

DOWN SYNDROME AUSTRALIA

Submission to the Productivity Commission Review of the
NDIS Costs

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ABOUT DOWN SYNDROME AUSTRALIA

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change, and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission.

Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 15,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.¹

Down syndrome is the most common cause of intellectual disability and everyone who has Down syndrome will have some degree of intellectual disability. In the past, many people with Down syndrome have not had the same opportunities as their peers. Often, they have been separated from the rest of the community, living in segregated settings such as care institutions. Low expectations were placed on them and there were limited opportunities for learning and participation in inclusive activities.

With better early intervention and medical care, as well as the increased inclusion and integration of people with Down syndrome into society, the quality of life for people with Down syndrome has increased. Children with Down syndrome often attend childcare settings, pre-schools and primary and high schools alongside other children of their age. Adults with Down syndrome are involved in their communities including through paid employment (open or supported) and voluntary work. An increasing number are living independently, with some level of support, within the community. The life expectancy of a person with Down syndrome has increased from only 25 years of age in 1983 to approximately 60 years in 2016 due to better support and health care, with one in 10 living to their seventies.²

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¹ http://www.downsyndrome.org.au/down_syndrome_population_statistics.html

² Torr J, Strydom A, Patti P, Jokinen N. Aging in Down syndrome: Morbidity and mortality. *Journal of Policy and Practice in Intellectual Disabilities*. 2010;7(1):70-81.

EXECUTIVE SUMMARY AND RECOMMENDATIONS

Down Syndrome Australia welcomes the opportunity to provide a submission to the Productivity Commission Study into the Costs of the NDIS. Our response focuses on the issues paper and the specific questions and information which relates to people living with Down syndrome and their families. We also make some comments on the impact of the Scheme on people with a disability and their families more broadly.

The introduction of the NDIS marked a fundamental shift in how disability services are provided in Australia. For people with a disability, for the first time, it means that they have control and choice over the services that they require. Like any transformational policy, the NDIS has experienced some challenges in implementation due to the scale of change required and the rapid pace at which the roll-out is occurring. There are also a range of interface issues with how other sectors relate to NDIS and what services continue to be provided to ensure supports for people with a disability who are not eligible for NDIS packages.

Down Syndrome Australia acknowledges it is important that to ensure that Government funds are used efficiently and targeted appropriately. It is also important, however, to recognise that people with a disability have a right to appropriate supports and services. The Government has a responsibility to ensure that those supports are available, and to source the funding for those services, even if this exceeds what was initially anticipated in modelling the costs of NDIS. It is not appropriate to suggest, as was noted in the issues paper, that additional costs will lead to reducing the scope of services or rationing of needed supports.

Down Syndrome Australia has identified a range of issues which should be addressed to ensure that funding is targeted appropriately and leads to the best outcomes for people with disabilities including:

- Supporting participants and families to be well informed about the NDIS, their rights and responsibilities and how the scheme will work. This includes having access to independent advocates particularly for people with Down syndrome who are older and may not have family who can provide this important support.
- Improving the planning process so that plans are better matched to the needs of participants and the services that are available
- Ensuring appropriate resourcing of Information Linkages and Capacity Building (ILC)
- Ensuring quick access to services and supports such as Early intervention which can reduce future costs to NDIS
- Developing better communication between NDIS and Mainstream services and resolving gaps in service provision

It is essential that the NDIS is understood as one component of how people with disability are supported in Australia. The success of the NDIS is dependent on inclusive mainstream services and supports. This creates some challenges as it is not within the remit of NDIS to directly address access to mainstream services. Therefore, the implementation of the National Disability Strategy which aims to improve access to inclusive mainstream services and the broader community, will have a major impact on both the success of the NDIS and the associated costs.

Scheme Costs

Are there any cost drivers not identified above that should be considered in this study?

The analysis of drivers of costs to the National Disability Insurance Scheme (NDIS) in the Productivity Commission (PC) issue paper focused on the following:

- Access
- Scope
- Pricing
- Volume
- Delivery

The analysis provided in the paper is limited by focusing only on the cost drivers which are specific to NDIS. Further work needs to be done to measure the impact of interface issues with other relevant sectors and on access, scope, and volume. For example, access to appropriate health care, housing, education, transport, and other key community resources will directly affect what support services a person will need through the NDIS and therefore the costs to the NDIS.

Currently, people with a disability, including those with Down syndrome experience significant barriers to accessing mainstream services and community supports. This leads to feelings of social isolation and increased dependence on formal supports. It is essential that Government invest in action to achieve more inclusive communities and accessible services primarily to ensure people with disability are included in our communities but this will have a significant flow-on affect to reduce costs for formal supports through NDIS.

The implementation of the National Disability Strategy (NDS) will have a key impact on the costs associated with NDIS. The goal of the strategy is to improve accessibility of mainstream services and the broader community people with a disability. The NDS includes action to achieve:

- Inclusive and accessible communities
- Rights protection
- Economic Security
- Personal and community support
- Learning and skills
- Health and wellbeing

Significant progress on these areas has the potential to reduce costs to the NDIS in the longer term through facilitating better access to mainstream services and community activities. On the other hand, if appropriate policy changes and investment do not accompany the NDS, there will be increased costs to the NDIS.

Down Syndrome Australia is concerned about the slow implementation of the NDS. There is a need for a more robust approach to monitoring implementation which provides specific measurable, public and accessible outcomes for the NDS which would also assist in understanding how progress under the NDS is impacting on costs associated with NDIS.

In a recent survey of more than 800 families of people with Down syndrome, 30% indicated that they or the person with Down syndrome had experienced discrimination or stigma due to having Down syndrome. 34% indicated that the person with Down syndrome had been discouraged from taking part in education or social activities because of their disability. This type of exclusion leads to greater need for formal supports and subsequently a greater dependence on funding through NDIS. Some of the examples provided by families included:

- Not being accepted or allowed to participate in sporting groups or dance activities. In some cases, this was complete refusal in other cases people were made to feel unwelcome
- Being discouraged from attending mainstream schools
- Lack of appropriate supports or understanding in the workplace
- Not being allowed to take public transportation
- Health professionals not providing appropriate care because they are focused on the disability.

As an example of the impact of barriers to services we can look at the issue of access to inclusive education. There is considerable evidence regarding the benefits of inclusive education for children with disabilities including gains in expressive language, literacy skills, better reading comprehension, higher levels on tests of mathematical skills, and fewer behavioural difficulties compared to segregated students (Blackorby, Knokey, Wagner, et al., 2007; Hehir, Grindal, Freeman et al., 2016). Yet despite these benefits, many families report experiencing barriers to accessing inclusive education, with only approximately half of children with Down syndrome receiving inclusive education. The differences in educational outcomes will likely have an impact on the future costs to the NDIS.

Similarly, access to meaningful employment for people with a disability is likely to have a longer-term impact on both the costs and the economic impact of the NDIS. The NDIS has the potential for providing support for employment under the category of “finding and keeping a job”. The challenge is of course in implementation. The NDIS in Perth Hills is piloting an initiative which provides each student with a disability in Yrs 10-13 with 150 funded hours per annum in their plans to help them prepare for life after school with a focus on employment. The aim is to avoid predestined pathways to the ADEs through skill development, work experience, job readiness and volunteer roles. This model is already showing some success and could potentially be rolled out nationally. Providing this early support in transitioning to employment could have a positive impact for people with a disability, the community and the economy, reducing needs for other funded supports.

Similar examples could also be provided in terms of how access to transport, appropriate housing, and health care can all impact on the future NDIS costs. For this reason, it is essential that costing of NDIS is considered in terms of a broader context including in terms of the NDS and interfaces with mainstream services.

The success of the ILC in supporting mainstream services to be inclusive and linking people with appropriate community supports and activities also has the potential for reducing funding needed in individual plans. This, however, is dependent on appropriate resourcing of ILC which is discussed in greater detail later in our submission.

Why are utilisation rates for plans so low?

There are a range of reasons for low utilisation rates for NDIS Plans including:

- Issues around planning
- Service availability
- Family availability to facilitate to access the supports
- Communication and technological issues with accessing NDIS

Utilisation rates depend to some extent on the quality of the initial plan. Families have indicated that in some situations, planners seem to not understand the needs of the person with a disability. As a result, services are put into their plans which are not useful or appropriate, and other services which the person needs are left out. Families may choose to not utilize the component of their plan that they feel does not match their needs. This does not equate to the person not needing support, but rather that the support has been inappropriately targeted. This highlights the need for families to be supported to have a better understanding of the planning process, participants having access to independent advocacy as required and support in pre-planning. Some of the current problems may also reflect on the delay in training for some of the planners which occurred due to the speed of the roll out.

Planners also do not consider what services are available in the community. Therefore, there may be a mismatch between what is planned for and what is available.

Specific feedback from families from the ACT regarding utilization of plans is provided below.

“My son was keen on doing drumming. Funds were provided to pay for a support worker to assist him attend group glasses. But to date I have not been able to find a class that he can attend. As a result, the funds were not spent and when the plan was reviewed, these funds were removed.”

“There seems to be a disparity between what clients want and what the NDIS thinks they want. For example, they always want to put in respite care for us, ignoring the fact that respite care for a few hours on a Friday or Saturday night is impossible to find. Consequently, the allocation in D.’s plan for this always sits unused.”

“I’ve often felt that the NDIS planners really have no idea who he is or what interests him and don’t believe us when we tell him. They see a young man who cannot read, write, or talk; we see a bright intelligent young man with a cheeky sense of humour. They see a young man isolated by his lack of communication; we see a young man who loves to socialize but isn’t given the opportunity because people think he’s too hard to deal with because of his communication difficulties.”

Service availability is also a barrier to plan utilization. This may be particularly problematic in regional and rural areas where there are fewer services available. However, even in metropolitan areas finding the services that match the needs and preferences of the person with a disability can be difficult and may take some time. This means that particularly in the first few years of having a plan, the plan may not be fully utilised as families may have difficulty identifying service providers that match their needs. This issue may be less of a concern over time as the sector adapts to the new funding model.

Examples from people’s experience regarding finding services is provided below:

“It can be difficult to find age appropriate activities for people with an intellectual disability and waiting times for accessing appropriate therapists can be 12 months or more. As a result, sometimes the supports are not utilized as the activities or services cannot be sourced from the community.”

“It can take years to find a carer (we have been looking for almost 3 years since our last carer left) so an annual review shows the service hasn’t been utilized but the reality is we just can find someone our son likes and trust; we like and trust; and a carer who enjoys being with him.”

Some families have also indicated that they simply do not know where to start to look for services or how to determine what service best matches their needs and goals. This highlights the need for families to understand options to include Support Coordination within their plan to assist them in managing, coordinating and monitoring the services they need to work towards their goals.

Another barrier to plan utilisation is the availability of informal supports such as family members to facilitate access to services, supports, and community activities. In the recent DSA survey, 70% of respondents indicated that it was family members who provided the primary support in taking the person with Down syndrome to community activities as well as any therapy sessions. In some cases, families find it difficult to make full use of NDIS funding because of limitations in their ability to provide support to attend the numerous therapy sessions or activities due to employment or other responsibilities. This issue can be exacerbated if there are health issues in the family or other stressors.

“There is still a high need for the family to implement aspects of the plan, or to action them particularly therapy homework which in itself is extremely demanding, and when coupled with other health demands for a person with a disability and other family members commitments can make it a juggle. When everyone is healthy and a system is able to be set up, the plan runs smoothly. But sometimes there are hiccups, like poor health, and it can be difficult and time consuming to get back to running smoothly again. Hence there maybe times/incidences when the plan cannot be utilized”.

Some families have indicated that the difficulty they have experienced in communicating with the NDIS has been a barrier in plan utilization. This has included problems with speaking to a person due to long periods on hold as well as problems with the IT system during the roll out which created difficulty in accessing the portal.

“During 2016/17 following national roll out of scheme, it was impossible to get help from NDIA. The 1800 number was ineffective, emails had 4-month processing time, or more! Visits to NDIA office, resulted in requests to complete forms for early requests! Portal was inactive for months. Some carers & service providers were unable to access funds which created a huge backlog that has only just been cleared. During this time, it was impossible to get changes or updates to plans due to 4 month, or more, wait for requests to be processed. This alone prevented some people from utilizing plans effectively during this time.”

There is also evidence that people do not fully understand what they can access through their plans. This is largely due to issues around NDIA communications. For example, many people are unaware that once a plan is established there is flexibility about the supports that they can access through their plan. Several families have reported to us that they are under the impression that they would

need to go through a full-plan review if they wanted to use their funding to increase number of occupational therapy sessions while offsetting that by decreasing speech therapy. The lack of clarity about flexibility is exacerbated by the difficulty in being able to communicate with the NDIA. With wait-times sometimes being over an hour long to speak with an NDIA representative, often people trust their assumptions rather than checking with NDIA staff about their options.

Why are more participants entering the scheme from the trial sites than expected?

More people are entering the scheme from the trial sites now due to slow uptake in the initial roll out. Many people in the community are just starting to understand the NDIS and the potential it has in providing support. Others have never been engaged with disability services and have just accessed support through their local government or Home and Community Care (HACC) provider. This means that even within the trial site there will be people with disability who are just now starting to consider accessing the NDIS.

Down Syndrome Australia has received questions from people who are in other ways well versed in disability such as “Will the person with the disability lose their access to Disability Support Pension if they enter the NDIS?” and “Will I be forced to join the NDIS?”. These questions clearly suggest that there is a need for better communication with the community about NDIS and how it works. As NDIS rolls out and becomes a more established program, more people will look to access supports through NDIS and the entrance rates will begin to match the projections more closely.

Why is there a mismatch between benchmark package costs and actual package costs?

There is a fundamental problem with using benchmark packages to estimate actual package costs as it assumes that people with the same disability of similar ages and functional ability will have the same support needs. There is wide variation in the needs of people with the same functional disability. This is due to a range of social, inter-personal, health and situational factors which impact on the need for support. For example, it is not surprising that someone with limited family supports and who is socially isolated would require more supports than someone with the same functional impairment but who has a large social network and a range of informal supports. In addition, factors such as dual diagnoses, health conditions and differing functional abilities will all impact on package costs. The various individual differences between people who have the same disability mean that using a bench-marking approach to estimate funding is problematic. As a result, planners take these factors into account and adjust the actual package costs.

Within the area of early-intervention, the mismatch is in part due to the use of an inappropriate tool to measure the need of children for early-intervention. The PEDICAT which is currently used to identify the benchmark package costs for early-intervention measures functional ability in three domains: Daily activities, Mobility and Social-Cognitive. It does not, however, measure the need of the child for early-intervention services or the potential impact that early-intervention might have on reducing future disability.

To provide an example, the PEDICAT does not distinguish between the abilities of a child who is non-verbal to a child who can speak if the child can use other ways to communicate. For a young child, who has the potential to improve language skills with the assistance of early-intervention, this approach to assessment is not appropriate. As a result, planners are making adjustments to packages to reflect the need for early-intervention based on reports and assessments by professionals.

There are also questions about some of the other tools being used for assessment of people with Down Syndrome. There is a need to work with researchers and consumer organisations to ensure that the tools being used are providing the information required to develop an appropriate package for the individual. With more accurate assessment, planners will need to make fewer adjustments and the benchmarking will more closely match the actual package costs.

Scheme boundaries

To what extent have the differences in the eligibility criteria in the NDIS and what was proposed by the Productivity Commission affected participant numbers and/or costs in the NDIS?

As outlined by the Issues Paper, the only changes to the eligibility criteria included:

- the extension of the disability requirements criteria to include substantially reduced functional capacity to undertake the activities of learning or social interaction (the activities proposed by the Commission were mobility, self-care, self-management, communication)
- the inclusion of children with a developmental delay under the early intervention requirements.

It is likely that the changes in eligibility criteria has had significant impacts on the number of participants and the initial costs to the NDIS. However, these costs must be considered in terms of equity of access as well as issues of longer-term investment and reduction in future disability.

People with disabilities whose primary impairment relates to learning and social interaction have the same rights to support as other types of disability. The functional impact of these types of disabilities can be just as severe as an impairment in mobility or self-care. Despite any increase in costs, it would be inequitable to exclude this group from NDIS and these costs must be accepted as the cost of providing reasonable and necessary supports to people with a disability.

With regards to developmental delays, there is considerable evidence highlighting the benefits of early intervention for children with delays. Although early intervention programs and services may initially result in an increase in costs, there is ample evidence indicating the long-term benefits for people with disabilities, reduced reliance on other systems including health and disability, and the need for expensive remediation efforts in later life (Center on the Developing Child, 2007; Shonkoff & Phillips, 2000). Therefore, inclusion of children with developmental-delays within the Early Childhood Early Intervention program is a sensible approach and will potentially reduce future costs to the NDIS.

Is the Early Childhood Early Intervention (ECEI) approach an effective way to ensure that those children with the highest need enter into the NDIS, while still providing appropriate information and referral services to families with children who have lesser needs?

The ECEI approach is an effective way to link families with early intervention providers and to ensure that children with the highest need get access to the NDIS. The challenges around this approach relate to communication and timely access. We have received feedback that families are confused about what ECEI means for them and for children who receive access to NDIS through ECEI when do they transfer to being a full NDIS Participant.

Perhaps more concerning, however, is the significant delays in access to support that many families are experiencing. For example, we have received reports about families waiting up to 9 months between first putting in an application to NDIS to receiving Early Intervention supports. This delay is significant if the child is unable to access services privately and can have an impact on the longer term functional outcomes for the child. Such delays also impact negatively on parent and family

wellbeing, mental health and coping. Children with significant delays should be granted immediate access to appropriate early intervention therapies while the formal planning and assessment process commences in order to ensure that during these critical early years, children have the support they need to reach their full potential.

We know that early intervention in infancy and early childhood is integral in giving children with disabilities or developmental delays the best start in life (KPMG, 2014). There is also considerable evidence regarding the economic benefits of early intervention. These benefits include improving educational, health and wellbeing outcomes for people with disabilities (KPMG, 2014; RACP, 2013). Early intervention with children who have developmental delays or disabilities has a number of flow on effects including educational attainment, earnings, and government savings through higher tax revenues and reduced spending on social welfare (Doyle, Harmon, Heckman & Tremblay, 2009; RACP, 2013).

There is also mounting evidence indicating that investing in early intervention programs may reduce the costs of interventions for people with disabilities in later life thus reducing pressure on other systems such as health and disability (Center on the Developing Child, 2007; Shonkoff & Phillips, 2000). However, it is essential that access to early-intervention is timely. The delays in access that some families are currently experiencing could in fact lead to increased costs to the NDIS later in the child's life.

Intersection with main stream services

There is currently a lack of clarity regarding demarcation of responsibilities, both for participants and families and for mainstream service providers. Discussions and questions on the NDIS and Me (Facebook group) and on other Facebook groups, show that participants and families are unsure what could be included in a plan and what is excluded as it is part of mainstream service responsibilities. This is especially so regarding education supports – it isn't clear what is the responsibility of education departments and what may be covered by NDIS.

Better communication on the boundaries between information for participants and families including examples and case studies would help people to understand the demarcation of responsibility. Good pre-planning assistance would help to weed out the ineligible supports before the plan is developed. Planners or LACs could help people seek those supports from the appropriate source/mainstream provider.

The challenge is that in many cases NDIS Planners are taking the view that the NDIS should have nothing to do with mainstream services. But at the same time, people with disabilities are having difficulty accessing those supports. For example, people with various kinds of disabilities frequently raise queries and concerns about not getting things in their plans because planners say it is the responsibility of health services. There have been some media stories where people seem to fall between the gap – not eligible for NDIS, but can't get what is needed from health services.

In education, some families are being told by NDIS that a support is the responsibility of the education department, but then the department declines to provide the support, saying it is their view that it is not the appropriate support for the child. An example of this is a young teenager with rapidly diminishing vision wanting to learn Braille. It is the responsibility of the education department but they say that because the child still has some sight they will not provide tuition.

NDIS says it is the role of the education department.

If ongoing gaps continue to emerge and are not addressed, these will lead to additional costs to the NDIS as well as worse outcomes for people with a disability. The example above illustrates how the shifting of responsibilities can lead to people unable to access supports that could reduce their need for formal NDIS supports in future. Part of the solution is to support families to be informed and understand their rights. There also needs to be a clear approach to monitoring areas where gaps are emerging and providing appropriate recourse for families who are being told that neither system can provide the appropriate services or supports.

Without access to mainstream services including housing, health, transport, education there will be increased demands and costs to the NDIS. This is where it is imperative that the intersection between NDIS and the National Disability Strategy be considered. The NDIS will only be successful if it is one part of a larger strategy to improve supports and access to services for people with a disability. Feedback from families suggests that currently this is not the case.

How will the full rollout of the NDIS affect how mental health services are provided, both for those who qualify for support under the scheme and those who do not?

People with Down syndrome have about a 30% incidence of a co-morbid mental health condition (Mantry et al., 2008). They often have difficulties accessing mainstream mental health services as some mental health providers are of the view that these individuals should be supported by disability services. Disability services often do not have the expertise required to provide appropriate support. Thus, people with Down syndrome often have difficulty getting the supports they need to address mental health concerns. A dual diagnosis such as this can have a significant impact on the person's capacity in self-care, independence, learning, employment and their support needs will increase. If untreated, this becomes a chronic situation.

Untreated mental health concerns will have an obvious impact on the supports in their NDIS plan, leading to increased costs. If mainstream mental health services were more responsive to people with intellectual disability this would lessen the cost to NDIS. This is an area that must be examined, not only for the cost implications but importantly for the person and their family/carers, all of whom will be affected practically, emotionally, and economically if the person has a chronic mental health condition.

Is the range and type of services proposed to be funded under the ILC program consistent with the goals of the program and the NDIS more generally? • What, if anything, can be done to ensure the ILC and LAC initiatives remain useful and effective bridging tools between services for people with disability?

The Information Linkages and Capacity Building (ILC) stream of NDIS is key to the sustainability and equity of the scheme. It is estimated that approximately four million Australians have some sort of disability and only approximately 10% will receive support through NDIS. The NDIS will only achieve its goals if it is built upon the foundation of access to mainstream services. ILC aims to achieve this through providing information, linkages and capacity building.

The ILC Outcomes Framework was built upon comprehensive consultation with people with disabilities and families, including those in the Australian Down syndrome community. DSA believes the framework provides a good balance between capacity building for individuals and a focus on helping to build an inclusive community. This will benefit both people who are eligible for funded

plans (such as people with Down syndrome) and people who are not, but still need some support and improved access.

The ILC is crucial to realising the NDIS vision – funded plans for eligible people alone will not do this. Peer support organisations, such as Down syndrome organisations, are the most effective and economically sound way of helping people to build their capacity. Peer organisations are close to people – often from birth or (even earlier for some families of children with Down syndrome), understand the issues from a lived experience perspective, have great knowledge of resources, relevant services, and strong networks. Peer organisations have always provided this kind of capacity building support, and are also good at operating within modest budgets to achieve quality outcomes.

Well targeted and peer-organisation delivered ILC capacity building support will have a positive impact on people's skills, confidence and independence and help the community to be more inclusive and accessible. Long term this has the potential of lowering costs of formal supports in participant plans.

Peer support organisations, such as Down syndrome organisations have also traditionally been involved in community education for teaching staff, health and allied health professionals and child care workers, as well as community sporting groups and employers. This expertise means that the local organisations are well-placed to deliver community capacity building services through ILC.

The implementation of the framework, however, is dependent on adequate resourcing. Under full roll out, only \$132 million is being allocated to the ILC. This is equivalent to approximately \$30 to provide services to each person with a disability as well as to support mainstream services in capacity building. Without appropriate levels of funding, ILC will not be able to achieve the vision set out in the ILC Framework and provide the services and supports needed by the broader disability community and mainstream services. The other challenge is that the ILC will be based on time-limited project funding. This means that while there may be some good ideas implemented there will be issues around sustainability and ongoing support.

There is also a need to develop the correct balance of funding between Local Area Coordinators who provide generalist advice and linkages and specialized disability organisations which provide disability specific advice. People with a disability usually turn to their relevant disability organization (e.g. one of the local Down Syndrome organisations) for information about the NDIS and linkages to supports. If people with a disability are not interested in seeking more generalist advice from LAC's and continue to seek support from their specific disability organisations the resourcing requirements need to be met.

Planning Process

Is the planning process valid, cost effective, reliable, clear and accessible?

The quality of planning for NDIS participants is highly variable, with some families reporting good experiences and others frustrated by NDIS Planners and Local Area Coordinators who have little understanding of Down syndrome and are not responding to the needs expressed by families. Within the initial trial sites, people generally said the planning process was appropriate and clear. However, changes which were implemented as part of the larger scale roll-out such as My First Plan and phone based planning meetings and information gathering created confusion and concerns for many people.

There was a lack of communication with participants about the changes to the planning process which occurred in the transition from trial sites to roll-out. Some people said they didn't realise that a phone call was their planning session, that it came 'out of the blue' and they weren't prepared. Many families feel that planning over the phone is not appropriate and does not enable them to provide a full picture to the planner of their experiences and needs. Although the agency has indicated that people still have the option to have face to face meetings, many families were either unaware of their options or felt that they were coerced into having phone meetings as they were told there would be a significant delay in getting the plan completed if they insisted on a face to face meeting.

We also know of people with intellectual disability who were contacted by phone for a plan review by a planner who did not know the person (but who did have their file). The person with intellectual disability agreed they were happy with their plan being continued as is; however, the person's parents and support coordinator did not know about this phone call. It then took several face-to-face meetings to ensure the person had a plan that reflected considerably changed needs.

Some of the recent difficulties with planning may be issues around adequacy of training for LACs and NDIS Planners. It was recently revealed that only one-third of the LACs had been trained by late June. This is in part due to the rapid implementation of the NDIS but is a significant concern as if the initial plan is not done well it has flow on affects to implementation and utilization of supports.

In a recent national survey by Down Syndrome Australia, feedback on the quality of planning was mixed with an average star rating of 3.4 out of 5. Nearly a third of participants were unhappy or were unsure about the outcome of the planning session. Specific feedback is provided below which outlines some of the concerns expressed.

"We live in one of the initial trial sites. First planning meeting was great, 2nd even better, 3rd an absolute horror. The planner had no concept of what the NDIS is about and was mostly concerned with getting my son back in to a day program. That was just the tip of the iceberg."

"The planner didn't listen to my concerns, plan was about what he thought not what we wanted and didn't have supporting documents with him to refer to."

"We are into our second plan, both plans had to be reviewed first one as the planner was a bully and the second as he didn't listen to anything. We went to both meetings fully prepared, the process has caused significant mental health issues for both my daughter and myself"

"The NDIA agent was a lovely lady but she seems to have made it sound like everything is going so well that I barely need any help and the Plan made no sense to me. I am a single mother with 4

children, all of them 6 and under. Closest family member is over an hour away and she wrote that I have plenty of support. I do not and even DSSA is over an hour away.”

“Different planners are very different to deal with and seem to follow different criteria. However, they were both pleasant to deal with and seemed to be trying hard to be helpful. The planner we met with for our younger son commented that she didn't really know much about Down syndrome! Also the 2 plans were 7 months apart and terminology and procedures had changed markedly in that time.

“LAC not as knowledgeable about either disability (DS in particular) or NDIS as I would have liked. meeting was too long. My son just about fell asleep. LAC did not notice.”

“Our review planner hadn't read our case file, not even the summary stating the family situation and number of siblings, or the equipment requests from therapists that had been sent ahead. This was very disappointing and caused us some anxiety because the planner did not understand our needs.”

How could the Planning process be improved?

The planning process can be improved by ensuring that Planners are well trained and have a good understanding of disabilities. It is essential that they are trained to actively listen to families and respond to their needs. At the same time, there is also a need to ensure that participants and their families are well-informed and well-prepared, so that they know how the process works, what is covered by NDIS, what is reasonable and necessary and what their rights are. More resourcing needs to go into building this knowledge and capacity, especially via peer support organisations. Having well prepared participants will be cost effective, producing better plans and minimising reviews and appeals.

It should be made clear to families that planning by phone is an option, and not the default option. Families should not be told that choosing to have a face to face meeting will have a negative impact on the timeliness of the outcomes. This is especially important for people with intellectual disability, to give time to prepare, have the support of family or an independent advocate and to ensure better communication and understanding. Similarly, there should be processes in place to ensure reviews are carried out correctly, involving both the person with the disability and their advocates.

How should the performance of planners be monitored and evaluated?

As part of the performance monitoring and evaluation, people with a disability and their families should be invited to provide input and feedback on their planning meetings. This should include input on a range of performance measures including knowledge about disability, listening to the needs of the person with a disability, responsiveness to concerns and satisfaction with the outcome. Without including the perspective of the person with disability, a true measure of the effectiveness of the planner will not be possible. In addition, it would be appropriate in some cases to consult with service providers or therapists to determine if they think the plan that has been put in place recognizes the needs of the client. The number of plan reviews requested should also be considered as part of the evaluation.

Are the criteria for participant supports clear and effective? Is there sufficient guidance for assessors about how these criteria should be applied? Are there any improvements that can be made, including where modifications to plans are required?

The criteria for participant supports themselves, as listed, seem clear and simple, but for people with Down syndrome and their families, some support will be required to put them into place, particularly with first plans. People could be helped to understand the criteria with examples of what kinds of supports are considered to be effective, value for money and so on. Some of the things that people query regarding the criteria have included:

- Not understanding that they aren't able to get funding for 'therapies' that are not evidence-based, when the person or family believes they are beneficial;
- Not getting funding for assistive technology such as iPads because planners say that 'all families buy their children iPads', when an iPad for a child with Down syndrome is a learning tool and communication device (and, if a parent can't work due to caring role an iPad may not be affordable);
- Not getting funding for swimming or other fitness fees, because planners say these are costs for anyone, when in fact for many people with disability regular fitness is crucial to improving and maintaining their capacity to function; and
- Participants and families comparing funding and questioning significant disparities that don't seem to have a clear reason.

DSA does not know if assessors receive sufficient guidance about applying the criteria, but based on feedback from families we believe it is likely that they do not have an adequate understanding of each type of disability to inform their decisions. Low societal expectations for people with Down syndrome (and intellectual disability generally) could be an unconscious contributory factor to people not always getting the level and/or type of supports they need. Expert advice from DSA could be useful for training and advising assessors and as part of advising when reviews are sought or appeals lodged.

To what extent does the NDIA's budget-based approach to planning create clear and effective criteria for determining participant supports?

The budget based approach provides participants with choice and control, while applying a lens that considers equity and scheme sustainability. As the scheme rolls out, analysis of the plans, funding and outcomes for different cohorts should inform these kinds of questions regarding equitable outcomes and how to uphold equity and best possible outcomes. The Down syndrome community would seem to be a suitable cohort to participate in this kind of analysis, having significant numbers of people with relatively similar kinds of goals and support types.

Are the avenues for resolving disagreements about participant supports appropriate? How could they be improved?

The internal review process seems to be a simple and effective way to address concerns about supports in the plan. However, it appears that people are not well enough informed about their rights to ask for an internal review within the timeframe. This is problematic as the agency often points to a low percentage of plan reviews as indicating satisfaction with the planning process when in fact it may represent a lack of knowledge about how to resolve concerns about a plan.

While the internal review process is an important recourse, it should not be seen as a replacement for good planning in the first place. Reviews are stressful to participants and families, and delay

people getting timely, appropriate and adequate supports. Reviews are also an additional cost to the scheme. Similarly, appeals processes are stressful, delay support provision and cost the scheme more. If better initial planning is done, it will reduce the number of appeals. Well informed planners and well-prepared participants and families will help to improve the processes over time.

Market Readiness

How well-equipped are NDIS-eligible individuals (and their families and carers) to understand and interact with the scheme, negotiate plans, and find and negotiate supports with providers?

As noted in previous responses, many people are ill-equipped to interact with the scheme and do not have a basic understanding of the NDIS. Our recent survey of families of people with Down syndrome only approximately 50% of people indicated they understood the NDIS and what it meant for getting access to supports. There is a need for further support and information for families to undertake the complex tasks of interacting with the scheme, negotiating plans, and finding appropriate supports. Families have indicated that they need broad information about the Scheme as well as detailed local information about where to access the best services and supports for their needs.

DSA and Down syndrome organisations in states and territories have been working to inform and equip people with Down syndrome and their families, but are not adequately resourced to meet the scale of need for information, advice and advocacy for around 15,000 Australians with Down syndrome, their families and carers. The NDIA's DSO project provided some funding in Victoria, NSW, and WA to develop peer support networks; however, this funding was not provided to Down syndrome organisations in the other states and territories. As the initial and ongoing peer support organisations for the Down syndrome community, they are dealing with people's queries as best they can. Down syndrome organisations are well-placed to equip people to interact with the scheme, negotiate plans and find appropriate supports, and should receive ongoing resourcing to be able to do this.

Paying for the NDIS

How should the financial sustainability of the NDIS be defined and measured? • What are the major risks to the scheme's financial sustainability?

Lack of understanding of the transformative potential of the scheme is the key risk. The NDIS vision has not been understood or grasped by many parliamentarians and by the public. Too often, discussions about the NDIS in the media is about the costs, and rarely about the benefits. It is still seen as being about people with disabilities, not as being a scheme for all Australians. Recent moves to shift funding from one area of the federal welfare budget to help fund the NDIS highlights the prevailing political mindset that must change.

The benefits to people with disability and the wider community must be highlighted and measured, especially including greater socio-economic participation. We need to be looking at how well the NDIS is enabling this important aspect that was forecast by the scheme's architects and the Productivity Commission. If it is not doing as well as predicted, we need to understand why, and address this. If it is going well, this needs to be promoted to show the scheme is working and encourage greater participation and community inclusion.

There also needs to be ongoing monitoring of the costs associated with delivery of the NDIS in remote areas. Although some of these costs are accounted for through a specific remote pricing guide, costs associated with travel may not be fully accounted for currently. Further work needs to be done to continue to monitor these costs and ensure equitable access to the scheme regardless of participants' location.

Another key risk is the under-estimation of numbers of eligible participants and a lack of understanding of certain disability cohorts, by disability type, age, location, ethnicity and culture. This has already been seen in some trial sites, with enormous impact on scheme roll out and costs. In WA, the number of likely eligible participants is being disputed by the Disability Services Commission. They say there will be 39,000 participants in WA, whereas the NDIS and Productivity Commission, using ABS statistics and other reputable measures including how many people have joined the scheme in other jurisdictions, say there will be around 50,000 – a significant difference with massive potential over run costs. Similar difficulties with estimation of need has been identified within the early intervention component of the scheme in the trial sites as well.

It is critical that these errors in estimates of need are not used as a justification to cut supports through the scheme. Instead it needs to be acknowledged that due high-levels of unmet need in the community, these estimates will need to be refined.

Are there other ways the scheme could be modified to achieve efficiency gains and reduce costs?

In this submission, we have identified several issues which could be addressed within the scheme to achieve greater efficiency and ensure that resources are appropriately targeted. These have included:

- Supporting participants and families to be well informed about the NDIS, their rights and responsibilities and how the scheme will work
- Improving the planning process so that plans are better matched to the needs of participants and the services that are available
- Developing appropriate review process for planners and ensuring input from participants and families

- Ensuring appropriate resourcing of ILC to enable local disability organisations to provide information, linkages and supports on an on-going basis
- Ensuring quick access to services and supports such as Early intervention which can reduce future costs to NDIS
- Monitoring the implementation of the National Disability Strategy and the interaction between the Strategy and NDIS
- Ensuring better communication between NDIS and Mainstream services and resolving gaps in service provision

DSA acknowledges the importance of ensuring that limited funds are used most effectively. It is also important to recognise that people with a disability have a right to appropriate supports and services. The Government has a responsibility to ensure that those supports are available, and to source the funding for those services, even if this exceeds what was initially anticipated in modelling the costs of NDIS. It is not appropriate to suggest, as was noted in the issues paper, that additional costs will lead to reducing the scope of services or rationing of needed supports.

The Western Australian situation

Down Syndrome Australia, as a federation of state and territory Down syndrome organisations, has advocated strongly for WA to be part of the national scheme. DSA is very concerned that people with Down syndrome in WA will not get an equitable level of support, nor the choice and control nor long-term certainty of the national scheme.

Our concerns include:

- While the WA Liberal Government (now no longer in government) claimed that the WA scheme would offer the same eligibility and portability of the NDIS, there are worrying signs that this may not be the case.
- The operational differences of the WA scheme are such that they reduce people's choice and control.
- The budget limit focus of LCs doing planning means people are not always getting the supports they need – people have reported getting a lower band of therapy funding than was professionally recommended. They have been told to rely more on informal supports, which may not be feasible, and does not support the ability of informal carers to be part of the workforce and community. This has implications in terms of the effectiveness of the scheme in promoting economic and social engagement.
- In-kind supports and budget-holder organisations in the WA scheme limit choice, result in sub-standard support due to no competition, and do not enable a market and competitive pricing to develop.
- The operational differences do not support the development of the provider market in the way the NDIS is doing. The Disability Services Commission favours certain providers and distributes funding accordingly. The Commission is currently offering block funding to organisations to enable them to operate in certain areas as the scheme rolls out.
- These aspects of the WA scheme have significant cost implications as well as disadvantaging WA participants and their families.
- The ILC initiative in WA that was recently opened to EOIs focused purely on people who are eligible or likely to be eligible for individually funded plans. The EOI did not reflect the national ILC Framework, which many Western Australian people and their families were consulted on along with people across the country. The then government and the Disability Services Commission included the planned development of a separate WA ILC framework. We do not know if this will include the critical focus on building both individual and community capacity.

Further to these effects on participants, the market and the wider community in WA, having a separate scheme sets a precedent for other states and territory governments to decide to opt out of the NDIS, threatening the whole scheme for all Australians. DSA believes WA should stay under the federal NDIS legislation to ensure Western Australians with Down syndrome and their families are not disadvantaged in any way compared with those in other jurisdictions.

References

- Blackorby, J., Wagner, M., Levine, P., Schiller, E., & Sumi, C. (2007). *What makes a difference? Influences on outcomes for students with disabilities* (pp. 1-25). Menlo Park: SRI International.
- Center on the Developing Child. (2007). *A Science-Based Framework for Early Childhood Policy*, Cambridge, MA: Harvard University. Retrieved from http://46y5eh11fhgw3ve3ytpwxt9r.wpengine.netdna-cdn.com/wp-content/uploads/2016/02/Policy_Framework.pdf
- Doyle, O., Harmon, C. P., Heckman, J. J., & Tremblay, R. E. (2009). Investing in early human development: timing and economic efficiency. *Economics & Human Biology*, 7(1), 1-6.
- Hehir, T., Grindal, T., Freeman, B., Lamoreau, R., Borquaye, Y., & Burke, S. (2016). *A Summary of the Evidence on Inclusive Education* (pp. 1-40). Brazil: Institute Alana.
- KPMG. (2014). Early childhood intervention – an overview of best practice. Retrieved from http://www.communityservices.act.gov.au/_data/assets/pdf_file/0007/635695/Early-Intervention-Best-Practice.pdf
- Mantry, D., Cooper, SA., Smiley, E., Morrison, J., Allan, L., Williamson, A., & Finlayson, J. (2008). The prevalence and incidence of mental-ill health in adults with Down syndrome. *Journal of Disability Research*, 52(2), 141-55.
- Royal Australasian College of Physicians. (2013). Position statement – early intervention for children with developmental disabilities. Retrieved from <https://www.racp.edu.au/docs/default-source/advocacy-library/early-intervention-for-children-with-developmental-disabilities.pdf>
- Shonkoff, J. P. & Hauser-Cram, P. (1987). *Early intervention for disabled infants and their families: a quantitative analysis*. *Pediatrics*, 80(5), 650-658.
- Shonkoff, J. & Phillips, D. (eds.) 2000. *From neurons to neighbourhoods: the science of early childhood development*. Washington DC: National Academy Press.