

Productivity Commission

Inquiry into National Disability Insurance Scheme Costs

**Children and Young People with Disability Australia
Submission – April 2017**

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INTRODUCTION

The National Disability Insurance Scheme (NDIS) is an extremely significant, complex and challenging reform. It has been a long journey to get to this point. Prolonged advocacy and community action from people with disability, families and advocates led to the Productivity Commission undertaking the Inquiry into *Disability Care and Support*. The Inquiry found that the disability service system was “underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.”¹ This led to the remodelling of the disability services system with the introduction of the NDIS.

The NDIS aims to clearly define disability services and support provision in the context of affording the rights of people with disability. It represents a significant shift from the previous model of providing block funding to disability services to providing portable and individualised funding packages, with a focus on enabling people with disability to exercise choice and control in relation to supports received.²

The NDIS is currently transitioning from several trial sites across the country to full implementation by 2019. This will involve an increase in people receiving Individual Funding Packages from around 35 000 to 460 000 within a short timeframe of three years.³ Experiences from the trial sites to date have also indicated that there are more people than expected entering the Scheme.⁴ There is a real tension between meeting the immediate, sudden and increasing needs of people entering the Scheme and realising the intent of the NDIS. The direct experiences of transition reported to CYDA, as well as discussions in the community and media coverage of participant and service provider experiences indicate that the NDIS, in this early stage, is highly stressed.

Amid this frenetic activity within the Scheme there is a lack of transparency around the operations of the NDIS and this makes developing a clear understanding of the Scheme extremely challenging for people with disability, member organisations, service providers and the broader community. This creates uncertainty for stakeholders in terms of engaging with the NDIS and effectively informing its development.

To date, CYDA has received mixed feedback regarding the experiences of children and young people accessing the NDIS. While there have been positive experiences reported, CYDA has also heard of lengthy delays in planning and implementation of services and challenges in establishing quality NDIS plans for children and young people.

It is commonly reported by potential participants, other people with disability, families and the broader community that they have limited knowledge about the NDIS. Much of this relates to poor understandings about how the NDIS works, eligibility and which services can be accessed through the Scheme. There remains unrealistic expectations held by many in the community, who view the NDIS as the sole ‘solution’ to the significant barriers to meaningful participation and inclusion experienced by people with disability.

¹ Productivity Commission 2011, *Disability Care and Support: Productivity Commission Inquiry Report Overview and Recommendations*, Commonwealth of Australia, Canberra, p. 2.

² *National Disability Insurance Scheme Act 2013 (Cth)*, section 2.3.

³ National Disability Insurance Agency 2016, *Report on the Sustainability of the Scheme: 1 July 2013 to 30 June 2016*, Geelong, p. 2.

⁴ *Ibid*, p. 3.

The complexity and size of the reform being undertaken, while much needed, is highly ambitious. It has involved a major philosophical shift in the principles and methods of service delivery; changes in roles, responsibilities and financing for jurisdictions; and also unique governance structures. A key driver of the establishment of this new system was the need to unravel the maze of disability services and supports which had been created in response to the crisis and service gaps. Many of the direct experiences of people with disability, including children and young people, highlight the real risk that we are developing a new kind of maze with the creation of the NDIS. The change from a funded sector to a 'market' is bewildering to many people, as is coming to terms with dramatically different, but opaque language, expectations and processes.

CYDA is of the view that the NDIS has the capacity to be an absolute game changer in affording human rights and equal opportunities to children and young people with disability in Australia. It is therefore important that there is honest discourse and critical reflection as the NDIS continues to roll out so we can ensure participants and other stakeholders are not overwhelmed by complex and unnecessary bureaucratic processes and that the fundamental principles of the Scheme are allowed to come to life in everything it does.

This submission is informed by the direct experiences of children and young people with disability and their families. It responds to key topics of relevance included in the inquiry issues paper. While CYDA has sought to minimise repetition, certain issues are highlighted throughout as they impact on multiple areas of focus of this inquiry. Due to limitations in organisational capacity and the limited time available to provide submissions, CYDA was unable to provide a more comprehensive response to the Commission's issues paper.

CHILDREN AND YOUNG PEOPLE WITH DISABILITY AUSTRALIA

CYDA is the national representative organisation for children and young people with disability, aged 0 to 25 years. The organisation is primarily funded through the Department of Social Services and is a not for profit organisation. CYDA has a national membership of 5300.

CYDA provides a link between the direct experiences of children and young people with disability to federal government and other key stakeholders. This link is essential for the creation of a true appreciation of the experiences and challenges faced by children and young people with disability.

CYDA's vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

CYDA's purpose is to advocate systemically 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:

- **Listen and respond** to the voices and experiences of children and young people with disability;
- **Advocate** for children and young people with disability for equal opportunities, participation and inclusion in the Australian community;
- **Educate** national public policy makers and the broader community about the experiences of children and young people with disability;
- **Inform** children and young people with disability, their families and care givers about their citizenship rights and entitlements; and

- **Celebrate** the successes and achievements of children and young people with disability.

CYDA and the NDIS

CYDA has undertaken extensive work regarding the NDIS, including involvement in the community campaign to reform disability services and supports that led to the establishment of the Scheme. This work has involved ongoing and extensive consultation with CYDA members and constituents regarding experiences of the NDIS. Extensive advocacy to members of parliament, governments and other stakeholders has also occurred.

CYDA has provided a range of submissions in relation to the NDIS, including to the:

- Productivity Commission Inquiry into *Disability Care and Support* (2010 and 2011);
- Proposed Criteria for NDIS “Eligibility and Reasonable and Necessary Support” (2012);
- NDIS Bill (2012 and 2013);
- Policy Paper on the NDIS and Education Interface (2013);
- Policy Paper on the NDIS and Family Support Program Interface (2013);
- National Disability Insurance Agency (NDIA) Draft Strategic Plan (2014);
- Framework for Information, Linkages and Capacity Building consultation (2015);
- NDIS Quality and Safeguarding Framework consultation (2015);
- Senate Inquiry into Violence, Abuse and Neglect Against People with Disability in Institutional and Residential Settings (2015);
- Senate Inquiry into Education and Students with Disability (2015);
- Independent Review of the Operation of the NDIS Act (2015);
- Senate Inquiry into the NDIS Savings Fund Special Account Bill (2016);
- Senate Inquiry into the Transition of the Mobility Allowance to the NDIS (2016); and
- Joint Parliamentary Inquiry into the Provision of Hearing Services under the NDIS (2017).⁵

Participation in a range of related advisory committees for the NDIS has also occurred, including: the Victorian taskforce of the *Every Australian Counts* campaign; Expert Advisory Group on Quality Standards and Safeguarding; NDIS Chief Executive Officer Forum; and the NDIS Practice Standards Technical Reference Group. CYDA has also presented to the NDIS Independent Advisory Council and has undertaken a range of work with the Department of Social Services in relation to the NDIS Quality and Safeguarding Framework.

CYDA has participated in a range of public consultations and events, including: consultation on the drafting of the NDIS legislation and rules; developing the Quality and Safeguarding Framework; Information, Linkages and Capacity Building frameworks; NDIS and advocacy conference; and NDIS website redevelopment. Finally, CYDA has presented to multiple public hearings about the NDIS, including to inquiries regarding the NDIS Bill (2013) and the NDIS Savings Fund Special account (2016).

CYDA has maintained a consistent dialogue with members about the NDIS, consistently seeking feedback about the member experiences and concerns. CYDA undertook a specific consultation in relation to this inquiry, through a survey of young people with disability and families of children with disability. CYDA received 161 responses to the survey which was conducted over an 11 day period in March 2017.

⁵ CYDA’s submissions are available at <http://www.cyda.org.au/cdasubmissions>.

Consistent with earlier feedback to CYDA in relation to the NDIS, the responses to the survey were highly variable. In CYDA's survey, approximately one third of experiences reported were positive. Positive aspects reported include:

- Access to useful information about the NDIS from community organisations and networks;
- Positive experiences of planning due to skills of individual planners and Local Area Coordinators (LACs);
- Opportunity to self-manage; and
- Better outcomes and access to services in comparison to previous system.

The majority of responses from young people and families have reported negative experiences of the NDIS. These include:

- Limited information provision about the NDIS and poor communication from the NDIA;
- Extremely limited understanding about how services and supports can be accessed for those who are ineligible for the NDIS;
- Significant variability in experiences of the planning process and expertise of planners;
- Delays in establishing plans and accessing services;
- Difficulties in changing an approved plan;
- Limited information and understanding about complaint and review processes; and
- Concerns the NDIS is not achieving its stated objectives.

Examples of direct experiences reported to CYDA include:

I have heard so many bad things about the NDIS, (my child) won't be accessing it.

(The eligibility criteria is) not clear at all...I think that my son will be eligible because we had services from the state disability sector but no one has told us.

(The NDIS application process is) very confusing. I could not have (navigated) it without specialist help.

Our application got lost. The plan was done over the phone and doesn't in fact represent our current situation or needs at all.

Applying for the NDIS was reasonably simple. However, it was a long process – approximately six months between the initial phone call and approved plan. There were numerous phone calls/interviews and no real transparency as to where we were in the process and what the next steps were.

The 1800 number is difficult to contact but I have a direct line of contact to our son's planner. She has been instrumental in our very successful plan along with our son's coordinator of supports. Without these two people our son would be VERY disadvantaged.

I feel like I don't know all that I can ask for from the NDIS. Am I doing a disservice to my son because I am not able to get him everything he needs?

Planners have been very friendly and supportive but for more recent plans they have used standardised questions which are not easily applicable to children.

Our current planner is fantastic but our first planner had very limited knowledge of our son's needs and proposed a minimal plan that was far from what we needed.

The first planner was skilled, friendly and available. The second less accommodating and totally unprepared...This was inefficient and resulted in a protracted process.

As far as I'm aware, the planner had no skills in relation to working with or understanding people with disability. They could not provide any guidance or advice and seemed to be simply a 'note taker.'

If the planner had listened to me in the first place I wouldn't be having to go through disability advocacy to get the right type of supports for my son and experience the red tape, frustration, anger and time consuming processes that I have been going through.

While accessing therapy has been ok, there are waiting lists, which are sometimes long. I'm still confused about what I can use the core funding for and the NDIS have given me conflicting answers.

The terminology used by NDIS is mind boggling.

My daughter now has better opportunities than what was available before the NDIS.

In the past three years, the NDIS has been a godsend. My son has gone from a child who didn't want to live anymore to a young teen who has a future. Their funding for our service provider has changed our lives... (But now) I am not getting the efficient assistance we have had in the past. Something that they previously did in two weeks is now going on for four weeks with no sign of it being sorted soon.

My life has been significantly improved by the support I receive through the NDIS. Before I was on the NDIS I was receiving hardly any support and the support I was receiving wasn't great. My support workers wouldn't show up or shifts would be cancelled and the service provider wouldn't notify me.

The rhetoric (of the NDIS) is wonderful, however, the reality has been somewhat different.

In some ways (the NDIS is facilitating social and economic participation) but the public still looks at (our family) like we have the plague so participating is still uncomfortable.

I feel lucky that I'm confident enough to self-manage my plan as that has given me a lot of freedom about the service providers and supports I choose.

KEY ISSUES IDENTIFIED IN THE DISCUSSION PAPER

Discussed below are key issues in relation to the development of the NDIS that CYDA believes impact participant outcomes and Scheme costs. The responses are framed in response to the topic areas contained in the issues paper for this inquiry. A key theme that runs throughout is the complexity of the NDIS as it has developed. This creates significant challenges in engaging with the Scheme for people with disability and families, as well as other stakeholders. While in many cases, the complexity of the NDIS has occurred as a result of transitional or administrative issues, there are flaws in the Scheme design that are also contributing to the difficulties being experienced. It is important that clear systemic actions are taken to address problems so they do not become

structural weaknesses embedded in the NDIS that undermine the effectiveness of the achievement of its objectives. On many levels Australia needs the NDIS to succeed.

SCHEME COSTS

This section highlights factors that CYDA views as potential 'cost-drivers' and risks to the NDIS that should be considered in light of the current inquiry.

Progress under the *National Disability Strategy*

It is important to situate the NDIS within the broader context of reform to ensure the rights of people with disability are afforded in Australia, particularly the *National Disability Strategy 2010-2020*. The implementation of the National Disability Strategy is a critical determinant of the level of success achieved in the NDIS.

The National Disability Strategy is a major policy framework to guide reform of policy and programs critical to the lives of people with disability. It sets a 10-year plan to address the barriers faced by Australians with disability across a range of life areas. The purpose of the Strategy is to:

- *Establish a high level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy;*
- *Drive improved performance of mainstream services in delivering outcomes for people with disability;*
- *Give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability; and*
- *Provide national leadership toward greater inclusion of people with disability.*⁶

Six main policy outcomes are covered by the Strategy. Identified under each of these outcomes are specific areas for future action and policy.⁷

- Inclusive and accessible communities;
- Rights protection, justice and legislation;
- Economic security;
- Personal and community support;
- Learning and skills; and
- Health and wellbeing.

The Strategy was developed by local, state, territory and Commonwealth governments under the auspices of the Council of Australian Governments (COAG). In doing so, a key aim was to ensure a cohesive approach between governments and the broader community is undertaken in relation to the goals and areas of policy action identified.⁸ Each level of government has roles and responsibilities under the Strategy and a series of implementation plans are being utilised to support implementation.⁹ The second implementation plan, entitled *Driving Action 2015-2018*, was recently released.

⁶ Council of Australian Governments 2011, *National Disability Strategy 2010-2020*, Commonwealth of Australia, Canberra, p. 9.

⁷ Ibid, p. 9.

⁸ Ibid, p. 8.

⁹ Ibid, p. 8.

The Strategy is a significant framework to ensure the rights of people with disability are afforded across all life areas in Australia. Providing quality services and supports to people with disability is only one focus area within the Strategy. Despite this, the NDIS has consistently dominated policy considerations and community discussions regarding much needed disability reform.

CYDA is concerned that there frequently appears to be an assumption that the NDIS will comprehensively address all barriers to participation and inclusion of people with disability. As a consequence disability services and supports remain extensively siloed and not embedded in a broader context of inclusive mainstream services and communities.

To date there has been limited progress in meeting the aims of the Strategy with mainstream sectors typically not embracing the required cultural shift and associated specific reform to support the inclusion of people with disability.

A lack of clear processes and accountability for implementing the Strategy, minimal resourcing and investment and a weak outcomes framework has left this vital reform languishing. A consequence of this is that attitudinal change has been limited within the Australian community. This contributes to a common view that the NDIS is simply a way of 'helping' people with disability which is contextualised in a 'pity' framework rather than a rights based context.

The recent political debates about whether the Australian community can afford the NDIS have unfortunately fed into this view, by giving voice to the outdated notion of people with disability being 'burdensome,' that the Strategy and the NDIS are intended to replace with genuine inclusion.

The impetus for changing culture and attitudes about disability in Australia needs to occur outside the disability sector, not just within it. There is a key map for driving this attitudinal and behavioural change in the Strategy. However, unless the Strategy is embraced and recognised there is a high chance that reform will be limited to a bigger and more efficient service system and we will not witness the cultural change which is imperative for affording the rights of people with disability.

There is a real need for re-invigoration of the National Disability Strategy to ensure it becomes a lived reality. The present implementation plan has a key focus area on increasing the knowledge and awareness of the Strategy. This needs to be accompanied by a rigorous outcomes framework which clearly defines roles, responsibilities, measures, timelines and evaluation.

In addition, there is an urgent need to develop mechanisms to ensure stronger monitoring of progress under the Strategy by governments. We are seven years into a ten year strategy and the bulk of the reform is yet to materialise. CYDA recommends inclusion of the National Disability Strategy as an agenda item at each meeting of COAG and each COAG council. This should also include consideration of interface issues between the NDIS and mainstream sectors.

Recommendation 1: Development of a rigorous work plan and outcomes framework for the implementation of the *National Disability Strategy 2010-2020* which includes clearly defined roles, responsibilities, measures, timelines and evaluation.

Recommendation 2: The *National Disability Strategy 2010-2020* and progress in meeting associated outcomes is a standard agenda item in COAG meetings, including the responsible COAG councils.

Systemic Failings in Education

The Australian education system is currently failing to adequately meet the needs of students with disability. Parallel reform is urgently needed or the current crisis in education will greatly undermine

the success of the NDIS. Not only will present barriers to education contribute substantial costs to NDIS participants who are currently school aged but they will have a significant impact on the opportunities and abilities for young people with disability to have increased social and economic participation throughout their post school lives.

Students with disability typically contend with profound barriers and disadvantage within the Australian education system. Direct experiences reported to CYDA and available statistics demonstrate that poor and compromised education experiences are currently the norm for students with disability. A typical education experience for students with disability involves discrimination, limited or no funding for support, inadequately trained staff, and a systemic culture of low expectations, exclusion and bullying. Disturbingly there are also increasing incidents of restraint and seclusion of students with disability reported to CYDA.

Poor education experiences and outcomes of students with disability are reflected in available Australian statistics:

- 45.8% of people aged 15 to 64 years with disability's highest level of education was Year 10 or below, compared to 25.7% of people without disability;¹⁰
- 41% of people with disability have completed Year 12, compared to 62.8% of people without disability;¹¹
- 17% of people with disability have completed a Bachelor Degree or higher compared to 30.1% of people without disability;¹²
- 38% of young people aged 15 to 24 years with disability either work, study, or do a combination of both on a full time basis compared to 56% of young people without disability;¹³
- The labour force participation rate for people with disability is 53.4% compared to 83.2% for people without disability;¹⁴ and
- People with disability experience higher rates of poverty than the total population (17.8% and 12.9% respectively).¹⁵

In recent years there have been initiatives that have contributed to a greater understanding of the needs and experiences of students with disability and modest investments in reform. Key examples include: the Review of Funding for Schooling; More Support for Students with Disability; National Partnerships; the Nationally Consistent Collection of Data on Students with Disability; and school funding reform. However, although this broad review and tepid reform is progressing, the direct experience of students with disability continues to be overwhelmingly poor.

¹⁰ Australian Bureau of Statistics 2016, 'Table 7.3 Persons Aged 15 Years and Over, Living in Households, Disability Status, by Selected Social Characteristics–2015, Proportion of Persons,' *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Commonwealth of Australia, Canberra.

¹¹ Australian Bureau of Statistics 2016, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Commonwealth of Australia, Canberra, viewed 12 April 2017, <https://goo.gl/cXkD3a>.

¹² Ibid.

¹³ Australian Bureau of Statistics 2012, *Australian Social Trends*, Commonwealth of Australia, Canberra, viewed 12 April 2017, <https://goo.gl/u0oAlp>.

¹⁴ Australian Bureau of Statistics 2016, 'Table 9.3 Persons Aged 15–64 Years, Living in Households, Disability Status, by Sex and Labour Force Status–2012 and 2015, Proportion of Persons,' *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Commonwealth of Australia, Canberra.

¹⁵ Australian Council of Social Service 2016, *Poverty in Australia 2016*, Sydney, p. 35. This data refers to people with disability "with a core activity limitation" as defined by the Australian Bureau of Statistics.

The impact of inadequate education provision on the life outcomes for these children and young people is profound. CYDA is concerned that the present education system is not providing students with disability with the necessary knowledge, skills and resources to support future meaningful social, community and economic participation.

CYDA has undertaken a significant body of work and advocacy in relation to education and students with disability and has made many recommendations to government and key stakeholders in this area.¹⁶ In particular, CYDA has strongly advocated for a national plan for education reform and students with disability.¹⁷ This should include clearly articulated aims, objects and measurable outcomes. Further, it needs to be grounded in a firm evidence base to provide a blueprint for embedded and systemic reform. A national plan should ensure that equal rights to an inclusive education are afforded to every student with disability.

It is also vital that there is explicit consideration of the linkages between education reform for students with disability and the developing NDIS. The interface of the education systems and the NDIS, as well as the integration of the two reform programs must therefore be a regular agenda item at COAG Education Council meetings.

CYDA would also like to highlight that despite the stated wish that the NDIS be nationally consistent, it will not be possible at present to achieve national consistency in the NDIS education interface because each state, territory and independent education system is different. Strong collaboration between jurisdictions and between the education and disability sectors will be required to address this.

In summary, without parallel reform in education, the aim of the NDIS to support social and economic participation of people with disability will be greatly diminished. It is therefore critical that systemic failures in education are seen as a major cost driver and risk for the NDIS. This must be a key consideration in the Productivity Commission's findings and urgently needed education reform must be prioritised by state and Commonwealth governments. These governments are co-owners of the NDIS and the costs of failures in education will be visible in the NDIS and will be borne by the same governments.

Recommendation 3: Development of a national plan for education reform and students with disability backed by strong political leadership regarding the implementation of the plan.

Recommendation 4: Inclusion of the education and NDIS interface as a regular agenda item at all COAG Education Council meetings.

Recommendation 5: Further refinement of strategies and actions to define and establish the education and NDIS interface. This needs to incorporate a mapping and future plan of relevant collaborative action and structures of relevant parties which include the NDIA, state, territory and Commonwealth governments, education authorities and relevant stakeholders including CYDA.

Recommendation 6: The development of a clear mechanism which ensures the direct experience of students with disability informs the establishment and ongoing work regarding the NDIS and education interface. This should include ongoing consultation with CYDA.

¹⁶ CYDA's education submissions are available at <http://www.cyda.org.au/cdasubmissions>.

¹⁷ Children and Young People with Disability Australia 2016, *Submission to Senate Inquiry into Current Levels of Access and Attainment for Students with Disability in the School System, and the Impact on Students and Families Associated with Inadequate Levels of Support*, Melbourne, p. 63.

Participant Entry Rates

The Productivity Commission issues paper notes that there has been more children than expected accessing the NDIS, particularly in South Australia, Victoria and the Australian Capital Territory.¹⁸ There has also been extensive reporting of this issue, particularly in relation to children with autism.¹⁹ Further, there have been calls to consider changes to the eligibility criteria for the NDIS in light of high participant entry rates.²⁰

It is important to consider issues in relation to eligibility in light of the insurance principles that underpin the NDIS. The NDIA's 2015-2019 Corporate Plan states the NDIS is based on four insurance principles:

- Actuarial estimate of long-term costs, based on the “emerging experience of utilisation and cost”;
- Long-term view of funding requirements, with a focus on “lifetime value for scheme participants, and will seek to maximise opportunities for independence, and social and economic participation, with the most cost-effective allocation of resources”;
- Investment in research, innovation and outcome analysis; and
- Investment in community participation and building social capital, including “encouraging the use of mainstream services to increase social and economic participation of people with disability.”²¹

In particular, these principles seek to provide early intervention and support to people who access the NDIS to support future social and economic participation. Conversely, the NDIS has been developed based on an understanding that not providing reasonable and necessary supports to people with disability is a violation of a range of human rights and would result in extremely poor outcomes for individuals. Further, inadequate disability services provision would contribute to increased costs for other services, particularly in a crisis context, such as in health, justice, homelessness, child protection or others.

The present focus on containing NDIS costs by limiting eligibility therefore does not reflect these insurance principles as supports denied to people who are no longer eligible will reappear elsewhere and the community and economy will not have the benefit of people's participation. A focus on ensuring that decisions around reasonable and necessary supports for people and how these can maximise the participation and potential of people with disability is therefore more pertinent to the issue of NDIS costs.

SCHEME BOUNDARIES

Eligibility

Eligibility for the NDIS as articulated in the *NDIS Act 2013 (Cth)* includes the following under 'disability requirements:'

¹⁸ Productivity Commission 2017, *National Disability Insurance Scheme Costs: Issues Paper*, Commonwealth of Australia, Canberra, p. 11.

¹⁹ Examples include: R Morton 2016, 'Surging Autism a Headache for NDIS,' *The Australian*, viewed 12 April 2017, <https://goo.gl/JkkE3U>, R Morton et al. 2016, 'Autism Explosion Leaves NDIS in Disorder,' *The Australian*, viewed 12 April 2017, <https://goo.gl/fPBjJR>.

²⁰ R Morton 2017, 'Tighten NDIS Entry or Watch it Fail, say Stakeholders,' *The Australian*, viewed 12 April 2017, <https://goo.gl/WSXE0M>.

²¹ National Disability Insurance Agency 2015, *2015-2019 Corporate Plan*, Geelong, p. 7.

The impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:

- i. Communication;*
- ii. Social interaction;*
- iii. Learning;*
- iv. Mobility;*
- v. Self-care;*
- vi. Self-management.²²*

The approach of providing services and supports on the basis of the functional impact of disability on a person's life represents a significant shift from previous state and territory service systems, which typically had rigid eligibility criteria based on diagnostic information and assessments. Using a 'functional' approach recognises that disability impacts each person differently and considers support needs on a personal level.

Despite the definition of 'disability requirements' included in the NDIS Act, it has been reported to CYDA that eligibility assessment processes for the NDIS do not always include due consideration of the functional impact of a child or young person's disability. In some cases there appears to be a stronger reliance on diagnostic information and assessments in determining eligibility, rather than through developing an understanding of the specific person and their individual needs and circumstances.

The following concerns have been raised to CYDA by members and constituents:

I was originally told you didn't need a diagnosis but have since heard you do need those doctors' reports. This makes it hard to get funding for those children that need speech therapy or hearing assessments when doctors are still unsure of their diagnosis.

The criteria does not seem needs or function based.

Eligibility criteria (seems) written around easily defined physical and chromosomal conditions. Its suitability for those with psychosocial conditions is poor, leaving this cohort at a distinct disadvantage, particularly as staff are not trained in this area.

In addition, the 'Access Request Form' requires provision of supporting information about the person's disability, including the option of having a health or education professional to complete a table assessing the person's needs in a range of areas. CYDA is particularly concerned about education professionals providing this information.

It has been well established that education professionals have minimal training and expertise in relation to meeting the learning needs of students with disability and this is a key contributor to poor outcomes and barriers typically experienced by these students. This was most recently reflected in the final report of the Senate inquiry into *Current Levels of Access and Attainment for Students with Disability in the School System, and the Impact on Students and Families Associated with Inadequate Levels of Support*.

²² *National Disability Insurance Scheme Act 2013 (Cth)*, section 24.1.c.

A key finding of this inquiry was that “too many teachers were inadequately aware of issues surrounding the education of students with disability, including the rights of students to an education and the necessity of additional adjustments and support for some students.”²³ This issue has also been raised by the Australian Education Union, whose 2015 survey found that 63% of teachers reported the level of training and professional development they had undertaken has not provided them with the skills and knowledge to teach students with disability.²⁴

Additionally some of the information required would not be under the purview of an education provider. They are educators first and foremost and few have the clinical expertise to provide comment or assessment on the information requested in the Access Request Form. For example the Form asks for information about whether the applicant requires home modifications to support mobility or support with personal care such as showering and toileting.

It is therefore the strong view of CYDA that educational professionals should not be able to assess the support needs of children and young people with disability to inform eligibility decisions or at a minimum should be required to provide evidence of their specific expertise which equips them to undertake this role.

Recommendation 7: Removal of the option for education professionals to provide information about the support needs of students with disability to inform eligibility assessments unless evidence of specific expertise to make these assessments can be provided.

Interfaces with Mainstream Services

As acknowledged in the issues paper for this inquiry, the intersection of the NDIS with mainstream services is critical to meeting the needs of participants and ensuring the sustainability of Scheme costs.²⁵ Further, poorly defined interfaces risk leading to service gaps and cost-shifting.²⁶ Since the NDIS’s inception, CYDA has frequently highlighted the need to clearly develop interface arrangements with mainstream sectors, particularly education. However, NDIS interface arrangements are not well advanced in 2017 and although their importance has been noted since the inception of the NDIS in 2013, they have not been a strategic priority for the Scheme or the Disability Reform Council.

Children, young people and families typically access a broad range of services and supports, including those provided by early childhood and school education; family and children’s services; health; employment; and more. These various systems are fundamental to our community and support the development of children. Many of these areas, as outlined previously in this submission, have significant barriers and gaps that work against the inclusion of children and young people with disability.

The articulation of the NDIS interface with these other life areas and associated service systems is critical to the success of the Scheme. On its own, the NDIS cannot fill the gaps resulting from barriers and inadequacies of other service areas. Rather, there needs to be a negotiated interface which reinforces that affording rights and inclusion of people with disability is everyone’s business, not just something that can be passed off to the disability portfolio, as has been the case in the system we are trying to leave behind. This also reaffirms the importance of the National Disability Strategy,

²³ Senate Standing Committee on Education and Employment 2016, *Access to Real Learning: The Impact of Policy, Funding and Culture on Students with Disability*, Commonwealth of Australia, Canberra, p. 65.

²⁴ Ibid, p. 65.

²⁵ Productivity Commission 2017, *National Disability Insurance Scheme Costs: Issues Paper*, p. 15.

²⁶ Ibid, p. 15.

which provides the framework and map for meeting obligations and rights to people with disability across the community.

Key issues raised to CYDA by members in regard to this area have included the visible lack of continuity and coordination between the NDIS and mainstream services, with some reporting a 'total disconnection.' Some have said that they feel as though they have to take some responsibility for connecting services and systems, which is a totally unrealistic expectation and no substitute for rigorous public policy development. Others stated that interface arrangements are ad hoc and extremely unclear. 80% of CYDA NDIS survey respondents reported that it is currently unclear what the NDIS funds in regard to other systems in the child or young person's life and how this is coordinated. Experiences reported to CYDA are provided below:

There is not a good understanding at the NDIA about the importance of continuity - there is an 'us and them' attitude with respect to education and health.

(Interface arrangements are) clear as mud. All involved seemed to be making it up as they go.

(The NDIA has) no idea of the role of schools. The planner suggested the school would give my child physiotherapy sessions.

Sometimes it seems like the boundaries keep moving.

It is not clear what NDIS will fund in regard to assistance during school hours and what will be funded by the education department.

The operation of the NDIS and the practicalities of the interfaces with mainstream programs will be complex and dynamic. Clear protocols will be needed between portfolios and funding agencies and effective coordination at the community level will be required as the NDIS is implemented. This will also involve defining clear roles and lines of responsibility, funding arrangements, present gaps in service provision and ensuring effective collaboration occurs.

While CYDA understands that a range of work around mainstream interfaces with the NDIS is occurring at different levels of government and community, the approach taken to date appears patchy, uncoordinated and far from resulting in better integrated services. Much of what CYDA hears is that a degree of this work is aimed at resolving the one dimensional question of 'who pays for what', rather than seeking to break down program silos to provide better government responses. There is a need to map out the interface issues, the current work that is occurring and, the roles of key relevant stakeholders to ensure that a clear, coordinated and comprehensive strategy is developed regarding the NDIS interface with other service systems.

Recommendation 8: Work is undertaken to map the interfaces between the NDIS and mainstream areas, define relevant actions and roles of key stakeholders, including community sector peak bodies. This should inform the development of a clear, coordinated and comprehensive strategy around the development of NDIS interface areas.

Information, Linkages and Capacity Building

The Productivity Commission inquiry report into *Disability Care and Support* identified three 'tiers' of people impacted by a potential NDIS. Tier two was defined as "people with, or affected by disability" who "could approach the scheme for information and referral services (as distinct from funded

support).²⁷ This component of the NDIS is now referred to as Information, Linkages and Capacity Building (ILC).

The ILC appears to have been an afterthought in the Scheme design and as it is currently conceived it will be of relevance to the largest number of people with disability, with it being potentially accessed by the 2.5 million people under the age of 65 known to have a disability.²⁸ ILC therefore needs to incorporate a flexible process for accessing services and supports for people with disability and families, including mainstream services. CYDA understands that ILC services are in the early stages of implementation and is expected to be fully implemented in 2019-2020 when it will attract annual funding of \$132 million, excluding funding for LAC.²⁹

CYDA has some concerns about the development of the ILC component of the NDIS to date, particularly around the way the ILC policy defines the role of the NDIS. One of the stated aims of ILC is to “promote collaboration and partnership with local communities and mainstream and universal services to create greater inclusivity and accessibility of people with disability.”³⁰ However, it is important to ensure the NDIA is not the key organisation that promotes and drives inclusion of people with disability in all areas of the community. It is important for mainstream sectors and the broader community to take the lead in this change, as articulated in the National Disability Strategy. Through ILC, the NDIS may facilitate opportunities and partnerships but should not be the ‘director’ of all things disability.

As an insurance scheme, it is inconceivable that the NDIS over time will not prioritise the ILC as a risk management tool to reduce cost pressures on individual packages. This is not the purpose of ‘tier 2’ of the original model. It was always more to do with genuine community connection and a support infrastructure that formed a critical part of the overall response to supporting people with disability. It cannot be allowed to be seen as being subordinate to the core funding business of the NDIS.

An issue that emerged in CYDA’s survey is that 68% of respondents are not aware of how to access services and supports if the child or young person is not eligible for the NDIS. Respondents also raised concerns that many state and territory funded services are withdrawing as a result of the NDIS. Relevant feedback included the following:

I am very worried about what will happen for kids with mild to moderate (disability), where will they access services?

There is very little available without NDIS funds. Community and state based services are all disappearing.

I only know how to access services privately such as occupational or speech therapy.

Access to services for young children are being withdrawn in New South Wales as the NDIS rolls out...Only services appear to be those provided by (the health department).

²⁷ Productivity Commission 2011, *Disability Care and Support Inquiry Report Volume 1*, Commonwealth of Australia, Canberra, p. 12.

²⁸ National Disability Insurance Agency 2015, *Framework for Information, Linkages and Capacity Building*, Department of Social Services, Canberra, p. 7.

²⁹ National Disability Insurance Agency 2016, *Information, Linkages and Capacity Building Commissioning Framework*, Geelong, p. 5.

³⁰ National Disability Insurance Agency 2015, *Framework for Information, Linkages and Capacity Building*, p. 1.

There really is no help if you are ineligible.

These experiences reflect the need for clear pathways to access services and supports for children and young people who are not eligible for the NDIS. However, in CYDA's understanding there currently appears to be a gap in service provision between the Individual Funding Package and ILC components of the Scheme that will impact a large group of people, namely people who are not eligible for the NDIS but who require periodic disability services and supports.

The following is a hypothetical yet common scenario:

Sam is 18 years old and has recently commenced a university degree. Sam requires support in some areas due to the functional impact of his disability but doesn't need or want an Individual Funding Package through the NDIS. He has previously accessed different supports and therapies at different stages throughout his childhood. Sam will require periodic support and services, including some allied health services. When this will be required will be variable according to circumstances and events in his life.

A key area where Sam currently requires additional support is in applying for employment. He is ineligible for existing disability employment support. A useful option given Sam's circumstances would be accessing mainstream services in conjunction with his existing therapists so support can be tailored to meet his particular needs and circumstances.

Sam still needs funding to pay for his variable needs for services and supports which are directly related to the functional impact of his disability.

In the scenario above, it appears the young person would have to pay privately which is not an option for many. Alternatively, support may be accessed through community systems. However, this may preclude people from accessing a favoured service or professional who has an extensive knowledge, expertise and relationship with the young person concerned.

Further, this scenario highlights some of the challenges in terms of practicalities encountered by people who are not eligible for the NDIS. It is presently unclear how the types of services described above will be provided and funded, as they are not included within the five activity streams under ILC. Further, split between 2.5 million people with disability, the allocated funds for ILC would not be sufficient to provide these services. This issue therefore requires explicit consideration. Options that can be considered include block funding some services or providing shorter term funding that can be used as needed.

Recommendation 9: Review of structure and funding of the ILC be undertaken.

Recommendation 10: Consideration of how service provision will be funded and accessed for people who are not eligible for the NDIS, given the current parameters around ILC funded activities.

AGE CONSIDERATIONS

Children

It is absolutely paramount that there is adequate understanding and recognition of the specific considerations for children within the NDIS. First and foremost it's important that children with disability are defined and responded to as children first in the context of the Scheme.

Australia is a signatory to the United Nations *Convention on the Rights of the Child*. This human rights instrument clearly articulates the obligations of States Parties to ensure children with disability are afforded their right to childhood and inclusion in their community on an equal basis to their peers without disability.³¹ The Convention details the rights of children in a range of life areas, including the right to: protection and care; live with and be cared for by family; express their views; health; social security and an adequate standard of living; education; play; and to be free from abuse.³² The Convention also states that consideration of a child's best interests must guide all decisions impacting children.³³

Despite this strong human rights framework, in Australia the present experience of childhood is typically very different for children with disability. Many of the activities and opportunities which are typically part of the active citizenship and participation of a child are frequently denied to children with disability. Examples include being able to play at a local playground, attending a local school or attend a friend's birthday party.

It is envisaged that the NDIS will play a significant role in changing this current reality for children with disability. This will occur by facilitating and supporting childhood development through timely and adequate early intervention and accessing appropriate services and supports to enable equal opportunities and participation throughout childhood. In addition, implementation of the National Disability Strategy and the NDIS will ultimately contribute to the development of inclusive communities.

Available evidence suggests almost all children with disability live with their families.³⁴ It is therefore critical that the context of *children in families* frames the delivery of services and supports. This means services must be 'wrapped around' the child and their family. Further, it is essential that developmental considerations are applied in all aspects of the NDIS where children are considered, including in eligibility, planning and service provision. As it is designed, there is not adequate recognition of the different context for children. The planning and funding mechanisms are virtually the same as they are for adults in the Scheme.

Also important is that Scheme operations are reflective of the specific protective needs of children with disability. Available Australian and international evidence indicates that children and young people with disability are over three times more vulnerable to experiencing abuse and neglect than their peers without disability.³⁵ CYDA is frequently informed of experiences of abuse and neglect of children with disability. This include incidents that are clearly defined and understood as abuse. Also of significant concern are the number of experiences that are not recognised as abuse by many

³¹ United Nations General Assembly 1989, *Convention on the Rights of the Child*, article 23.

³² Ibid.

³³ Ibid, article 3.

³⁴ Australian Bureau of Statistics 2008, *Families with a Young Child with a Disability*, Commonwealth of Australia, Canberra, viewed 12 April 2017, <https://goo.gl/71z5p3>.

³⁵ P Sullivan et al. 2000, 'Maltreatment and disabilities: A population-based epidemiological study,' *Child abuse and neglect*, Vol. 24, No. 10, p. 1257, M Maclean et al 2017, 'Maltreatment Risk among Children with Disabilities,' *Paediatrics*, Vol. 139, No. 4.

when a child disability is involved. Examples include a child being restrained to 'manage behaviour' or a student being denied food, drink and toilet trips during long bus trips to and from school.

These specific protective and safeguarding needs of children with disability must be embedded in all aspects of the NDIS. Of key importance is the *NDIS Quality and Safeguarding Framework*, however this document contains minimal specific reference to children. The *Royal Commission into Institutional Responses to Child Sexual Abuse* has highlighted the need for child-specific safeguards and standards to prevent abuse in institutional contexts. However to date it is unclear how the significant body of work of the Royal Commission and the findings to be released in December 2017 will inform the NDIS and its approach to working with children.

Protective considerations and safeguards must also be at the core of the NDIS systems and processes as they relate to children, including planning. It is currently unclear what risk assessment tool is being used for children's plans and how considerations around safeguarding are incorporated. Information about the tool being used is not publically available and CYDA has repeatedly requested access to this document which has not been provided to date.

NDIS planning for children needs to be informed by an evidenced-based safeguarding framework. It is critical that work is undertaken to examine how available evidence around safeguarding children with disability can be applied to planning processes. In 2012 CYDA released an issues paper entitled *Enabling and Protecting: Proactive Approaches to Addressing the Abuse and Neglect of Children and Young People with Disability*.³⁶ This paper provides a detailed discussion of the causes, experience and responses to abuse of children and young people with disability, much of which is relevant to NDIS planning. For example, it highlights a range of factors that increase the risk of abuse of children with disability, including negative attitudes about disability and organisational cultures that devalue children with disability.³⁷ It is vital there is an understanding of these factors embedded in planning.

Additionally, despite there being vastly different considerations for children and adults in the development and provision of disability services and supports, there are no specific principles that guide the way the Scheme works with children and families. For example, there are no specific principles included in the 'children' section of the *NDIS Act*. Legislative change to more clearly define principles for working with children could provide an opportunity to embed developmental and protective considerations in all aspects of the NDIS as it relates to children.

Recommendation 11: Amendment of the NDIS Act to include specific principles that guide the way the NDIS applies to children. This should include ensuring that developmental and protective considerations are applied at all levels of the NDIS, including eligibility, planning and service delivery.

Recommendation 12: Considerations of how findings of the *Royal Commission into Institutional Responses to Child Sexual Abuse* will inform safeguards embedded in the NDIS.

Early Childhood Early Intervention

The NDIS Early Childhood Early Intervention (ECEI) approach for children aged 0 to 6 aims to "ensure that parents or primary caregivers are able to provide young children who have developmental delay or disabilities with experiences and opportunities that help children gain and use the functional skills

³⁶ Available at <http://www.cda.org.au/enabling-and-protecting>.

³⁷ Children and Young People with Disability Australia 2012, *Enabling and Protecting: Proactive Approaches to Addressing the Abuse and Neglect of Children and Young People with Disability*, Melbourne, p. 12.

they need to participate meaningfully in their environment.”³⁸ The approach has three key stated features that guide the provision of ECEI, namely: capacity building for children and families; a family centred approach; and provision of support in “everyday environments.”

A key component of the ECEI approach is the ‘ECEI Partners.’ These are designated to be a “first contact point for families” who provide information about appropriate supports for the child and make referrals.³⁹ ECEI Partners have been contracted alongside community organisations providing LAC services in some rollout regions. It is CYDA’s understanding that in some jurisdictions, it is still to be identified who will undertake this ‘partner’ function so it is not an operational role of the NDIS in those areas.

The ECEI Partners are intended to be organisations with strong local knowledge and expertise around early intervention.⁴⁰ However concerns have been raised with CYDA that in some jurisdictions appointed ECEI Partners don’t have local knowledge or the expertise which is stipulated for organisations undertaking this role. It is also understood that like the LAC partners in some regions, ECEI partners, where required, are having and will have an ongoing planning role for children. Further concerns reported to CYDA about these arrangements are that limited time is made available for these ECEI partners to develop an understanding of the child and family in going about their role.

We note that Noah’s Ark have outlined these points in detail in their submission to this inquiry and additionally have raised issues in relation to the clarity of the ECEI approach taken by the NDIS. CYDA is of the view that the issues raised by Noah’s Ark accurately reflect critical areas of future discussion and consideration and recommend these points to the Commission. CYDA would appreciate the opportunity to meet with the Commission to further discuss the issues raised around ECEI.

Key Considerations for Young People

It is also important that NDIS processes include adequate consideration of the specific circumstances of young people. Young people often experience a context of increasing independence, consideration of potential future life directions and rapid changes in a range of life areas. Researchers have theorised and conceptualised this time of life in different ways. One key example is the concept of “emerging adulthood,” recognising this time as crucial for developing identity and considering future life possibilities, while still requiring support in certain areas.⁴¹

The experiences and needs of young people with disability will vary significantly depending on individual circumstances. In many cases young people with disability will require different types of support and protective considerations. This will be impacted by a range of factors, one of which is the functional impact of disability. Many of these issues are discussed in a document developed by the NDIS Independent Advisory Committee (IAC) entitled *Promoting Independence for People with Disability*.⁴²

³⁸ National Disability Insurance Agency 2017, *Early Childhood Early Intervention*, Geelong, viewed 12 April 2017, <https://goo.gl/wumdSX>.

³⁹ Ibid.

⁴⁰ Ibid.

⁴¹ J Arnett 2000, ‘Emerging Adulthood: A Theory of Development From the Late Teens Through the Twenties,’ *American Psychologist*, Vol. 55, No. 5.

⁴² National Disability Insurance Agency 2017, *Promoting Independence for People with Disability*, Geelong, viewed 12 April 2017, <https://goo.gl/Ldn52n>.

Despite the issues highlighted by IAC, it is currently unclear how principles and evidence around the specific context of youth and meaningful participation are informing the approach of the NDIS to working with young people. It is crucial that available evidence, theoretical frameworks and the individual circumstances of young people are considered in relation to the practical implementation of the NDIS, including eligibility, planning, information provision and more. Critically, the Scheme needs to ensure the views and experiences of young people are the central informant of planning for funded supports.

Further, the IAC advice around increasing independence of young people is focused on those aged 18 to 25. For young people aged under 18, particularly older adolescents, the considerations will differ significantly than for younger children. However, again it is unclear what principles guide the approach of the NDIS to working with these young people.

Recommendation 13: Consideration of mechanisms to ensure available evidence and theoretical frameworks guide the practical implementation of the NDIS as it relates to young people (including those aged under 18 years), including eligibility, planning and information provision.

PLANNING PROCESSES

Plan Establishment

Experiences of developing an NDIS plan for children and young people with disability reported to CYDA have been highly variable. In the transition phase of the NDIS, the 'My First Plan' approach is being used. For many, this approach involves using previously accessed services and supports to inform plans. Some positive experiences of planning have been reported to CYDA, however a range of concerns have also been reported, with some being extremely dissatisfied with the process. Key issues reported to CYDA in relation to plan establishment include:

- Perception that young people and families must advocate strongly or 'work hard' to achieve a quality plan;
- Variability in the skills of planners, with some having limited expertise and experience;
- Limited understanding of the needs and circumstances of the child or young person and services and supports included in the plan reflecting this;
- A rushed planning process and a lack of preparation by planners;
- Some plans being done remotely by telephone and people actively discouraged from having face to face planning meetings; and
- Final plans not reflecting what was discussed at the planning meeting.

Examples of experiences reported to CYDA include:

It was a very 'scripted' meeting. It felt like they said the same thing 100 times and I was not able to give any ideas about what would help us.

(The planner was) very 'green' and inexperienced...I didn't like being told what my son needed or didn't need in his plan by a virtual stranger that clearly had no idea about (my son's disability).

Our first planner was terrible. I feel these people have a very small understanding of disability...Our second planner was great and understood my daughters needs and we received a very good plan that I am happy with.

The planners have listened and seemed to understand the needs, however conversations had do not seem to be reflected in the final plan.

(The planner) was polite and efficient. I couldn't help thinking that a lack of understanding of how my son's disability really impacts his life would affect his recommendations.

(The planner) had no idea of a child's needs and was not a competent listener.

(The planning process) seemed easy but really felt I had no idea what I was going to get and when the plan came out it was totally unsuitable and included things like respite care which I had strongly said was not suitable and we were not comfortable with. Felt like a standard plan and no one really listened.

The phone conversation we had was not represented in the plan. When I got the plan it was like the lady hadn't been listening to me and just made something up. The budget allocations are all wrong for what we need. Not impressed at all.

Issues such as the hurried nature of planning or experience and expertise of planners have clearly been affected by the Scheme's current transitional phase and administrative capacity. While CYDA understands the significant pressures associated with a large number of people accessing the NDIS as it rolls out, it is unclear what strategies are being put in place to ensure these issues do not become entrenched.

For example, there is no information available about how a shift away from the 'My First Plan' approach will occur to ensure planning reflects the intent of the NDIS to provide supports based on individual needs and circumstances including the functional impact of disability. Further, there is a need to articulate how appropriate training and evaluation of planners will occur to ensure quality planning processes. It is critical that adequate flexibility exists around plan establishment and review so current practice in terms of planning does not become entrenched.

An additional concern of CYDA's relates to rigid planning requirements, particularly the requirement that a *Participant Statement of Goals and Aspirations* is developed. This is seen as not reflective of the reality of the lives of children, young people and families. For school age children, goals and aspirations may be related to ongoing health issues or educational attainment, which are not the primary role of the NDIS. The formal setting of goals is viewed by CYDA as a highly contrived and unnatural activity. CYDA did not support the inclusion of this requirement during the drafting of the original legislation and rules and there has been no evidence that this statement adds anything other than an intrusive administrative burden for young people and families.

For children and young people with disability, frequently circumstances are ever-changing and complex. Needs, circumstances and the impact of disability may change or are unclear at certain stages and it is critical that services and supports are flexible in recognition of this. CYDA accepts that there needs to be a service plan in order to activate funding, however the relevance and purpose of this additional layer is highly questionable.

In addition, direct experiences reported to CYDA highlight that review processes for plans are frequently not sufficiently timely to be responsive to the lives of children and families. Living circumstances frequently change so it is absolutely critical that NDIS planning processes, including reviews and changes to plans, are not so rigid that they are incompatible with these circumstances. Without having a timely and flexible review process, it is unclear how the Scheme can be responsive

to the lives and circumstances of NDIS participants. The processes of planning and funding need to be improved to enable this greater flexibility and timeliness.

Recommendation 14: Development of a strategy to ensure that issues with the NDIS planning process described in this submission do not become entrenched and that planning processes are sufficiently flexible to the lives of children and young people with disability and families.

Recommendation 15: Development of clear guidance and expectations regarding the development of the plans for children with disability.

Recommendation 16: Development of clear process for ensuring child safeguarding considerations are a component of the planning process.

Recommendation 17: Removal of the requirement for all NDIS participants to have a statement of goals and aspirations (Section 33.1) from the NDIS Act.

Recommendation 18: Consideration of mechanisms to ensure NDIS review processes are timely and flexible so NDIS plans can adapt to suit the changing circumstances of NDIS participants.

Privacy

There is a lack of clarity around the privacy considerations in NDIS planning processes. Currently it appears the NDIA are able to access a range of information about NDIS participants, including information from disability services, health, education, Centrelink or state or Commonwealth government departments and services. However, it has been reported to CYDA that young people and families are often unaware of what information has been provided.

It is critical that NDIS participants and families are aware of what personal information has been disclosed to the NDIA and that there is informed consent for information sharing. Currently the Access Request Form includes a blanket consent form for the NDIA to obtain information about the participant by third parties.

CYDA strongly supports the development of information maps that inform participants and families where their personal information has been collected from and where it will go. This should provide the basis for a more refined consent process for disclosure of personal information by third parties to the NDIA. Critically, NDIS participants or their nominee should be provided with clear parameters around why the NDIA is seeking particular information and from which parties and be required to consent to any information sharing. In future circumstances where the NDIA is seeking additional information from different sources, participants or nominees should be informed and provide specific consent again.

Recommendation 19: Development of an information map for NDIS participants to inform participants of who accesses their personal information.

Recommendation 20: Introduce requirements for the NDIA to obtain specific consent from participants or nominees for personal information being provided by third parties.

Complaints

An effective and timely complaint mechanism for the NDIS is critical to ensuring the Scheme is responsive to participant concerns. A range of work around complaints is currently occurring, particularly in relation to the *NDIS Quality and Safeguarding Framework* and the announcement of the NDIS Complaints Commissioner.

CYDA has regularly been approached by young people and families around specific issues of concern in relation to the NDIS and has been able to provide assistance around relevant contacts to address these issues. In these cases, the NDIS has typically been responsive to issues and concerns raised.

In terms of the formal complaint processes regarding the NDIA, CYDA members and constituents have highlighted that the process is time consuming and has involved long wait times for resolution. In addition, for many young people and families the complaint process is unclear. This was reflected in CYDA's survey, where 52% of respondents reported being unsure of how to make a complaint to the NDIS. It is important that accessible information is provided around how to make complaints. This should include clear information about when different complaint mechanisms are relevant, for example in relation to complaints about the NDIA as opposed to service providers.

Recommendation 21: Review and improvement of existing processes and communication of existing provision of information about complaint mechanisms regarding the NDIS.

MARKET READINESS

Sector and Workforce Issues

Given the significant change associated with the NDIS, it was anticipated that services would require support and market stewardship to adapt to the new system. Currently, there are transitional issues associated with this change and this is impacting access to services and supports for some NDIS participants. Many of these are stated in the Productivity Commission issues paper, and include: challenges in recruiting staff; challenges in transitioning from block funding to a fee-for-service model; and thin markets. These sector and workforce issues will have significant impacts on participant experiences and have in some cases inhibited access to services and supports.

In CYDA's survey, 38% of respondents reported they had developed a plan but services and supports were not being accessed. A range of circumstances were reported including significant wait times to access services and supports, particularly in relation to allied health therapies and additional challenges in regional areas. It is important that there is sufficient consideration of ways to ensure these sector and workforce issues are addressed.

Demand has greatly increased and thus skilled therapists are far more difficult to access.

Due to there being no services close to our area of residence, I have to travel up to an hour away or more to access services. In addition to this some services are too expensive to use.

Because there are such long waiting lists, it can be quite difficult to see the support worker you want.

There are waiting lists for services and you have delays with providers getting back to you. I have been trying for 12 months to build up a group of suitably trained staff to support my son.

Participant Readiness

The Productivity Commission issues paper discusses factors that will impact participants' ability to negotiate the NDIS and exercise choice and control over services and supports accessed. This is an important consideration for the success of the NDIS.

A key issue that CYDA is frequently informed of is that information about the NDIS can be unclear and difficult to obtain for many young people and families. This was illustrated in CYDA's survey,

where 44% of respondents reported they did not feel they have an adequate understanding of the NDIS. Key concerns reported include:

- Challenges in accessing information on the NDIS website which for many is unintuitive;
- Lack of information in clear, accessible language;
- Challenges when contacting the NDIA directly, with long waits for phone calls and emails often not being responded to; and
- NDIA staff not having a clear understanding of NDIS processes themselves.

Survey participants reported that independent information and support was often highly useful in navigating and understanding the NDIS. Examples of some experiences reported to CYDA include:

The rules keep changing as it seems that people who work for NDIS don't know the rules thoroughly enough either.

I have done extensive research and have a background in disability advocacy so I came into NDIS with a good understanding of the 'system' however if I didn't have any working background...I would have REALLY struggled to successfully advocate for my son's needs.

The NDIS is an overcomplicated scheme, but the fundamentals are clear. It is inconsistencies around interpretation by staff that make it difficult to manage. Ever changing rules and (no responses to) calls also are concerning.

The NDIS is so new and I believe it is a huge learning curve for everyone involved. Each day I feel I am understanding it better, then something new will come up and I feel there is still so much more to learn.

I had difficulty navigating the official NDIS website. I often relied on other sources to direct me to relevant NDIS policy documents.

A critical consideration around 'participant readiness' is advocacy. Individual advocacy is an important source of support and advice for many children and young people with disability and their families. People are often unaware of the rights of children and young people with disability, relevant legislation and protections and require support in accessing complex service systems or resolving a specific issue.

Access to independent advocacy is particularly critical during the current period of transition to the NDIS. There is presently significant uncertainty around how advocacy will be provided in the context of the new funding and regulatory environment associated with the NDIS. Capacity for people to access skilled support for preparation for planning and support throughout the process has proven to be extremely valuable and this can be a key role for advocacy organisations.

Young people with disability and families of children with disability frequently contact CYDA seeking individual advocacy. Despite the acknowledged work of existing advocacy organisations, there is presently extremely high demand, there often appears to be limited support available and often organisations are time and task limited. There is a need for a clear articulation of how independent advocacy will be available to young people with disability and families of children with disability in the context of the NDIS.

An important element of 'participant readiness' is self-management of plans. The options for NDIS participants or their nominees to self-manage all or part of their funding package is of significant

interest to CYDA members as they see this as being a way of achieving greater levels of choice and control over their supports, but some are unsure of the mechanics and the responsibilities involved.

Self-management can operate at varying levels, with options available to self-manage all or part of a package. It can only work where the appropriate support is available to assist people to self-manage. In CYDA's survey, 46% of respondents reported their or their child's plan is self-managed. This differs significantly to the 7% reported by the NDIA.⁴³ These skewed results seem to indicate that many young people and families do not understand what self-management means. Increased information around this option would be useful in addressing this.

Some of the tasks undertaken to self-manage include: choosing and arranging supports including workers; directly paying invoices for services and supports accessed; keeping appropriate records; and reporting to the NDIA.⁴⁴ Pursuing this option therefore affords a greater level of choice and control around services and supports accessed. It also involves increased administration and organisation required by the person or family.

An important consideration for self-management is how it is safeguarded. Currently, self-management allows people to access service providers that are not registered with the NDIA.⁴⁵ Further, it allows people to hire workers who may not necessarily have undertaken pre-employment screening such as a police or working with children check. In the case of children with disability, this poses significant risks, particularly given their vulnerability to abuse as previously discussed in this submission. Strengthening safeguards and oversight for self-managed NDIS supports is therefore critical, particularly in the context of children and young people.

Recommendation 22: The NDIS website is comprehensively reviewed and overhauled to ensure it provides clear information and is easy to navigate.

Recommendation 23: Additional funding is provided to independent systemic and individual advocacy organisations to have a clear role in supporting people with disability in the context of the NDIS.

Recommendation 24: Provision of information around work being undertaken to support self-management and consideration of how this can be further applied or extended to increase utilisation of this option.

GOVERNANCE AND ADMINISTRATION OF THE NDIS

Governance

The governance model for the National Disability Insurance Scheme is outlined in the NDIS Act. The NDIS is a nationally based Scheme with funding and governance shared amongst all governments. All Australian governments are involved in decisions relating to the Scheme's policy, funding and governance. Key mechanisms include: the Standing Council on Disability Reform Council; the Joint Parliamentary Committee on the NDIS; the NDIA; the NDIS Board; and the Independent Advisory Council.

⁴³ National Disability Insurance Agency 2016, *Quarterly Report to COAG Disability Reform Council 30 June 2016*, Geelong, p. 23.

⁴⁴ National Disability Insurance Agency 2017, *Self-Managing Budgets in your Plan*, Geelong, viewed 12 April 2017, <https://goo.gl/akNJMv>.

⁴⁵ Ibid.

As with much of the NDIS, governance arrangements for the Scheme are complex. This creates challenges in terms of locating the appropriate body to make decisions. The role of the Board is compromised at this early stage of the Scheme's implementation with many decisions that would normally be the responsibility of a board being taken by the Disability Reform Council or directly by the Commonwealth. The structure of the NDIS bi-lateral agreements have also meant that the resolution of many of the implementation problems experienced by the NDIS (such as the My First Plan process and the collapse of the IT system) were not able to be addressed by the Board, but rather were decisions of governments.

As the NDIS matures it is important that the governance arrangements be simplified to enable clear lines of accountability and to minimise the influence of governments on the running of the NDIS. There are a range of cost drivers and risks that the Scheme must manage and if it does not have maximum independent control of these then the overall sustainability of the Scheme will be difficult to sustain.

The IAC has done some very good work but as the Scheme grows, a more sophisticated and extensive advisory structure will be needed, with a greater focus on the involvement of stakeholders in local regions.

Recommendation 25: Review of current governance structure and identification of areas of refinement.

Administration

In the context of a rapidly transforming service system, CYDA acknowledges and commends the significant work and commitment of NDIA staff to date in terms of implementing this unprecedented reform.

Feedback provided to CYDA about the experiences of children and young people with disability and families around accessing and contacting the NDIS indicates that challenges in terms of administrative capacity are significant. Issues with the online payment portal, challenges in contacting the NDIA and significant delays in having eligibility assessed, undertaking planning and accessing supports have all been reported. These experiences highlight that the administrative capacity of the NDIS is currently stressed.

A particular concern reported to CYDA relates to people's contact with the NDIS. Significant challenges in contacting the NDIS reported to CYDA include emails not being responded to. Phone calls often involve long wait times, young people and families having to repeat information to multiple staff members and general challenges in obtaining information sought. These experiences are encapsulated by one member who referred to the NDIA as a "black hole."

Terribly long waiting periods (for phone calls). Ridiculously long. There should be a greater appreciation of how time poor families actually are.

It is VERY difficult to get anyone useful on the phone. Messages are seldom passed on. We have almost given that avenue up for any real source of information. The website is interesting, but still hard to navigate.

Today I called the 1800 number, spent five minutes on hold then spoke to someone, told her my story and they looked up notes on our file then couldn't help, put me through to someone else who I had to repeat my story to and they couldn't help. Then finally I got through to the person I had asked to speak to in the first place. Ridiculous!

Terrible communications at every level. This includes extremely discourteous automatic email replies telling people how busy the staff are.

Phone calls are a waste of time, with long on hold times, poor and rude responses, and no receipt of call logged or provided...Emails are rarely responded to.

Long phone delays, inaccurate information, failure to return calls or emails – I have been waiting for email responses for three months now!

Further, limited administrative capacity of the NDIS has flow on effects for other organisations such as CYDA. Many young people and families have contacted CYDA because they've experienced challenges in contacting the NDIA such as not being able to get through using the phone line.

Barriers in contacting the NDIA are evidently affected by capacity and transitional issues as the NDIS rolls out. However, there currently appears to be limited systemic response or forward planning to address this issue. While CYDA notes that recently there has been improved provision of specific contact information in correspondence to some young people and families, there appears to be no overarching response to addressing difficulties in contacting the NDIA. In many cases this will require increased administrative capacity.

Additionally, CYDA has been informed of lengthy delays in accessing the NDIA, having planning meetings and having plans approved. Issues around sector readiness, such as wait times to access services and supports or limited services available such as in regional areas can also increase delays. This includes for young children for whom delaying access to supports and therapies can have significant negative impacts on childhood development. These issues have been further compounded by well documented issues with the NDIS participant portal.

It's been over three months and we've just (had eligibility) approved. It's tedious. You need a lot of mental and emotional energy to work your way through the NDIS.

It has been difficult at times (to access services) due to the huge waiting lists and inability to find staff that are willing to work in the area that we live.

I had to pay privately (for services and supports for my child) whilst waiting for NDIS approval and a planning meeting, at a cost of approximately \$5000.

I have waited several years to get into the portal!

These direct experiences indicate that increased investment in the administrative capacity is required to ensure the Scheme is responsive to the needs of participants.

Recommendation 26: The administrative capacity of the NDIA be increased, and the notional cap on administration costs be lifted for the period of transition.

PAYING FOR THE NDIS

Funding arrangements for the NDIS have been negotiated through a series of agreements between the Commonwealth and state and territory governments. Recently there has been a focus on the proposed *Savings Fund Special Account* for the NDIS by the Commonwealth.

It is critical that funding arrangements for the NDIS reflect the crucial role of the Scheme in affording the human rights of Australians with disability. In particular, it is important that the NDIS is understood and positioned as a core area of government spending. This was acknowledged by the Productivity Commission *Inquiry into Disability Care and Support*, which recommended that the “costs of supporting people with significant disability from year to year through the NDIS should be viewed as a core funding responsibility of government and met from claims on general government revenue.”⁴⁶

It is for this reason CYDA does not support the creation of an *NDIS Savings Fund Special Account* as proposed by the Australian Government. It is CYDA’s understanding that this is not a typical funding arrangement for other core areas of government spending such as health or education.

In addition, the proposed *NDIS Savings Fund* allows the Australian Government to identify savings from other areas of the budget to be placed in the NDIS Savings Fund. Funding for the NDIS will therefore be dependent on the capacity of the government of the day to identify savings according to their priorities and have them passed through Parliament. This puts funding for the NDIS in a precarious position, determined by the budget cycle. This conflicts directly with the Productivity Commission’s position that an insurance scheme requires ‘sufficient’ and ‘predictable’ funding sources⁴⁷ and that the NDIS be funded through general revenue or a levy, rather than being tied to the “annual budget cycle.”⁴⁸ CYDA strongly believes that NDIS funding arrangements must reflect the role of Scheme as crucial to the affording of human rights for people with disability and therefore not be contingent on savings identified in line with the priorities of the government of the day.

Recommendation 27: An *NDIS Savings Fund Special Account* is not created.

ADDITIONAL COMMENTS

Stakeholder Engagement

The complexity associated with the NDIS creates significant challenges in terms of stakeholder engagement for all involved, including in terms of expectations and how engagement is undertaken. NDIS decision making processes are complex with mixed responsibilities being held by different parties including the Disability Reform Council, separate jurisdictions, the NDIS Board, the NDIA and the Commonwealth Department of Social Services. Additionally, the NDIA structure is new, complex and large. This reality sits in constant tension with the need to meet the targets and goals of an extremely ambitious implementation timeline. This is rightly fuelled by an ongoing demand to deliver services and supports to people with disability as soon as possible who experience the unacceptable consequences of being denied equal opportunities and rights.

There has always been an expectation that stakeholder consultation regarding the establishment of the NDIS would be extensive. The circumstances described however make the task of stakeholder

⁴⁶ Productivity Commission 2011, *Disability Care and Support Inquiry Report Volume 1*, p. 85.

⁴⁷ *Ibid*, pp. 648-649.

⁴⁸ *Ibid*, p. 11.

consultation not only complex but endless. There is a clear need for expectations and processes of stakeholder engagement to be well defined and communicated.

While being extremely complex and challenging, stakeholder engagement is fundamental to the success of the NDIS. In particular, it will assist in ensuring that the experiences and expertise of a broad range of stakeholders can inform the Scheme and collaborative work occurs to achieve the best outcomes for people with disability.

In CYDA's view stakeholder engagement regarding the NDIS has been inconsistent and uncoordinated to date. The major issues are seen to be a lack of transparency around the operations of the NDIS and a general failure by the Agency to consult or engage with CYDA around issues of relevance for children and young people with disability.

CYDA's experience is that there is a lack of transparency and clarity around the operations of the NDIS and which personal or operational areas are responsible for different aspects of the Scheme. It has thus been difficult to proactively engage with the NDIA regarding identified problems of which CYDA members have direct experience, or about emerging policy related gaps. For example CYDA is keen to engage and contribute with the NDIA on issues regarding child safeguarding and processes within the planning phase for individual participants. Yet despite numerous requests, CYDA has been unable to obtain a copy of the risk assessment framework being used in planning for children or young people. This does not appear to be publically available, but it is an important component of NDIS processes that needs to be part of an ongoing conversation with stakeholders.

Additionally it is difficult for CYDA to obtain an overall picture of what initiatives and areas of work are being undertaken by the NDIS of key relevance to children and young people with disability. As the national peak body representing children and young people with disability, CYDA is in a unique position to offer expertise and inform of the lived experiences of children and young people with disability, yet we do not have a consistent process through which we can work collaboratively with the NDIA.

In addition, CYDA is concerned that public consultations on different aspects of the NDIS has been limited and inconsistent to date. In many cases, consultations have had very short associated timeframes, which creates barriers to organisations such as CYDA consulting with members and providing comprehensive responses.

An example was the consultation regarding the ILC framework, a significant policy document that represents a major part of the NDIS reform will impact the majority of people with disability in Australia. Consultations were invited less than one month after the release of the draft Framework and an easy read version was released late in the process. Further, the Framework and supporting information frequently used jargon and did not include definitions of key terms. Examples include 'social insurance model,' or 'systemic level' supports.⁴⁹ These terms are inaccessible for many of CYDA's members.

A further key issue for CYDA is our limited organisational capacity to deliver the volume of work required to ensure the NDIS and governments are fully briefed on the risks and benefits of various initiatives for children, young people and their families. Despite being the national representative organisation for all children and young people with disability aged 0 to 25 in Australia, CYDA has a small operational team. While CYDA has a significant output in relation to its organisational size, capacity issues have inhibited CYDA's ability to engage with the NDIS. Additional resourcing to

⁴⁹ National Disability Insurance Scheme 2015, *Framework for Information, Linkages and Capacity Building*, p. 1.

provide for a dedicated position is therefore required to ensure CYDA is able to have more extensive input and involvement in the development of the NDIS.

Recommendation 28: Review of stakeholder engagement strategy for the NDIS to ensure opportunities for input relevant to the expertise of organisations are provided.

Transitional and Structural Issues with the NDIS

The inquiry issues paper notes that at present it is “difficult to separate out transitional (short term or ‘teething’) issues from the more structural (systemic) issues that could affect the financial sustainability of the scheme over the longer term.”⁵⁰

Many of the direct experiences of children and young people with disability reported to CYDA appear to reflect transitional issues, including administrative capacity, challenges in accessing information, communication with the NDIA, and planning processes and planners. Responses to concerns raised to date have appeared often been reactive and a “temporary fix.”

As discussed throughout this submission, there appears to be limited strategies in place to ensure that current transitional or administrative issues within the NDIS do not become embedded in the structures and design of the Scheme. This inquiry provides an opportunity to highlight the systemic change needed within the NDIS to ensure temporary processes, such as the ‘My First Plan’ approach or processes for contacting the NDIA, do not become cemented into the Scheme.

Meeting the Intent of the NDIS

This submission has described a range of structural and transitional challenges currently facing the NDIS. Of key concern is that many of these issues appear to be impacting on perceptions regarding the capacity of the Scheme to meet its stated purpose and objectives, to:

- Support economic and social participation of people with disability;
- Provide reasonable and necessary supports;
- Ensure people with disability can exercise choice and control over services and supports received;
- Facilitate the development of nationally consistent disability service system;
- Promote the provision of high quality and innovative supports;
- Raise community awareness around “issues that affect the social and economic participation of people with disability;” and
- Give effect to Australia’s human rights obligations for people with disability.⁵¹

Key results from CYDA’s survey are provided below:

⁵⁰ Productivity Commission 2017, *National Disability Insurance Scheme Costs: Issues Paper*, p. 8.

⁵¹ *National Disability Insurance Scheme Act 2013 (Cth)*, section 2.3.

QUESTION	RESPONSES	RESULT %
Do you think the child or young person's human rights have been better advanced through their participation in the NDIS?	Yes	42
	No	31
	I don't know	27
Has the NDIS resulted in enhanced social and economic participation for the child or young person?	Yes	36
	No	37
	I don't know	27
Do you think the child or young person is able to access reasonable and necessary services and supports?	Yes	39
	No	34
	I don't know	27
Do you think the NDIS ensures you have choice and control over services and supports received?	Yes	43
	No	28
	I don't know	29
Is it your understanding that we are developing a nationally consistent service and support system for people with disability across Australia?	Yes	49
	No	35
	I don't know	16
Do you think that innovative and high quality supports are available and accessible to the child or young person through the NDIS?	Yes	40
	No	36
	I don't know	24
Are services and supports accessed through the NDIS different to what the child or young person received previously?	Yes	66
	No	34

CONCLUSION

The establishment of NDIS is arguably the most exciting and innovative area of social reform Australia has seen in recent history. The reasons why Australia is committed to this reform remain compelling. People with disability were "shut out" from the community largely because of the dysfunctional and inadequate service and support system of the time. Australia was failing to afford people with disability their rights and many people were denied an "ordinary life." The NDIS has already set many people on different pathways and enabled significant opportunities. It is making rights a reality for people with disability and contributing to better lives for many.

This submission discusses a range of concerns and current problems confronting the NDIS. It is hoped that this inquiry will provide an opportunity to review and evaluate what changes can be made to ensure the Scheme going forward is sustainable and meets its objectives.

The complexity and challenges in reforming existing systems and establishing the new model are massive.

CYDA remains fully committed to the reform and would welcome an opportunity to discuss the issues raised in this submission with the Commission.

SUMMARY OF RECOMMENDATIONS

Recommendation 1: Development of a rigorous work plan and outcomes framework for the implementation of the *National Disability Strategy 2010-2020* which includes clearly defined roles, responsibilities, measures, timelines and evaluation.

Recommendation 2: The *National Disability Strategy 2010-2020* and progress in meeting associated outcomes is a standard agenda item in COAG meetings, including the responsible COAG councils.

Recommendation 3: Development of a national plan for education reform and students with disability backed by strong political leadership regarding the implementation of the plan.

Recommendation 4: Inclusion of the education and NDIS interface as a regular agenda item at all COAG Education Council meetings.

Recommendation 5: Further refinement of strategies and actions to define and establish the education and NDIS interface. This needs to incorporate a mapping and future plan of relevant collaborative action and structures of relevant parties which include the NDIA, state, territory and Commonwealth governments, education authorities and relevant stakeholders including CYDA.

Recommendation 6: The development of a clear mechanism which ensures the direct experience of students with disability informs the establishment and ongoing work regarding the NDIS and education interface. This should include ongoing consultation with CYDA.

Recommendation 7: Removal of the option for education professionals to provide information about the support needs of students with disability to inform eligibility assessments unless evidence of specific expertise to make these assessments can be provided.

Recommendation 8: Work is undertaken to map the interfaces between the NDIS and mainstream areas, define relevant actions and roles of key stakeholders, including community sector peak bodies. This should inform the development of a clear, coordinated and comprehensive strategy around the development of NDIS interface areas.

Recommendation 9: Review of structure and funding of the ILC be undertaken.

Recommendation 10: Consideration of how service provision will be funded and accessed for people who are not eligible for the NDIS, given the current parameters around ILC funded activities.

Recommendation 11: Amendment of the NDIS Act to include specific principles that guide the way the NDIS applies to children. This should include ensuring that developmental and protective considerations are applied at all levels of the NDIS, including eligibility, planning and service delivery.

Recommendation 12: Considerations of how findings of the *Royal Commission into Institutional Responses to Child Sexual Abuse* will inform safeguards embedded in the NDIS.

Recommendation 13: Consideration of mechanisms to ensure available evidence and theoretical frameworks guide the practical implementation of the NDIS as it relates to young people (including those aged under 18 years), including eligibility, planning and information provision.

Recommendation 14: Development of a strategy to ensure that issues with the NDIS planning process described in this submission do not become entrenched and that planning processes are sufficiently flexible to the lives of children and young people with disability and families.

Recommendation 15: Development of clear guidance and expectations regarding the development of the plans for children with disability.

Recommendation 16: Development of clear process for ensuring child safeguarding considerations are a component of the planning process.

Recommendation 17: Removal of the requirement for all NDIS participants to have a statement of goals and aspirations (Section 33.1) from the NDIS Act.

Recommendation 18: Consideration of mechanisms to ensure NDIS review processes are timely and flexible so NDIS plans can adapt to suit the changing circumstances of NDIS participants.

Recommendation 19: Development of an information map for NDIS participants to inform participants of who accesses their personal information.

Recommendation 20: Introduce requirements for the NDIA to obtain specific consent from participants or nominees for personal information being provided by third parties.

Recommendation 21: Review and improvement of existing processes and communication of existing provision of information about complaint mechanisms regarding the NDIS.

Recommendation 22: The NDIS website is comprehensively reviewed and overhauled to ensure it provides clear information and is easy to navigate.

Recommendation 23: Additional funding is provided to independent systemic and individual advocacy organisations to have a clear role in supporting people with disability in the context of the NDIS.

Recommendation 24: Provision of information around work being undertaken to support self-management and consideration of how this can be further applied or extended to increase utilisation of this option.

Recommendation 25: Review of current governance structure and identification of areas of refinement.

Recommendation 26: The administrative capacity of the NDIA be increased, and the notional cap on administration costs be lifted for the period of transition.

Recommendation 27: An *NDIS Savings Fund Special Account* is not created.

Recommendation 28: Review of stakeholder engagement strategy for the NDIS to ensure opportunities for input relevant to the expertise of organisations are provided.

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