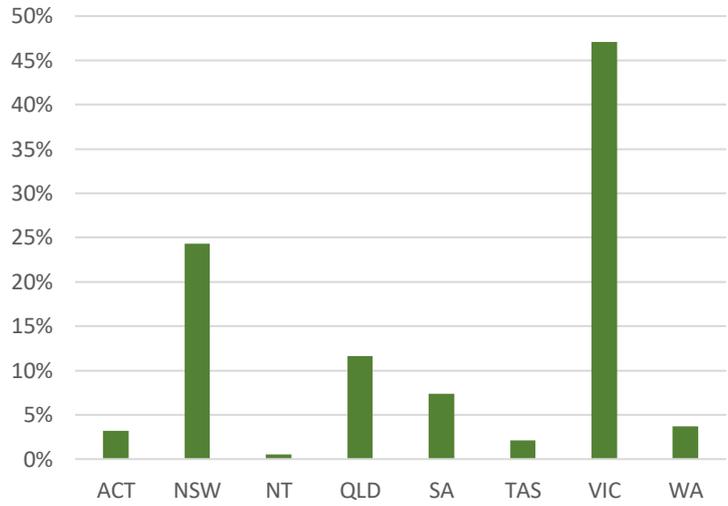
The respondents to the survey are outlined below.



Location of respondents



State/territory of respondents



Streamline access into NDIS for children and young people with disability

Recommendations

The NDIA and state and territory governments work together to trial new models of health and diagnostic assessment so children and young people with disability can access the NDIS, with a particular focus on hard to reach cohorts including Aboriginal and Torres Strait Islander children, and children and young people living in families facing poverty and disadvantage

The NDIA regularly monitor access to the scheme by hard to reach cohorts of children and young people with disability

Expand and continue to provide funding for information support services targeted at children and young people and their families/caregivers through the Information, Linkages and Capacity Building (ILC) grants

42% of young people and family/caregivers of children and young people with disability faced barriers to accessing the NDIS.

There remains significant barriers to access the NDIS for children and young people with disability. This includes challenges in sourcing the evidence that is required, understanding of the scheme and information about the NDIS not being clear.

The range of diagnostic assessments required to prove a child or young person is eligible to the NDIS provides many challenges. Access to specialists such as paediatricians and other allied health providers is costly and there are often long waiting lists. For many families the cost of and travel to specialists to get the required assessments can be prohibitive.

These challenges are particularly acute for families and caregivers living in poverty, in rural and remote Australia, and for children and young people from Aboriginal and Torres Strait Islander families.

“None of the many reports I had were written specifically for the NDIS. I had to arrange updated psychologist reports and assessments which was very costly and purely for the NDIS application. I also struggled to find an OT with many waiting lists closed due to them being busy with NDIS clients already. Finally managed to have my child assessed after my application was sent. Again extremely costly process. Also unsure what would be considered child’s main diagnosis as her case is complex.” Family of a young person aged 13-15 years, metropolitan Victoria

“The requirement to continually provide external reporting to justify need is expensive and duplication”. Family of a young person aged 16-18 years, metropolitan NSW

The cost of assessment to obtain the diagnostic evidence is a significant NDIS interface issue with the health system. For example the Autism CRC found that the cost of accessing private autism assessment in Australia could be up to \$2,750 when accessing private services with the median cost of \$580¹. They also found that few clinicians provided diagnostic assessments for ASD in regional, rural and remote areas of Australia.

¹ Taylor, L et al 2016. Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards? Autism Co-operative Research Centre, Brisbane.

The Australian Autism Alliance has recommended establishing clear and consistent eligibility criteria for autistic people² and a range of other recommendations to improve the NDIS for children and young people on the autistic spectrum.

It is well known that families facing poverty and disadvantage face significant barriers to accessing services generally and there is under-diagnosis of disability. This makes it harder for children and young people with disability living in these families to receive services to support their disability and be included in mainstream services such as education and health, let alone secure the assessments required to prove eligibility to the NDIS.

The onus is on NDIA and state/territory funded services and systems to support children and young people with disability to access the scheme, particularly where there are barriers for families in facilitating their child and young person's access. Health, early childhood services, schools and other services all have a role to play in facilitating ease of access for children and young people with disability to the scheme and in assisting families with understanding the benefits of the NDIS. In rural and remote areas, these mainstream services are often the sole providers of information to young people with disability and families/caregivers of children with disability.

² See Australian Autism Alliance, http://www.australianautismalliance.org.au/wp-content/uploads/2019/02/Australian-Autism-Alliance-Federal-Election-Manifesto_web.pdf

Improve the planning process so the right services and supports are included for children and young people with disability

Recommendations

Require NDIA, LAC and ECEI workforces to receive training in family-centred practice, child development and youth empowerment

Develop accessible, evidence-based guidance and information for families of children and young people with disability and for NDIS, LAC and ECEI workforce

Increase transparency and oversight of NDIA contracted partners so there is a clear process for people to complain and organisations to be held accountable for poor performance

71% of young people and family/caregivers of children and young people with disability had problems with the NDIS planning process.

Families are the key caregivers of children and young people but their role is reported as not being recognised. There is a long history of family centred practice in early childhood intervention but families report this is missing from NDIS plans because it is seen as families 'normal parenting' responsibility. It is reported plans are being developed which fail to recognise the important roles families play along with focus on community supports that will enrich the child and young person's life.

"Denied support worker hours, denied riding for the disabled, denied help with support workers for after school hour care. Planner didn't know what after school care was! All occurred at planning meeting." Family of a child aged 4-6 years, regional Queensland

"The ECEI planners do not provide a family model considering simply the child and do not consider the importance of prompt early intervention" Family of a child aged 4-6 years, metropolitan Queensland

"Respite was difficult to get as "parental responsibility" kept getting quoted, even though the single parent was not able to do these parental responsibility due to physical & mental health issues". Family of a child 10-12 year old child, metropolitan NSW

"I would still like more services around inclusion and getting my son out in the broader community. There is a lot of camps and programs for people with disabilities but not a lot of stuff that intersects into mainstream groups." Family of a child aged 10-12 years, metropolitan Melbourne

The other significant challenge for families with children and young people with disability is being unable to work because of the care requirements. They report that they would like to work, but are unable to because caring for their child is seen as their "parental" responsibility. There is little understanding of the higher-level support provided by families to meet their child's everyday needs. Forcing families to live on low incomes or poverty because they are unable to work will not ultimately assist the child or young person live a good life.

CYDA organisational members report that there is a push by planners to medicalise supports for children and young people disability with a preference for individual therapies, rather than consider all the environments children and young people need to support their development and wellbeing. Families also said planners are focusing on individual therapy, rather than other supports such as

respite, and community based supports such as swimming, riding for the disabled and other activities which will help their child or young person participate in community/sporting activities. The majority of learning for children and young people occurs in their home, community and educational environments. Therefore individual therapy cannot be a major driver of development – what drives development is children’s meaningful participation in everyday activities and environments. The reliance on medical models, rather than natural supports for children and young people and their families was criticised.

“This year we have not been able to access support for any social community inclusion for our eldest son with autism. NDIS deemed it parental responsibility. We cannot take him to social events like a sport group with someone available to solely focus on him. He has to have a support person with him to guide him through the difficulties that arise from social difficulties.”
Family, with 2 children in the NDIS, metropolitan South Australia

While individual therapy is important for many children and young people with disability, if planners are exclusively prioritising individual therapies over natural supports in the community then this is likely to lead to thin markets. Waitlists and availability for allied health professionals, particularly in rural and remote areas is challenging.

Young people and families also report they do not have enough information and what the best services and supports may be for their child or young person with disability.

“We have no help to identify suitable goals and are left with a sum of money but no idea how to use it to meet those goals. We have been given “support coordination” funds but experiences with support coordinators are poor.” Family of a young person aged 16-18 years, metropolitan South Australia

“Difficulty understanding what I could ask for. Being told to ask for everything I possibly might want led to receiving a plan of things that “might be nice” to have, but are utterly impractical. I can’t afford to reduce my work and study load sufficiently to be able to do the things I have funding for, because otherwise I will lose my Centrelink payments and be unable to pay my rent.”
Young person with disability aged 18-25 years, rural Victoria

Another significant challenge in the planning process, is the mismatch between the goals and aspirations for the child or young person and what is in the plan. This is undermining the important tenet of the NDIS which is choice and control. Many families report the difficulties in having staff understand the complexity of their child’s disability, confusion and lack of information about what can be funded and the goals provided in the planning process not being reflected in the plan.

“Plans didn’t reflect child’s support needs and contained inaccurate information. A large proportion of funds were allocated to things we didn’t ask for or need (i.e. incontinence nurse) whilst things that would have made a tremendous difference were denied.” Family of a child aged 7-9 years, metropolitan Victoria

Address thin markets for children and young people with disability

Recommendations

Provide support coordination for all children and young people with disability

The NDIA and state and territory governments provide active market stewardship to ensure children and young people with disability receive the right services and supports at the right time

The NDIA urgently review the provision of equipment and assistive technology and thin markets for these supports

The Thin Market Framework considers service availability for children and young people with disability as distinct from adult services

Ensure whole of government responsibility for the NDIS to address interface issues between health, education, justice, child protection and other systems

67% of young people and family/caregivers of children and young people with disability have had some difficulty or not been able to access the right services and supports needed.

Challenges in accessing the right services and supports for children and young people with disability were present across all geographic locations, as outlined in the following table. However it was more difficult in regional and rural and remote locations.

Location	Number of survey respondents	% with barriers to accessing the right services and support
Metropolitan	121	63%
Regional	52	71%
Rural and remote	16	87%

There were multiple barriers to accessing the right services and support for children and young people with disability as outlined in the following table

Barriers to accessing supports and services	Number
Not enough services available in the area	37
Plan doesn't allow for services needed	25
Waiting lists	23
Support coordination challenges including difficulty in navigating services, time and self-management	16
Workforce capability	15
Equipment and assistive technology	11
Accessibility of the service including flexibility and location	8
Cost of services and funding shortfall between NDIS plan and services and supports needed	8
Respite and family support not being available/funded	8
Interface issues with other systems	4
Other/unspecified	17

Not having the right services and available in the area plus the plan not allowing for the services needed were reported as the top issues for children and young people with disability.

“There is a severe shortage of therapist, support workers, treating doctors and long wait lists. Even when signed up with a service, there is a shortage of available appointments. We have accepted, in desperation, untrained and (previously) unacceptable support workers just to have another pair of hands on board. All the wonderful skill development that we previously could work on has now become purely survival.” Family, young person aged 18-25 years, metropolitan New South Wales

“One year, everything will be funded. The next plan/year will cut vital supports that change his whole Life, causing huge anxiety. Given funding for what they think he needs not what we have requested.” Family of young person aged 18-25 years, metropolitan New South Wales

Other challenges included the long waiting lists for services, lack of service availability and no services to choose from.

“Not a lot of support in my area. Support workers/therapists come from outside the area and therefore add transport costs. Have to go to review to become plan/self-managed so I can find support networks.” Family of a young person aged 16-18 years, metropolitan Victoria

“Long waiting list for therapists. No consistency in support workers that change every fortnight.” Family of a child aged 10-12 years, metropolitan New South Wales

“Living in the western suburbs there is a dearth of services and supports. So even when one has a plan, it's difficult to find suitable qualified and experienced professionals to hire”, Family of a child aged 10-12 years, metropolitan Victoria

Respondents to the survey provided multiple examples of difficulty in accessing Assistive Technology and equipment which is essential for children and young people.

“Electric wheelchair required new batteries and charger, but because this wasn't included in the original plan, we had to wait until the new plan was in place to get this item as the provider wouldn't let us pay for them outside of the NDIS.” Family of a young person aged 18-25 years, Australian Capital Territory

“It took over twelve months to get new ankle foot orthotics for my daughter - I had to go to my local member of parliament I was so frustrated. My daughter was 6 years old and had been wearing them since she was 3 years old. I also had to fight for a budget in her new plan for a replacement set - god forbid she has the audacity to grow in the next 12 months!! Planners are too 'insurance' focused, I am trying to build my daughters capacity NOW so she is a more capable adult - but all the planners can see is trying to save money.” Family of a child aged 7-9 years, regional Victoria”

Waiting over 18 months for essential equipment for my son's physical disability has been a joke. He has also been in a too small of wheelchair for two years and NDIS kept fobbing everything off. Thankfully now the new wheelchair is being made, but two years of my son being in a too small of wheelchair has caused physical pain and issues and increased anxiety. NDIS is supposed to help the participant, not make them worse” Family of a child aged 10-12 years regional Queensland

The need for more information about the services available, support with service navigation and support coordination was raised multiple times by respondents to the survey.

“No one helped me to get a support coordinator, or told/showed me how to find one. It took me three months to find one. Have spent a month with them trying to understand the system, and the

support coordinator has now been made redundant, I am going to have to start over with a new one. Have set up one provider (plan manager).” Young person aged 18 -25 years, rural Victoria

“Still learning the system and as the carer expected to do more than ever before. NDIS has us as a family worse off. All the headaches full on me the primary carer.’ Family, young person aged 18-25 years, metropolitan Victoria

“Very difficult to navigate. Everyone should have a support coordinator - we don't”. Family of a young person aged 13-15 years, metropolitan Victoria

Build the NDIS workforce of the future

Recommendations

Develop a cross-government national NDIS workforce strategy to grow a quality, sustainable workforce, targeting areas of workforce shortages.

Fund a range of workforce development initiatives, co-designed with children and young and their families and advocates, to improve workforce capability in supporting children and young people with disability.

Thin markets have been broadly defined in the review as where there is a gap between the needs of participants and the services available in the market. This includes location, service type, and certain cohorts of participants and is driven by difficulties in servicing a client's needs or their location, such as cost.

However, the availability of highly qualified and skilled workers cannot be seen in isolation of services. The Health Care and Social Assistance industry is projected to make the largest contribution to employment growth in Australia between 2018 and 2023 (up by 250,300 or 14.9 per cent), due to the National Disability Insurance Scheme (NDIS), the ongoing ageing of the population and increasing demand for childcare and home based care services.³

Hence it would be remiss to ignore the workforce in considering thin markets. Time and again families reported the difficulty they had with engaging with the NDIS process because of the lack of skills of staff they are interacting with at the NDIA, ECEI Partners and LACs.

There is a lack of understanding in family-centred practice, early childhood early intervention and disability, particularly in the planning stage.

“Planner was cold and wanted to put what she thought my son needed.” Family of a young person aged 18-25, metropolitan Victoria

“Planner was inattentive, lacked knowledge, read from a script, did not try to understand, was rude, provided a plan that was less than previous supports . . . would not review plan or discuss or explain reason the way the way was given” Family of a young person aged 13-15 years metropolitan Western Australia

“Our current LAC is terrible (devoid of compassion) and seems to show little interest or possess sufficient knowledge of disability and its impact on the individual and family” Family of a child aged 10-12, regional Victoria

In finding the right services and supports for children and young people with disability, workforce turnover, qualifications and competency were raised by many survey respondents.

“I think so but there are undoubtedly problems with the training, supervision and mentoring of new staff - and the staff turnover is very high. I wonder how many of them have actually read my daughters plan/goals, much less know how to help her achieve them. It's all a bit cookie cutter.” Family of a young person aged 18-25 years, metropolitan Western Australia

³ Australian Government, Department of Small Business, Employment Outlook to May 2023, accessed at <http://lmip.gov.au/default.aspx?LMIP/GainInsights/EmploymentProjections>