



Improving the NDIS planning process for children and young people with disability and their families

Children and Young People with Disability Australia Submission – September 2019
Joint Standing Committee on the National Disability Insurance Scheme

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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.

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 problems with the National Disability Insurance Scheme (NDIS) planning process are many and significant improvement is required to ensure children and young people with disability receive the right services and supports.

There are problems with the information and the process of the NDIS being unclear for participants or their families/caregivers. There is much confusion about what can be funded (or not) in NDIS plans. Access to the scheme is a consistent problem highlighted by CYDA survey respondents, along with long waiting periods and the burden of medical diagnostic reports and assessments to prove the child's disability adding cost and stress to families.

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 staff 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. Other challenges with the planning process include the mode of meetings with telephone meetings not being appropriate and the need for face to face discussion. Families reported they did not have the opportunity to review the draft of the NDIS plan before approval, and there is no detailed explanation when a service or support is declined or underfunded.

Major concerns about the lack of knowledge, experience and qualifications of the NDIA planners, LAC's and ECEI workforce were consistently highlighted by our survey respondents. The lack of consistency in information demonstrated the need for further training and professional development in the NDIS processes, family centred practice, child and adolescent development and knowledge of disability. Workforce capacity building is needed across a range of areas including: working with parents/caregivers with disability; family violence; families and children and young people at risk including those involved with the child protection system; children and young people living in families facing disadvantage; working with people from culturally and linguistically diverse (CALD) backgrounds; Aboriginal cultural safety; and the challenges for families living in rural and remote Australia.

In addition to problems with the NDIS planning processes, thin markets remain a challenge and there needs to be a focus on availability, accessibility and quality of services for children and young people with disability. The service needs of children and young people with disability are distinctly different to adults with disability and hence targeted strategies are required.

Survey participants reported their main 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 for service providers. This was followed by the need for assistance in service navigation and support coordination.

Finally the availability of a highly qualified disability workforce a key issue that needs to be addressed. Workforce shortages and staff turnover are barriers 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 planning challenges and thin markets. Workforce shortages, particularly in rural and remote Australia, need to be urgently addressed, but not at the expense of quality.

Building the disability workforce of the future requires concerted effort by government in order to enhance the future outcomes of NDIS participants including children and young people with disability..

Recommendations

Improve information about the NDIS for children and young people with disability

- The NDIA provide targeted information and phone support for families of children and young people with disability
- The NDIA simplify its terminology using simple and clear language and train staff in communicating this with potential and current participants and their families
- Provide information about what the NDIS can fund and what is not part of the scheme
- Improve accessible information resources for children and young people with disability and their families/caregivers using different methods including factsheets, short videos and online forums

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
- Simplify the process for eligibility for children and young people with disability allowing previous diagnostic reports or assessments to be sufficient evidence when the condition has not changed
- 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
- Provide increased funding for advocacy services to assist families of children and young people with disability access the NDIS and help with the planning process

Improve the NDIS planning process

- Include face to face planning meetings as mandatory where the family of a child or young person with a disability can review and agree with draft plan or extension of plans
- Develop accessible, evidence-based guidance and information for families of children and young people with disability and for the NDIA, 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
- Ensure draft NDIS plans can be reviewed by families/caregivers and participants before they are finalised
- Establish a standard process to explain reasons of services or support declined or underfunded, preferably face to face

Build the capability of NDIS planners

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

- Standardise the recruitment process for NDIA planners by adding minimum requirements of experience and qualifications
- NDIA to provide training for planners about the different types of disabilities and different needs accordingly and include regular professional development.
- Monitor satisfaction about planners work and capabilities in the COAG Disability Reform Council Quarterly Report

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 and disability 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 and their families and advocates, to improve workforce capability in supporting children and young people with disability.

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 including young people with disability, families and caregivers of children and young people with disability, advocacy and community organisations.

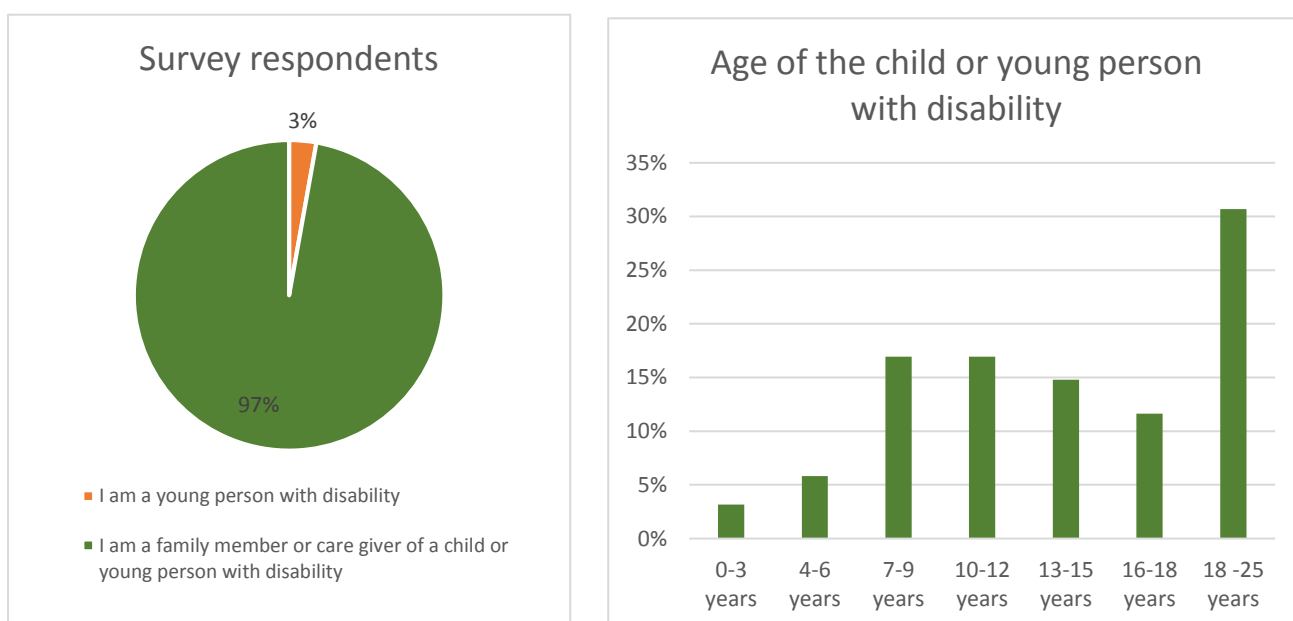
CYDA's purpose is to systemically advocate at the national level for the rights and interests of all children and young people with disability living in Australia and undertakes the following to achieve its purpose:

- 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.

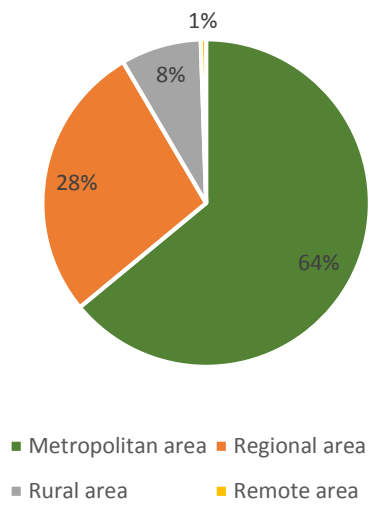
CYDA welcomes this opportunity to provide a submission into the Joint Standing Committee on the National Disability Insurance Scheme on NDIS Planning.

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, families and caregivers of children with disability.

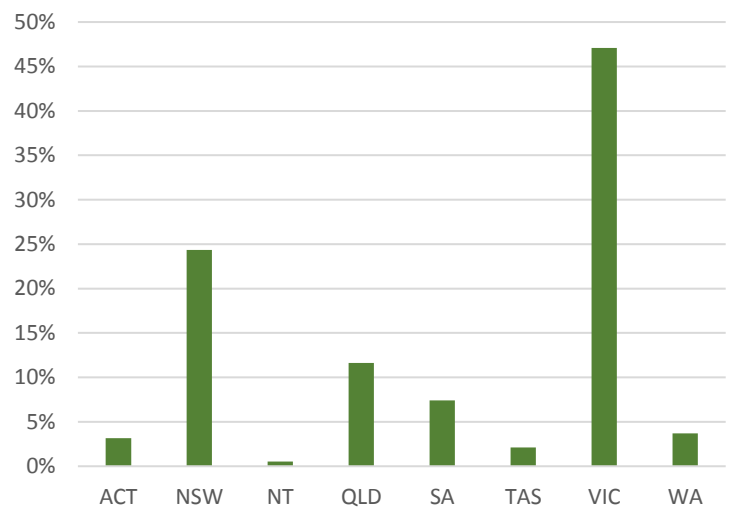
The respondents to the survey are outlined below.



Location of respondents



State/territory of respondents



Improve information about the NDIS for children and young people with disability

Recommendations

The NDIA provide targeted information and phone support for families of children and young people with disability

The NDIA simplify its terminology using simple and clear language and train staff in communicating this with potential and current participants and their families

Provide information about what the NDIS can fund and what is not part of the scheme

Improve accessible information resources for children and young people with disability and their families/caregivers using different methods including factsheets, short videos and online forums

50% of young people with disability and family/caregivers of children with disability reported issues with information about the NDIS.

Challenges included lack of communication from NDIA planners, LAC and ECEI staff on how the scheme works as well as lack of understanding the different types of disability and support needed accordingly. NDIA staff, LACs and ECEI partners need a better understanding of the scheme and to further explain the terminology used by the NDIA when meeting with families of children with disability and young people with disability.

Clear information about what the scheme covers and does not as well as guidance about the support not included in the NDIS plan is required. Our survey respondents have also confirmed the lack of information during the transition period from state funding to the roll out of the NDIS, where some have been disadvantaged by getting less support than what they have had in the past.

"1. Lack of information as to the correct way to apply for NDIS due to the new roll out. 2. Long delays waiting for acknowledgement that we would be contacted from NDIS. Several phone calls to the NDIS hotline with differing advice. 3. Concerns about if our son would meet the NDIS threshold for support. This in part was associated with our decision to have our son receive main stream education rather than specialist" Family of a child aged 13-15 years, metropolitan Victoria

"A lot of paperwork. The staff at NDIS and the LAC didn't have much of a clue how the system worked - they were learning with the participants and this made for an unnecessarily frustrating time" Family of a child aged 10-12 years, regional Queensland

Furthermore there is a key information gap about how the NDIS will support child and adolescent development across the different stages of childhood, adolescence, transition to adulthood and adult life. There is the need for evidence-based tailored information with a developmental lens for different stages in life, for example 0 to 6 years, 7 to 14 and 15 to 25 years.

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

Simplify the process for eligibility for children and young people with disability allowing previous diagnostic reports or assessments to be sufficient evidence when the condition has not changed

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

Provide increased funding for advocacy services to assist families of children and young people with disability access the NDIS and help with the planning process

50% 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 required evidence and diagnostic assessments, 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 and CALD 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

“We were asked to supply a new diagnosis that turned out to be unnecessary. Additional information was asked for over several communications (could have been one). Without an advocate we would have struggled and would still be waiting to get that unnecessary new diagnosis” Family of a child aged 13-15 years, rural TAS

The costs 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 being \$580¹. They also found that few clinicians provided diagnostic assessments for autism in regional, rural and remote areas of Australia. If the diagnosis has not changed the families should be able to use the medical reports they already have without asking them to update documentation exclusive for NDIS.

The Australian Autism Alliance has recommended establishing clear and consistent eligibility criteria for autistic people and a range of other recommendations to improve the NDIS for children and young people on the autistic spectrum.²

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 the NDIA and national, state and 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 supporting their child'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.

Long wait periods to access the NDIS have been highlighted by our survey respondents as another significant hurdle. The cause of this issue was reported as understaffing and high staff turn-over of NDIA planners, LACs and ECEI workers and a lack of qualified staff with appropriate training. The negative and direct consequence of this is the detriment to children and young people during the waiting period and the extra costs families need to cover while waiting.

"It took twelve months from applying to receiving funding. Early in the piece someone made an error and deemed I had not submitted all the information. I spent 2 hours at month 3 on the phone with them while they clarified it had been their mistake and actually the application could proceed. During this time they did not write or communicate to me that they believed there had been an error I just had to call repeatedly to ask them what was going on. After this initial confusion was sorted it took another 9 months to progress to being funded. Every time I called I was told it was my fault as I had made a mistake initially (despite it being clarified that I hadn't). During these 9 months I had a 10 year old child that was suicidal." Family of a child aged 10-12 years, Metropolitan Victoria

Some families felt that the process of entering the scheme was not designed for children and young people with disability as they did not have enough guidance and support throughout the planning process. Families of children and young people with disability benefit from independent advocacy support to access the scheme and during planning process to minimise mistakes, plan revision and reduce stress levels on families.

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

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

State and federally funded advocacy organisations are overwhelmed with demand for advocacy about the NDIS, however funding for advocacy has not been substantially increased to cope with this demand.

Improve the NDIS planning process

Recommendations

Include face to face planning meetings as mandatory where the family of a child or young person with a disability can review and agree with draft plan or extension of plans

Develop accessible, evidence-based guidance and information for families of children and young people with disability and for the NDIA, 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

Ensure draft NDIS plans can be reviewed by families/caregivers and participants before they are finalised

Establish a standard process to explain reasons of services or support declined or underfunded, preferably face to face.

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 role 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.³ 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.

The planners, LAC’s and ECEI need to increase attention on the needs of the child and young person so they can achieve their goals.

“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)

³ Centre for Community Child Health (2011). DEECD Early Childhood Intervention Reform Project: Revised Literature Review. Melbourne, Victoria: Department of Education and Early Childhood Development. <https://www.education.vic.gov.au/Documents/childhood/providers/needs/ecislitreviewrevised.pdf>

whilst things that would have made a tremendous difference were denied.” Family of a child aged 7-9 years, metropolitan Victoria

Additionally some families report planning meetings over the phone where communication was poor and interrupted by staff having to attend other issues in their office. The planning meetings should be face to face as it is the opportunity to explain the process, supports available, service providers, funding and different ways to manage the NDIS plan. Some of our survey respondents state they were denied self-managed option in first plan or others were directed to agency-managed without having choice about this.

“I wanted to self-manage the first year of NDIS for both my disabled children BUT the NDIS and the LAC staff could NOT tell me how to do this. An entire lever arch file later (a BIG lever arch file) and I gave up on the NDIS entirely. I did not spend a cent that year as I could not figure out how to” Family with two children in the NDIS, regional Queensland.

Families of children and young people with disability confirm they were not given access to the draft of the NDIS plan giving them no opportunity to review that all the supports needed are included. Some families report that the planner, LAC’s or ECEI will finish the plan on their own as the meeting was too long and therefore families were dissatisfied with the approved funding on the NDIS plan. Enabling review of the draft plan will provide opportunities to both parties the NDIA staff, its contracted partners and families and participants to amend mistakes and reduce internal revisions.

The current planning process does not establish a standard national procedure to communicate with families as to the reasons why a service or support is declined in the plan. This factor has increased the stress level of families of children and young people with disability whose have had to request reviews that also take long periods without a fixed time for resolution.

“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

Build the capability of NDIS planners

Recommendations

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

Standardise the recruitment process for NDIA planners by adding minimum requirements of experience and qualifications

NDIA to provide training for planners about the different types of disabilities and different needs accordingly and include regular professional development.

Monitor satisfaction about planners work and capabilities in the COAG Disability Reform Council Quarterly Report

25% of young people with disability and family/caregivers of children with disability experienced difficulty with the NDIS planning workforce

The respondents to our survey stated that some planners did not have the experience, knowledge or qualifications relevant to the role and hence the plans were not tailored to the needs of children and young people with disability. The family/caregivers reported the support for carers is not included in the plans and the funding approved does not cover all the required supports. Planners are not focusing on family centred practice and this will disadvantage children and young people with disability obtaining the right services and support.

“Planners do not have the qualifications or necessary experience to deal with PWD who have complex needs” Family of a child 13-15 years, regional VIC

“Planner was inattentive, lack of knowledge, read from a script, did not try to understand, was rude, provided a plan that was less than previous supports from DSC, provide no core support, despite full documentation, would not discuss her qualification, would not review plan or discuss or explain reason the way the way was given, had to cancel bonded core support workers whilst in review, lots a year of rapport building and enabling transition to school, (school refusal due anxiety disorder) required 4 months to rebuild, Planner unaware of autism presentation in females or PDA, was unaware of the Ehlers DANLOS/Marfan's, not included in diagnosis, so no physical supports provided, unable to contact NDIS, different people, different stories/advice, Review process STRESSFUL, the language used is difficult to understand, staff twisted enquiry in knots and creates stress for the career, Poor understanding of mental health impact on careers caring for those with MENTAL health issues, respite not provided, not understanding of financial impact when careers unable to obtain employment, when caring for teen with mental issues 24/7” Family of a child 13-15 years, metropolitan WA

Another difficulty mentioned by our survey respondents was the lack of consistency between planners leading to underfunding through not having enough knowledge, ignoring relevant information or misinterpreting medical records.

The issues concerning the capability of the NDIA planners, LAC and ECEI staff was also raised by CYDA organisational members. There is a need for NDIA planners, LAC's and ECEI to not only have operational knowledge of the scheme but also extensive training about disability, and relevant experience or qualifications in areas like early childhood intervention, youth and disability work.

NDIS planners, LAC's and ECEI staff need to be trained in and attuned to the individual circumstances of the children and young people with disability in their families for example families

in crisis, parents with a disability, CALD families, families experiencing domestic violence, children living in out of home care, Aboriginal families, grandparents raising children, families living in rural or remote areas as the NDIS plan must reflect and acknowledge all these special circumstances.

Additionally knowledge is required in child and adolescent development and transition to adulthood as the needs and goals will change for children and young people with disability and families/caregivers will need guidance throughout these transitions.

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 availability 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

Other challenges included the long waiting lists for services, lack of service availability and no services to choose from especially for families with CALD background where language is a top barrier. These issues decrease the choice and control by NDIS participants and their families.

"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 (AT) and equipment which is essential for children and young people children's changing needs, for example maintaining or updating the AT or equipment. It is not clear for families the criteria to access AT or funds under the Capital Supports Budget.

"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 fall 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 and disability 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.⁴

Hence it would be remiss to ignore the workforce improving the planning process and addressing 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.

The workforce of the future needs training in child and adolescent development, family-centred practice, early childhood early intervention and disability.

"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.

"... 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

Workforce shortages were consistently reported by CYDA respondents. Dealing with many planners, ECEI planers and LACs in a short amount of time causes much stress for young people

⁴ Australian Government, Department of Small Business, Employment Outlook to May 2023, accessed at <http://lmip.gov.au/default.aspx?LMIP/GainInsights/EmploymentProjections>

and families of children with disability. The turnover of staff was identified as an issue for the consistency of decisions around funding and services. Families reported they did not have a key contact worker to facilitate information about the NDIS process for example plan reviews, approval of AT or to amend administrative errors made by NDIS staff.

“3 different LAC's over 4 plans” Family of a child over 6 and 18 -25 year, metropolitan VIC

“Need more staff and key person approach to take you right thru the process and be a contact to resolve issues” Family of a young person with a disability aged 16 – 18 years, metropolitan SA

The turnover of staff has negative consequences for plan content and reviewing plans due to mistakes made by planners or LACs. Some CYDA respondents stated that in the first plan they were underfunded or denied support and the second plan introduced different staff which provided improvement, however still not enough funding.

Families reported that they found it difficult to build rapport with NDIA, LAC and ECEI staff as the changes and lack of knowledge of new staff affected the plan outcomes. There is none or little explanation to young people and families of children with disability when their planner or LAC has left and who will be the new point of contact available. The workforce shortages are also affecting the meeting duration with NDIA staff and the volume does not allow for extra time to answer all the questions required. Parents have expressed concerns about missed opportunities to review the draft plans, get a review in a timely manner and also stretching the budget over the twelve month period.

“Not given the opportunity to review draft plan, LAC rushing the meeting, goals were rewritten, have to trust LAC to complete the questions when meeting went overtime and LAC had to go, requested funding not approved and no reason was given” Family of child 10-12 years, metropolitan NWS

“Have had a planning meeting where the planner we'd had a relationship with didn't show up, another planner took the meeting and it was as though the meeting didn't occur at all. Plan was totally unsuitable for my child's needs. Consequently plan needed review. Consequently funds allocated for the 12 month plan period are now expected to stretch for 16 months” Family of child 10-12 years, metropolitan VIC

“The waiting, the understaffing and the lack of clarity of information” Family of child aged 10-12 years, metropolitan NSW