



**Submission
to the Productivity Commission
on
National Disability Insurance Scheme
(NDIS) costs**



27/3/2017

Introduction

Autism Aspergers Advocacy Australia, known as A4, appreciates this opportunity to make a submission to this study into the National Disability Insurance Scheme (NDIS) costs.

A4 suggests that potentially the NDIS will contribute more to the Australian economy than the cost of services and supports for autistic people, provided

- a) the NDIA adopts best practice for autistic people, and
- b) long-term costs and benefits are considered.

Community expectation for the NDIS are very high after the Productivity Commission “found that Australia’s system of disability supports was inequitable, underfunded, fragmented, inefficient and gave people with disability little choice and no certainty of access to appropriate supports (PC 2011).” The creation of the NDIS created the expectation that these issues would be solved.

The 2015-16 NDIA Annual Report says ...

‘For the first time, Australians will have access to a national scheme that will support people with disability, providing certainty, consistency and equity.’

David Bowen, NDIA Chief Executive Officer

In the following, A4 shows that the NDIS has enormous potential however many of the expectations for the NDIS are not being realised for autistic Australians. The main reason is that the NDIA has poor responses for autistic people as it failed at the outset to engage with the Autism Spectrum Disorder (ASD) community ... and continues to exclude and ignore the ASD community from policy development and planning. The NDIA’s refusal to recognise and respect ASD as a distinct disability means that currently the NDIS does not provide “certainty, consistency and equity” for autistic NDIS participants. The ILC provide is not designed to provide actual services and supports for autistic Australians who are not NDIS participants at the Tier 3 level ... so those autistic Australians will not experience the “certainty, consistency and equity” that they need.

About autism spectrum disorder

The diagnostic criteria for *Autism Spectrum Disorder* are given in the *Diagnostic and Statistical Manual of Mental Disorders, fifth edition 2013* (known as the DSM-5). ASD is a *disorder* that is described in a manual of disorders. The diagnostic criterial say that a person with ASD needs support.

ASD is a spectrum disorder. There are a number of different aspects to ASD and autistic people vary across a spectrum in each aspect.

The DSM-5 classifies ASD as a *neurodevelopmental disorder*. The previous edition, the DSM-IV, classified several disorders including Autistic and

Asperger's Disorders, as *Pervasive Developmental Disorders*. These were sometimes called autism spectrum disorders (plural).

When it was published, the DSM-5 combined the autism-related disorders into one spectrum diagnosis called *Autism Spectrum Disorder* (singular).

The neurology and etiology of ASD are unknown. The genetics of ASD are essentially unknown ... but are known to be complex.

On the prognosis for autistic people, the DSM-5 says

Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naïve and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression. Many adults report using compensation strategies and coping mechanisms to mask their difficulties in public but suffer from stress and effort of maintaining a socially acceptable facade.

The Australian Bureau of Statistics (ABS) reports that its *Survey of Disability Ageing and Carers* estimated in 2009 and 2012 that over 70% of autistic people had severe or profound disability (down from 87% in 2003). The remaining 30% of autistic people had mild or moderate disability. The number of autistic children up to 16 years and with a formal ASD diagnosis age registered with Centrelink for Carer Allowance (child) was similar to the ABS estimate of severe or profound autism in Australia.

Note that the DSM-5 diagnostic criteria for ASD require the person in question has support needs. People who do not need support, who only need "acceptance" for example, do not meet the DSM-5 diagnostic criteria for ASD. These people are not autistic; they belong to a broader class that is increasingly called "neuro-divergent".

Indications are that initial estimates of the number of autistic NDIS participants, especially children, was turned out to be "conservative". A report in 2011 said

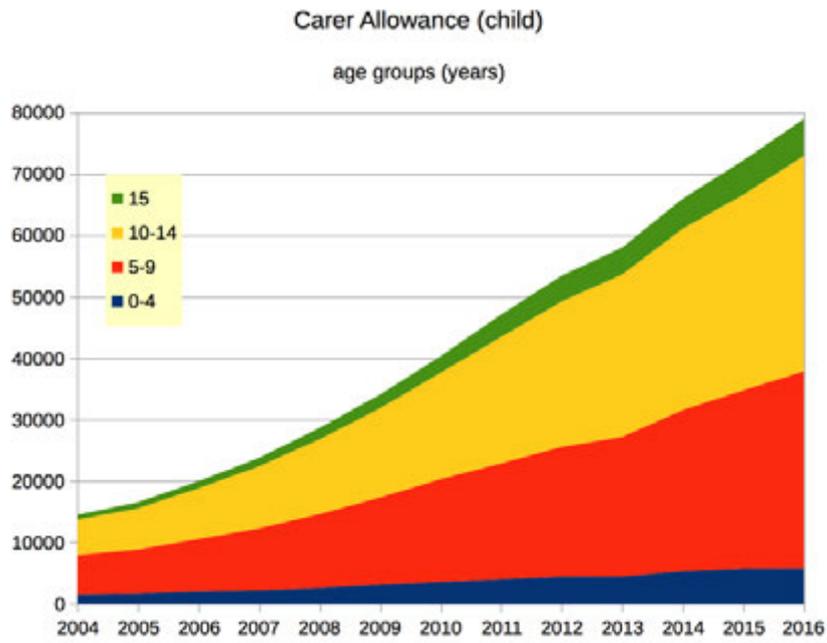
Every 7 hours, an Australian child is diagnosed with an autism spectrum disorder.

This estimate was about 25% of the autism diagnosis rate at the time (see [Disability report chronically underestimates ASD diagnoses](#)). As the NDIS trial progressed, it became increasingly clear that more autistic participants had emerged than governments and the NDIA had predicted.

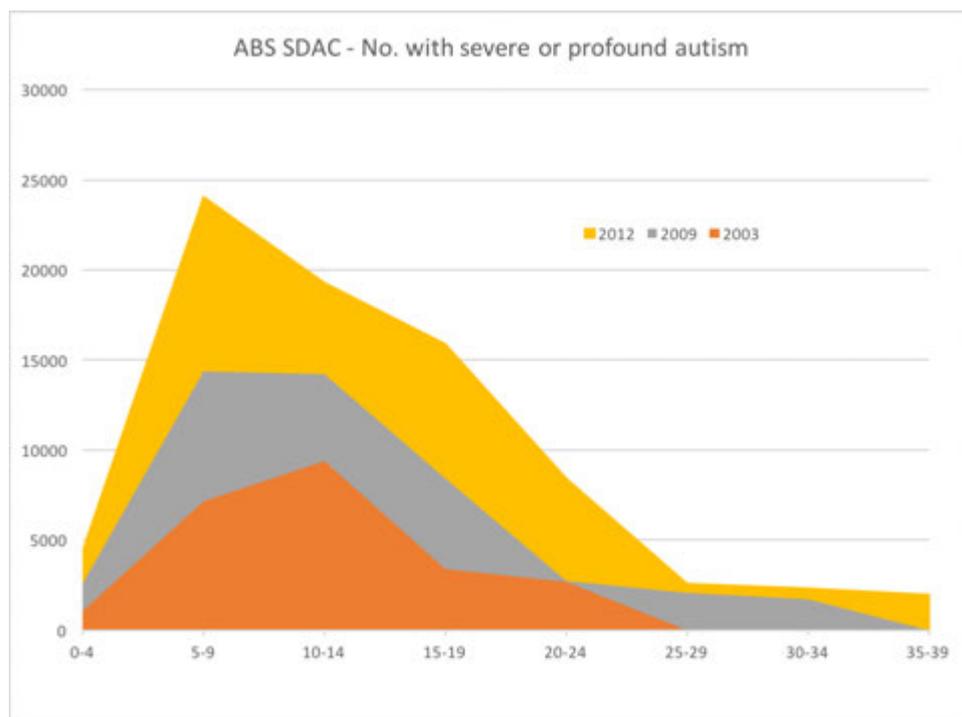
The designers of the NDIS convinced themselves that growth in autism numbers was due to the introduction of the Government's *Helping Children with Autism* (HCWA) package for autistic children up to 6 years of age in 2007. Officials told an A4 member that introducing the HCWA package caused the growth in autism numbers. A4 regards this conclusion

as *unlikely*, since ASD numbers are increasing worldwide, mostly affecting people who are oblivious to HCWA, and the increase started well before HCWA was envisaged.

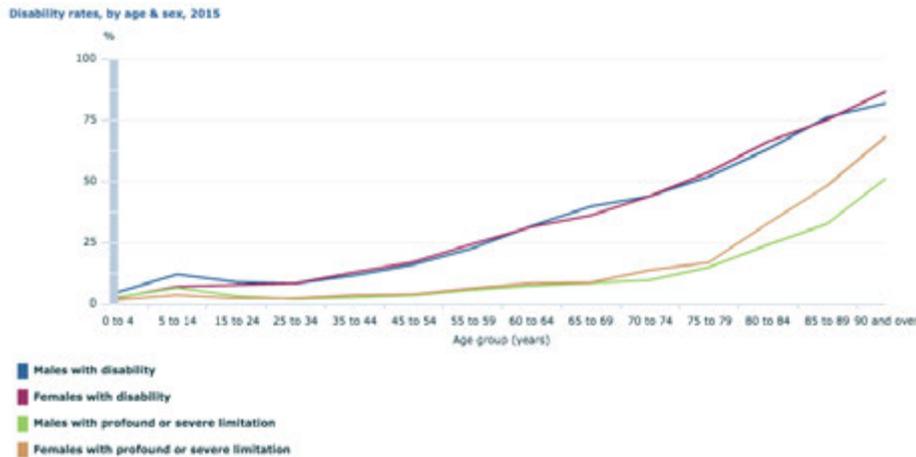
Increasing numbers of ASD diagnoses is a fact. The following shows the growing number of autistic children whose families receive Carer Allowance (child) from 2004 to 2016.



The following figure shows the ABS's estimated number of autistic people whose disability is rated severe or profound; moderate and mild autism is omitted from the figure. These data show especially strong growth over time in the 5-9 year age group.



The age distribution of autistic people in these data is very different from [the age distribution of disability generally](#).

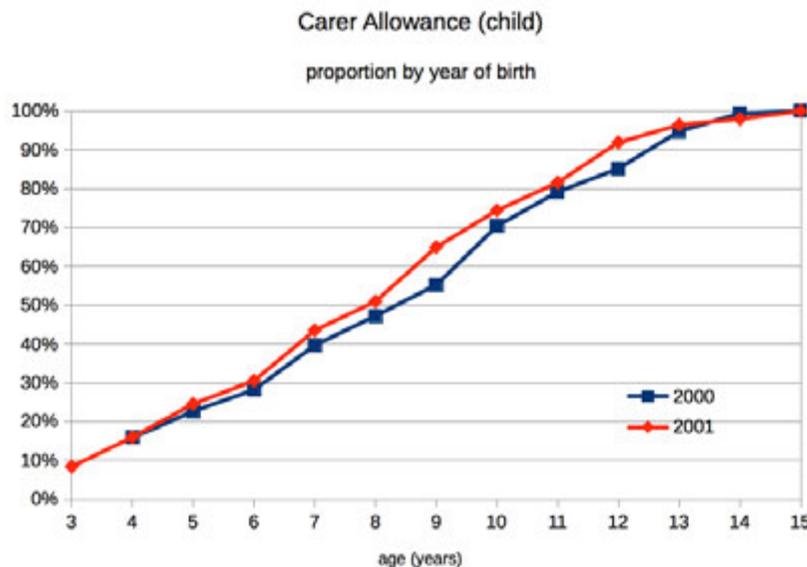


Government officials, the NDIA and some researchers claim that actual ASD prevalence is stable at around 1% of the population. If this is true then it means that in 2016 clinicians chronically over-diagnose of ASD in Australian children; on this basis, 3 in 5 children diagnosed formally with ASD are misdiagnosed. At the same time, clinicians severely under-diagnose autistic adults.

A4 cannot discern real NDIA recognition that the number of autistic NDIA participants is increasing significantly.

With plan costs staying the same and autistic numbers increasing, the overall cost of the NDIS increases. Increasing NDIS cost is inevitable.

Sadly, most autistic people are diagnosed too late to access government funded early intervention for their ASD. The age pattern of ASD diagnoses for children exiting from Carer Allowance (child) in 2015 and 2016 is shown below. Around 30% are diagnosed before age 7 years when they become ineligible for federally funded early intervention.



Recently, the AMA expressed concern about late diagnosis of ASD (see [AMA: Early diagnosis and intervention essential for children with ASD](#)). A4 will be very interested to see whether AMA interest can reduce the age of typical diagnosis.

A4 is concerned that the NDIA's ECEI Approach apparently avoids ASD diagnosis. Diagnosis is not mentioned in the pathways that the NDIA describes.

Questions from the Issues Paper

People have little understanding of what “insurance principles” means. The consequent confusion and uncertainty is difficult for people with disability, their carers and associates.

Similarly, people generally are concerned that they do not understand what the Government and the NDIA mean by “reasonable and necessary”. Its open to interpretation. This seems to be a key phrase, but it is devoid of meaning.

People in the ASD community are disappointed that the NDIA has particularly poor understanding of the distinct nature of ASD, and of the evidence related to best practice early intervention for autistic children.

Following are discussion and answers to questions that the Productivity Commission asked in its Issues Paper February 2017.

- *Are there any cost drivers not identified above that should be considered in this study? If so:*
 - *how do they impact costs in the short and long term?*
 - *how, and to what extent, can government influence them?*

A4 has very little information about the cost breakdown of the NDIS. We do not know what is spent on stakeholder engagement. A4 cannot see what is spent on early intervention for autistic children and what is spent on long-term or adult autistic NDIS participants.

The short-term cost of the NDIA's ECEI Approach is unknown, as is the long-term cost of autistic people who start in this model. Many people in the ASD community doubt that the NDIA's ECEI Approach will result in optimal life outcomes and the lowest long-term cost.

A4 does not know what the NDIS has spent on creating capacity to deliver services and supports in the disability sector.

A4 has relatively little information about how the costs of the NDIS was estimated or predicted.

The information we do have is concerning.

A scheme like the NDIS has start-up costs. Cutting costs at the start usually increases the overall cost of the NDIS.

A4 is not confident in the 460,000 estimate of participants. This could be a significant under-estimate. There is also the issue of increasing numbers of autistic people.

Government is encouraging the NDIA to skimp on administration and regulation. The NDIA is expected to have 7% overhead when the average, according to the White Paper, is 10%. Again, initial under-funding usually results in increased cost in the long-run. Cost cutting will adversely affect quality and safety which will increase costs in the long-term.

A scheme like the NDIS needs supporting research. The costs drivers listed in the White Paper do not mention research, its cost and its role in cost management.

- *Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?*
- *Why are more participants entering the scheme from the trial sites than expected? Why are lower than expected participants exiting the scheme?*
- *What factors are contributing to increasing package costs?*
- *Why is there a mismatch between benchmark package costs and actual package costs?*

Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?

In relation to autism, utilisation rates are low because services are unavailable. Services have not kept pace with growth in demand. Growth in demand is driven by increasing number of diagnoses and increased funding for early intervention.

Staff turnover is high in the disability sector. Far too often, disability services simply do not deliver scheduled services.

Few service providers understand the needs of autistic people so they don't offer/develop service appropriate for autistic clients. Clients with other disabilities are easier to support, so their needs get priority.

For older autistic NDIS participants, there is insufficient behaviour specialists. And the NDIA has yet to recognise the Board Certified Behaviour Analysts (BCBA) that are in the country.

At this stage, A4 cannot determine or estimate how many older autistic NDIS participants cannot access services as a result of disability service providers refusing to manage difficult and challenging behaviour. This cherry-picking of clients usually happens when disability service providers

have little or no understanding of (or experience with) appropriate behaviour management. Or families may refuse services from service providers who they consider have inappropriate responses to unwanted behaviour.

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

There are more autistic clients entering the NDIS than expected because the NDIS severely underestimated the number of autistic Australian and the number of prospective NDIS participants. From the beginning, Government and the NDIA rejected advice from the ASD community that its estimates were wrong.

A4 does not know what the NDIA's expectation were for the number of autistic participants exiting the scheme.

It may be that the NDIA has unrealistic expectations for autistic children who enter the NDIS for early intervention. The traditional view in Australia is that autism is life-long, that ASD is permanent.

There is a body of research that suggests early intensive behavioural intervention (EIBI) or early intensive intervention using applied behaviour analysis (ABA) results in children losing their ASD diagnosis or being educated without disability supports. The original research suggested that this result was observed in almost 50% of children; more recent research suggests that [optimal outcomes or very positive outcomes](#) are seen in 10% to 20% of children who receive EIBI in non-research settings.

The NDIA's approach to early intervention for ASD is to avoid funding EIBI or ABA as often as achievable. Rather than fund best practice early intervention for ASD, the NDIA aims to provide the largely ineffective placebo intervention from autism research ... or avoid even funding that if possible.

Data suggest that a majority of autistic children, whose response to early intervention is less positive, are affected permanently with severe or profound disability. Research indicates that best practice early intervention significantly improves long-term outcomes (and reduces over support costs) for most autistic children.

Predictably, very few autistic children will leave the NDIS following placebo or largely absent early intervention for their ASD.

The NDIA's approach to early intervention for ASD is not what A4 understands to be "insurance principles".

So, while the NDIS with its recently introduced ECEI Approach avoids ASD diagnoses and best-practice ASD-specific early intervention the likely

result is that few autistic people will “exit” the NDIS following their early intervention.

It may be that the NDIA is overly optimistic about outcomes for its early intervention approach for ASD. Recent research reports suggest that even with best practice early intervention for ASD, autistic children with “optimal outcomes” or “very positive outcomes”, who lose their ASD diagnosis, may still have ongoing needs for mental health services and other (non-ASD related) supports in education, employment, independent living and later life.

Very few autistic children in Australia can access best practice early intervention for the ASD so it is no surprise (to A4) that few autistic children in Australia lose their ASD diagnosis or exit from the NDIS.

What factors are contributing to increasing package costs?

The issue is not really “increasing package costs”; it appears that the initial estimate (benchmark) of package cost was too conservative, unrealistically low.

Possibly, people are being better prepared for their initial NDIS planning interview.

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

A4 is not aware of any meaningful stakeholder consultation relating to package costs for autistic NDIS participants.

Apparently, NDIA staff felt the ASD community over-estimates the severity and support needs of autistic people – so it made its own estimates of what their services and supports were likely to cost. Likely it ignored the widespread exclusion of difficult autistic adult clients from services, and the prospect that their service needs would be expensive to meet.

The ASD community was well aware of these issues and would have informed the NDIA had it engaged with ASD stakeholders.

- *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?*
- *Are there other aspects of the eligibility criteria of the NDIS that are affecting participation in the scheme (to a greater or lesser extent than what was expected)? If so, what changes could be made to improve the eligibility criteria?*
- *To what extent is the speed of the NDIS rollout affecting eligibility assessment processes?*

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?

The difference in criteria between the Productivity Commission recommendations and the NDIS are “interesting” in relation to ASD.

It may have been that autistic children with mild or moderate communication issue, but who were profoundly socially disabled would be excluded from any support since the NDIS took their pre-NDIS funding and excluded them from NDIS plans. Many people who were profoundly disabled by what was called Asperger’s Disorder in the DSM-IV would fall in this category.

Similarly, autistic children who are sometimes called “verbal”, but who have functional learning disabilities, would also have been excluded from the NDIS and denied services.

The Productivity Commission’s proposed criteria would have created challenging divisions between children diagnosed with ASD. A4 is not aware that there is an evidence base for any such division.

As it is, the NDIA’s eligibility criteria for “autism and related disorders” are gobbledygook (see [Massive row over NDIS autism eligibility gobbledygook](#)). The NDIA expects an ASD diagnosis to have one severity level when the DSM-5 clearly says that two should be given. Having NDIA planners, who often have little or no knowledge of ASD, reviewing Level 1 ASD severity and rejecting the advice of specialist clinicians about support needs is inappropriate.

Are there other aspects of the eligibility criteria of the NDIS that are affecting participation in the scheme (to a greater or lesser extent than what was expected)? If so, what changes could be made to improve the eligibility criteria?

Anecdotally, families report that they haven’t tried to get into the NDIS because the eligibility criteria are unclear to them.

Some families say that they cannot face up to the planning process; they are concerned that they will have to portray the most negative picture that they can in order to get access to essential supports. Some families find this too challenging.

Others are worried about the increased levels of bureaucratic burden in dealing with NDIS processes.

To what extent is the speed of the NDIS rollout affecting eligibility assessment processes?

From our observation, eligibility does not seem to be the issue. It seems that planning issues are bigger problems.

- *Is the 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?*
- *What impact will the ECEI approach have on the number of children entering the scheme and the long-term costs of the NDIS?*
- *Are there other early intervention programs that could reduce long-term scheme costs while still meeting the needs of participants?*

Is the 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?

A4 and other ASD advocates have serious problems with the NDIA's ECEI Approach (see [ASD, early intervention and the NDIS](#) or [here](#)).

Children who may have a disability are first referred to an NDIA Access Partner. While it may mean that a child does not have to wait for an ASD diagnosis to first access an initial service, A4 is concerned that autistic children may miss out altogether on diagnoses and crucial ASD-specific early intervention since

- Access Partners are not required to have an adequate knowledge of ASD so they are likely to miss autism symptoms.
- The NDIA ECEI Approach does not mention diagnosis. ASD diagnosis is crucial since it guides effective early intervention.
- Access Partners are not impartial; they give families incomplete and seriously partial information and advice about early intervention. Typically, they provide misinformation and prejudice about autism and early intervention.

The NDIA rejected the advice of its ASD-specific early intervention consultants, its advisory panel on ASD and ASD stakeholders. It prefers advice on generic early intervention that does not relate to autistic children.

What impact will the ECEI approach have on the number of children entering the scheme and the long-term costs of the NDIS?

The ECEI Approach is likely to divert autistic children from entering the NDIS. This may reduce the NDIA's early intervention costs.

However, without effective early intervention, autistic children get less out of their education. And they usually have higher support needs in education.

Autistic children who missed out on early intervention and effective education then go on to have higher support needs as adults, and reduced prospects for employment. They are harder to treat in the health system

so their treatment may be less effective. They are likely to have greater stress and mental illness as adults.

Best practice early intervention for ASD is likely to cost \$40K to \$80K per child per year for at least 2 years per child. For a few children who could lose their diagnosis through best practice early intervention, the cost of their early would be recovered before the child leaves school – actually, the full cost of federal funding for best practice early intervention for ASD would be totally recovered in the state/territory funded education sector by the time the children leave school.

Research result indicate that best practice early intervention for ASD improves education outcomes for most autistic children, not only those who lose their ASD diagnosis. Only a small percentage, around 15%, of autistic children do not benefit in their education from early intervention.

Best practice early intervention significantly improves the lives of most autistic adult. The NDIA has not published the average cost of packages for autistic adult NDIS participants – it is likely that the cost for the NDIS of autistic adults would also be substantially reduced for autistic participants who received best practice early intervention for their ASD.

The NDIA's ECEI Approach will increase substantially the cost of ASD in the NDIS in the long-run.

In the USA, legislation increasing ensures that early intervention for ASD is largely funded through private health insurance. The insurance companies want value for money so they insist on *best practice*. A senior insurance executive from the USA told us “no private health insurance company is going broke funding early intervention for ASD”.

Are there other early intervention programs that could reduce long-term scheme costs while still meeting the needs of participants?

The NDIA should promote and facilitate early diagnosis of ASD.

It should then ensure families of young autistic children get comprehensive and impartial information about early intervention for ASD. It should improve rather than abolish the Autism Advisor service.

It should ensure that best practice ASD early intervention is available. Autistic children need comprehensive early interventions services, not schemes that expect parents to deliver 20+ hours of clinical early intervention services and supports on their kitchen table after dinner. They need clinicians who actually supervise the full 20+ hours per week ... and have been trained to do so (it takes a lot more than 1 or 2 lectures in a 3- or 4-year degree to know how to deliver a comprehensive 20-hour per week program). ASD-specific early intervention for most autistic children needs a *fully* trained behaviour specialist as part of the clinical team that closely supervises individual programs.

- *Is the current split between the services agreed to be provided by the NDIS and those provided by mainstream services efficient and sufficiently clear? If not, how can arrangements be improved?*
- *Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?*
- *How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?*

Is the current split between the services agreed to be provided by the NDIS and those provided by mainstream services efficient and sufficiently clear? If not, how can arrangements be improved?

Currently, the split, the allocation of responsibility between the NDIS and mainstream services, is very unclear. Frequently, questions are raised on the Facebook NDIS Grassroots discussion group ... and often there is no clear answer.

In many cases, the best advice is to ask the NDIS for the desired service. If the NDIS says “no” to an essential service, then the NDIS participant can start a review process.

The NDIA and other systems could be more constructive in helping people with disability access mainstream services. Often a person with disability is unable to fight for the service they need from a mainstream service provider. The NDIS could contact a disability advocate and provide the advocate with the support and information that is needed to ensure the person with disability can access the mainstream service.

It would help for the NDIS included funding for this kind of advocacy in people’s individual disability plans. It would reduce the NDIA’s review burden, improve advocacy services and promote better support for people with disability from mainstream services.

Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?

There is plenty of cost-shifting. The NDIA quite aggressively sucked up all the state disability funding. That funding is now directed to private providers. Private providers are expanding their previous/traditional service delivery. Some of them are introducing new services, but they will all cherry-pick the types of services they will provide first.

Previously, state disability services had aspects that were more like providers-of-last-resort for people with severe or profound disability ...

though families were always (and remain) the ultimate *provider of last resort*.

This cost-shift/change to privatised services leaves serious gaps in service availability.

The phrase “duplication of services” has no place in discussion of disability services, especially in privatised disability services. Bureaucrats have extremely unhealthy phobias about *duplication*; which shows they have little or no understanding of privatisation and essential competition. Apparently, bureaucrats despise service reliability and resilience ... for which duplication of service providers is fundamental. Bureaucrats in the NDIA love to talk about “choice and control” while they do their utmost quash duplication thereby preventing it from happening.

Mainstream services could provide services that replace disability services. The NDIA could negotiate and work with mainstream service providers. In some areas, there could and should be scope shifting from disability services to mainstream. It is hard to see this happening while NDIA administration is hamstrung by its 7% administration constraint.

How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?

It is easiest to think of situations where the interface is not working especially well. Examples include

- transport to school for students with disability
- after- or out-of-school care for students with disability
- health and dental care
- behavioural services
- employment
- sport and recreation.

The NDIS could lift its game; it could be much more active in facilitating and promoting inclusion of people with disability in many aspects of the community. Possibly, the NDIA sees some of these issues as lower priority ... they may be too much for the NDIA to tackle in its very challenging start-up phase.

- *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?*
- *What, if anything, needs to be done to ensure the intersection between the NDIS and mental health services outside the scheme remains effective?*

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?

It is impossible for A4 to answer this question. The NDIA has not discussed issues relating to mental health with ASD stakeholders. A4 has no idea what services are meant to be available.

Services for autistic people with mental illness are largely non-existent. If/when funding is allocated in an individual's NDIS plan, people will have substantial difficulty finding anyone who can/will provide the mental health services that autistic people needs.

What, if anything, needs to be done to ensure the intersection between the NDIS and mental health services outside the scheme remains effective?

This question assumes (incorrectly) that before the NDIS there were effective mental health services for autistic people.

The NDIA or maybe the mainstream mental health service sector need to develop mental health services for autistic people with mental illness.

The Burdekin Report (1993) identified a massive gap in services for people with a dual diagnosis of mental illness and intellectual disability. Governments responded by creating services to specifically address that gap.

Since 1993, the number of autistic Australian has grown substantially. Many autistic people also have mental illness. The same gap as Burdekin identified in 1993 exists for autistic people with mental illness today. This substantial gap in mental health services for autistic people is largely unrecognised and unaddressed today.

Since 1993, we have seen efforts to include people with disability in mainstream service provisions in most sectors. Sadly, the health sector and the mental health sector have been slow and unsuccessful in this regard. And the need that Burdekin identified for mental health services for people with intellectual disability is being forgotten ... so the services created are being dismantled.

Rather than maintain segregated mental health services, the mainstream mental health service sector should become more inclusive of people with intellectual disability and autistic people.

- *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?

- *Is the way the NDIS refers people who do not qualify for support under the scheme back to mainstream services effective? If not, how can this be improved?*

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?

The “*range and type of services proposed to be funded under the ILC program*” covers only part of what is needed to achieve the goals of the NDIS and the *National Disability Insurance Scheme Act 2013*.

Limiting services to Information, Linkage and Capacity Building leaves people with disability, but who are not participants in NDIS Tier 3, and people supporting them without many actual services and supports that are crucial.

In the information area, the ILC seems to focus on online information ... yet over 40% of Australians are functionally illiterate. That means they will have difficulty accessing online information. And the rate for functional illiteracy may be higher than 40% in the disability sector.

Observation of the NDIS Grassroots Discussion Group (on Facebook) shows that many people cannot access basic information about the NDIS effectively from the existing NDIS website. It is optimistic to expect more of the same to achieve a different outcome.

The NDIA abolished the national Autism Advisor service, a crucial information service, and dissipated the intellectual capital. The NDIA has no replacement for this service. Assistant Minister The Hon. Senator Prentice announced that “the Government recognises the continued need for these support and advice services during this time of change” (see <http://janeprentice.dss.gov.au/media-releases/children-disability-support-services-03022017>) ... but it is too late in South Australia and the ACT.

The Autism Advisor service addresses the needs of people during a stage before they become NDIS participants. The need for the service does not go away with the arrival of the NDIS. The need is on-going; the need is not limited to “during this time of change”.

No! The ECEI Access Partners cannot deliver the essential service that Autism Advisors provided.

The linkage element of the ILC is a bit of a mystery. Most of the services that that non-NDIS participants need to link to simply don't exist. The role of the NDIS LAC is to link NDIS participants to services; so, the purpose of ILC's linkage is to link non-participants to services for their disability.

The targets of the linkage are either mainstream services or fee-for-service disability services that few non-participants can afford.

Generally, people with disability seek “linkage” because mainstream services do not address or meet their needs. The ILC’s linkage elements have to recognise and respect this difficulty or they will be frustrating to use and they will fall quickly into disrepute.

Mostly, fee-for-service disability services do not exist. And there is little likelihood that they will exist in the future under the NDIA’s current model.

For the fee-for-service disability services that will exist, ILC linkage effectively *duplicates* advertising for those services.

The ILC capacity building is about building

1. Personal capacity, and
2. Capacity for mainstream service providers to provide services and supports for people with disability.

Both of these are worthy and valuable. A4 commends such endeavours.

However, A4 is concerned that there is no discernible effort to develop crucial disability services that simply do not exist. For example, there is no discernible recognition from the NDIA or Governments of the lack of behavioural services and supports for many autistic people who need them (see [Behavioural needs of autistic Australians must be met](#)).

The NDIA and Governments in Australia do not recognise the severe shortages of staff trained to provide services and supports for the rapidly growing numbers of people diagnosed with ASD. There is no discernible effort or even a plan to build service capacity.

The NDIA met A4 briefly in December 2016 for a very limited discussion. The NDIA did not recognise any of A4 concerns. Instead, Ms Rundle wrote (5/2/2017) to A4:

I wish to acknowledge that I have read your correspondence and I am sorry that your views do not align with the views of the Agency on the implementation of ECEI.

As we understand it from this and previous correspondence (or the lack thereof), the NDIA does not recognise or respect any of A4’s concerns about its ECEI Approach. It seems that the NDIA expects the ASD community to simply “align with” whatever early intervention scheme the NDIA dreams up for autistic children; research, evidence and experience relating to ASD are irrelevant to the NDIA *although this is true...will this be considered aggressive.*

We understand that A4’s views align with the authors of the NDIA’s own review (see *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers* [PDF 530KB](#) or [MS Word 190KB](#)), with the NDIA’s “expert panel” appointed to monitor that review (its members are listed in the review), and with other major autism groups in Australia (see [ASD, early intervention and the NDIS](#)). A4 is a member of the Australian Federation

of Disability Organisations (AFDO), Disability Australia (DA) and the Australian Autism Alliance (AAA).

The NDIA refuses to discuss any further concerns with A4 for at least six months.

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 ILC and LACs will be most useful if they can report accurately to NDIS participants on immediate/current service quality and availability.

They will also be useful if they monitor and measure unmet needs and feedback into capacity building processes for actual services.

Is the way the NDIS refers people who do not qualify for support under the scheme back to mainstream services effective? If not, how can this be improved?

A4 expects this aspect of the NDIS will be a serious deficit in meeting the needs of people with disability who are not eligible to be Tier 3 NDIS participants.

- *How will the NIIS affect the supply and demand for disability care services?*
- *What impact will the full establishment of the NIIS have on the costs of the NDIS?*
- *Are sufficiently robust safeguards in place to prevent cost shifting between the NIIS and the NDIS?*

ASD is not a “catastrophic injury” so the NIIS has less relevance for A4.

A4 is concerned that *Occupational Health and Safety* law does not protect clients in disability services. We regard this as a massive failing. We would like to see this addressed nationally.

- *Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?*
- *How should the performance of planners be monitored and evaluated?*

Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?

A4 has very little information about the planning process. The NDIA works pretty hard to hide its planning process from people until they have to go through it. This makes people nervous.

The results observed in the ASD community of the planning service seem rather random or arbitrary from what we can observe. This suggests that training and procedures for NDIS planners are inadequate in relation to autistic NDIS participants.

The erratic planning outcomes observed for autistic NDIS participants suggest that the planning process may not be “valid”. From the perspectives of prospective participants and advocates, “clear” and “reliable” are not applicable terms in relation to the NDIS planning process.

There are some planners providing good plans for autistic people, but planning expertise in ASD is variable. A4 often hears about planner who have little or no understanding of ASD. Some planners are clearly misinformed/misguided about ASD.

There seems to be an effort to minimise the immediate cost of early intervention for autistic NDIS participants. This may *appear* to be cost effective in the short term, but experience shows that it will be expensive in the long term.

Anecdotally, the NDIS may be a challenge to access for some school age autistic students. Families are often overwhelmed with challenges/difficulties in the education system so they are reluctant to complicate their lives with NDIS participation.

NDIS planning would be substantially improved through making NDIS planning a far more open process, through stakeholder consultation about planning, and through improved training about ASD for planners who work on plans for autistic people.

NDIS planning would be improved by ensuring planners for autistic people are adequately trained in planning for ASD. A4 has received reports that better plans come from NDIS planners with lived experience of ASD, and planners with no lived experience of ASD often produce poor and unacceptable plans. The NDIA must ensure that planners for autistic NDIS participants have lived experience of ASD or appropriate training.

Some planning practices, like providing 75% of transport needs in a plan, are especially ineffective. Are NDIS clients expected to use transport for 75% of their journey then walk the rest each time? Or do they only go to ¼ of their appointments/activities ... maybe live a “normal” life for 9 months then stay at home for 3 months each year!

Many plans do not include the case management needed. And even when it's included, it is rarely delivered effectively.

How should the performance of planners be monitored and evaluated?

This is a tough question.

Ideally, measurement of planner performance should reflect timely achievement of plan goals, provided plan goals are both sufficiently ambitious and realistic on an individual basis.

Plan review is usually very stressful for autistic NDIS participants and their informal carers. Hopefully, the NDIA monitors the rate that each planner triggers plan reviews and seeks to minimise planning reviews.

Possibly, collecting data that relates service provision to progress and completion of specific and individual goals may inform performance monitoring across the NDIS. Research is needed to find effective measures and evaluations that relate to long-term goal achievement for individuals.

The performance of LACs and case managers in terms of client goal realisation should also be monitored and reported.

It is reasonable to include some cost factors in performance evaluation ... but it would be a mistake to only use those measures.

- *Do NDIA assessment tools meet these criteria? What measures or evidence are available for evaluating the performance of assessment tools used by the NDIA?*
- *What are the likely challenges for monitoring and refining the assessment process and tools over time? What implications do these have for scheme costs?*

Do NDIA assessment tools meet these criteria? What measures or evidence are available for evaluating the performance of assessment tools used by the NDIA?

“These criteria” means valid, reliable, accurate, efficient.

Since the NDIA’s assessment tools are invisible to us, it is very hard to comment. We observe inconsistent and sometime inappropriate outcomes so we are convinced that they are invalid, unreliable and inaccurate.

As the number of people progressing through them are not meeting expectation, they may be inefficient.

ASD is a spectrum ... as its name indicates. Few measurement methods report effectively on a spectrum disorder.

The above pretty much answers the second question.

What are the likely challenges for monitoring and refining the assessment process and tools over time? What implications do these have for scheme costs?

A4 cannot answer this question because it does not know what the NDIA’s assessment tools and assessment process are. The NDIA keeps this information secret.

The implications are that:

1. The NDIA cannot be trusted to measure and report outcomes realistically ... it will always guild the lily,
2. The assessment tools are likely to be inappropriate for autistic participants (or the NDIA would readily reveal them)
3. Performance cannot be monitored or it would reveal what the assessment tools are (and they would not be secret any longer).

We understand that the NDIA uses the PEDI-CAT assessment tool (secretly? Its use is not mentioned on the NDIS website). A4 is aware that the PEDI-CAT was considered inappropriate for autistic children, and was significantly [modified to include autistic children](#). While [the authors of the revised instrument have published their validation](#), some A4 members are concerned by its use and A4 awaits independent evaluations.

- *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?*
- *To what extent does the NDIA’s budget-based approach to planning create clear and effective criteria for determining participant supports? To what extent does it lead to equitable outcomes for participants? What improvements could be made?*
- *What implications do the criteria and processes for determining supports have for the sustainability of scheme costs?*
- *Are the avenues for resolving disagreements about participant supports appropriate? How could they be improved?*

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?

Section 34 of the Act says funding may be available for “supports” when “the [NDIA] CEO [is] satisfied of all of the [six] following [criteria]”. In practice, it is a planner and possibly a reviewer, not the CEO, who must be satisfied.

Many autistic people have limited or minimal goals or prospects for “social and economic participation” as required for s34 (1) (b) so either most of the supports that an autistic person wants do not meet the criteria, or the NDIA has to invent its own goals for autistic individuals.

S34 (1)(d) does not provide for a situation where there is no support with a known or likely outcome ... as is often the case with services for autistic people. The criteria should allow for a degree of testing or experimentation when there is no support available with a known or likely outcome. It should not prohibit the provision of any support in these circumstance (as would appear to be currently the case).

Current practice in the NDIA does seem to be more flexible than the law requires. This may be because the criteria are not clear ... or effective.

A4 has no idea what actual guidance assessors (planners) are given. We observe inconsistent outcomes so we have doubts that guidance is sufficient and/or effective. Or the guidance may be inconsistent or confusing.

Changing the criterion in s34(1)(b), that requires supports “to facilitate the participant’s social and economic participation”, to a priority (instead of being a requirement) would be an improvement for autistic participants.

Apparently, NDIS planners are told to approve supports that are “reasonable and necessary”. These criteria are completely arbitrary: different people have very different views of what is “reasonable and necessary”. For example, Government Ministers and senior Government officials regard [fabricating debts](#) for many of our most vulnerable citizens as “reasonable and necessary”. They regard scamming money from the poorest citizens as “reasonable and necessary”. They regard having a mostly unworkable system for contesting or addressing fabricated welfare debt as “reasonable and necessary”. Many other citizens disagree completely.

The NDIA’s “reasonable and necessary” criteria are very unclear.

To what extent does the NDIA’s budget-based approach to planning create clear and effective criteria for determining participant supports? To what extent does it lead to equitable outcomes for participants? What improvements could be made?

A4 does not know what “*the NDIA’s budget-based approach to planning*” is. A4 doubts that it does anything to “*create clear and effective criteria*” since that is the role of the legislation.

A4 expects that a “*budget-based approach*” means focussing on short-term budget issues. Real improvement in the disability sector requires attention to long-term goals as well.

A4 is very concerned that existing NDIS processes are not producing “*equitable outcomes for participants*” for autistic NDIS participants.

Improved outcomes for autistic NDIS participants can be achieved through

- openness about NDIS planning,
- planners with knowledge and experience of living with ASD,
- recognition of the distinct need of autistic people,
- actual engagement with ASD stakeholders, and
- pro-active approach to creating/developing essential services and supports for the increasing number of autistic Australians.

The NDIS now has a “first plan process” that differs from the process used in the NDIS trial. Apparently, the initial face-to-face meeting has been

abolished; the first meeting is over the telephone. Many autistic people will find this difficult.

Advice from the NDIA on the “first plan process” is essentially to get a cup of tea and find a comfortable place to sit. It isn’t especially helpful.

What implications do the criteria and processes for determining supports have for the sustainability of scheme costs?

The “*criteria and processes for determining supports*” have no real effect on “*sustainability*”. The NDIS was under-funded from the outset, as are all projects of this type. The difference here is that the Government will be highly intolerant of cost over-run.

Over time, political and bureaucratic processes will cut funding (demand “efficiency dividends” or whatever euphemisms they choose) until the NDIS breaks. Then Government will choose to either cut the NDIS completely or maintain it in a barely operational state for as little financial outlay and client benefit as possible. This is standard practice in mediocre government.

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

This is a difficult issue.

Many people with disability and/or their families are extremely conflict averse. They are poor or unwilling self-advocates. Many autistic people or parents of autistic children, if they are treated unfairly, simply cannot ask for a review.

Many autistic people have little or no idea what is reasonable to ask for. They cannot judge whether anyone else has expressed similar needs to theirs and what the outcomes were of a) any initial requests, and b) reviews of similar requests.

There is no discernible support for autistic people in disagreements with the NDIA about participant supports. Contrast this with the other side: planners have the whole NDIS, DSS, the Government and the legal system backing any decision to deny a request for service or support.

- *What factors affect the supply and demand for disability care and support workers, including allied health professionals? How do these factors vary by type of disability, jurisdiction, and occupation? How will competition from other sectors affect demand (and wages) for carers? What evidence is there from the NDIS trial sites about these issues?*
- *How will an ageing population affect the supply and demand for disability carers (including informal carers)?*
- *Is increasing the NDIS workforce by 60 000-70 000 full time equivalent*

positions by 2019-20 feasible under present policy settings? If not, what policy settings would be necessary to achieve this goal, and what ramifications would that have for scheme costs?

- How might assistance for informal carers affect the need for formal carers supplied by the NDIS and affect scheme costs?*
- To what extent is the supply of disability care and support services lessened by the perception that caring jobs are poorly valued? If such a perception does exist, how might it best be overcome?*
- What scope is there to expand the disability care and support workforce by transitioning part-time or casual workers to full-time positions? What scope is there to improve the flexibility of working hours and payments to better provide services when participants may desire them?*
- What role might technological improvements play in making care provision by the workforce more efficient?*
- What are the advantages and disadvantages of making greater use of skilled migration to meet workforce targets? Are there particular roles where skilled migration would be more effective than others to meet such targets?*

What factors affect the supply and demand for disability care and support workers, including allied health professionals? How do these factors vary by type of disability, jurisdiction, and occupation? How will competition from other sectors affect demand (and wages) for carers? What evidence is there from the NDIS trial sites about these issues?

The factors that affect the supply of disability care and support workers are many and complex. They range from pay and conditions, perceptions of young people entering the workforce, etc. to the advice given by career advisors and employment agencies. Supply of allied health professionals depends on career choices that student entering university make.

Demand depends mostly on funding and policy decisions.

In relation to ASD, the supply of behaviour specialist is massively impeded by:

- governments and the NDIA refusing to recognise and require appropriate qualifications (see [Behavioural needs of autistic Australians must be met](#)), and
- unavailability of training in best-practice in Australian universities.

It is likely that the lack of behavioural specialists affects services and supports for autistic people more than for people with other disability.

The lack of behaviour specialists means that other workers do not have adequate support in their workplace. The resulting problems in the workplace increases turnover. It means many workers leave the disability sector.

Evidence from HCWA is that increased demand for allied health professionals for early intervention did not increase supply adequately.

A4 is not aware of data from the NDIA trial relating to this issue. In this regard, the NDIA trial appears to be a missed opportunity.

How will an ageing population affect the supply and demand for disability carers (including informal carers)?

A4 has little knowledge of the ageing population and services for it.

Is increasing the NDIS workforce by 60 000-70 000 full time equivalent positions by 2019-20 feasible under present policy settings? If not, what policy settings would be necessary to achieve this goal, and what ramifications would that have for scheme costs?

Increasing the size of the workforce is readily achievable.

The present policy setting will result in a seriously undersized workforce with major gaps in its skills set.

How might assistance for informal carers affect the need for formal carers supplied by the NDIS and affect scheme costs?

A4 does not really understand this question.

Informal carers carry an enormous burden at present. Sometimes their support breaks down; there are significant numbers of people with disability languishing in massively inappropriate setting ... like in prison (without any conviction), young people in aged care, etc.

Better assistance and support for informal carers is likely to maintain informal carers for longer. That will reduce the cost of the scheme.

Increasing support for informal carers is likely to increase the care that they provide, but it may reduce their workforce participation.

To what extent is the supply of disability care and support services lessened by the perception that caring jobs are poorly valued? If such a perception does exist, how might it best be overcome?

That caring roles are poorly valued is not perception, it is reality.

Caring jobs are poorly valued. Pay rates are mostly minimal. Good or exceptional performance of the role is rarely valued financially.

Massive cultural change is needed. It must start with politician, bureaucrats and journalists recognising that people with disability are not mostly bludgers and rorters.

What scope is there to expand the disability care and support workforce by transitioning part-time or casual workers to full-time positions? What scope is there to improve the flexibility of working

hours and payments to better provide services when participants may desire them?

There is significant scope for increasing the number of people who see disability services as a career and choose to work full-time in the sector.

It is unclear whether existing part-time or casual workers are the most likely to make that shift.

Finding people to work short periods at varied time during the day – perhaps helping people get out of bed or at the end of the day – is always a challenge. Possibly, schemes that simplify/reduce the administrative burden associated with smallish payment for this type of work would help.

What role might technological improvements play in making care provision by the workforce more efficient?

Technology should be able to decrease the enormous administrative burden that the NDIS brings. It should also assist in improving scheduling flexibility and reliability.

What are the advantages and disadvantages of making greater use of skilled migration to meet workforce targets? Are there particular roles where skilled migration would be more effective than others to meet such targets?

Skilled migration offers potential for growing the disability service workforce. Some unskilled workers can learn skills quickly.

A4's concern is that communication with severely autistic clients, especially verbal communication, is diminished with some dialects of spoken English.

The lack of training of behavioural specialists in Australia means that skilled migration is an essential source of clinical services.

- *Are prices set by the NDIA at an efficient level? How ready is the disability sector for market prices?*
- *How do 'in-kind' services affect the transition to the full scheme and ultimately scheme costs?*
- *What is the capacity of providers to move to the full scheme? Does provider readiness and the quality of services vary across disabilities, jurisdictions, areas, participant age and types/range of supports?*
- *How ready are providers for the shift from block-funding to fee-for-service?*
- *What are the barriers to entry for new providers, how significant are they, and what can be done about them?*
- *What are the best mechanisms for supplying thin markets, particularly rural/ remote areas and scheme participants with costly, complex,*

specialised or high intensity needs? Will providers also be able to deliver supports that meet the culturally and linguistically diverse needs of scheme participants, and Aboriginal and Torres Strait Islander Australians?

- *How will the changed market design affect the degree of collaboration or co-operation between providers? How will the full scheme rollout affect their fundraising and volunteering activities? How might this affect the costs of the scheme?*

Are prices set by the NDIA at an efficient level?

Pricing is complex. Most service providers say that they still have trouble recruiting staff. Staff issues may be partly “cultural”, where young people just don’t regard the disability service sector as a career option.

Currently, the increased administration that the NDIA requires affects costs and prices.

How ready is the disability sector for market prices?

The real question here is, how ready is the NDIA for market prices. The NDIA sets the price it will pay for a service. That is not our understanding of “market prices”.

Perhaps the real question is whether the disability sector is ready for competitive servicing. People with disability need to better understand when their choices and what control they have. Disability service providers need to be better at delivering the services that their customers want.

And market prices are what the agreed services (including overheads and *reasonable* profit margins) actually cost.

How do ‘in-kind’ services affect the transition to the full scheme and ultimately scheme costs?

State and territory governments seem to withdraw their services as soon as they can. Often services are withdrawn before full rollout.

So, no ‘in-kind’ service remains. This means ‘in-kind’ services have little or no effect on the transition to the full scheme.

What is the capacity of providers to move to the full scheme? Does provider readiness and the quality of services vary across disabilities, jurisdictions, areas, participant age and types / range of supports?

Many providers, hopefully those that provide the bulk of disability services, can and will transition to the NDIS model.

In relation to services specifically for ASD, the transition is “interesting”. ASD services provided via the *Helping Children with Autism* package were already in an NDIS-ready state but they were very under-developed because HCWA funding was a small percentage of what was needed and

the constraints on funding use meant that it would not always contribute to evidence-based or best practice.

The NDIS is also inhibiting evidence-based and best practice early intervention for autistic children.

How ready are providers for the shift from block-funding to fee-for-service?

Many service providers were able to transition easily from block-funded to fee-for-service.

However, some services only make sense as block-funded. For example, Autism Advisors mostly provided essential services for people who do not have a diagnosis or who do not yet have individual funding. The NDIS has eliminated this essential service. This is a very bad outcome.

The NDIS is for 460,000 participants ... yet there are 2.4 million Australians with disability. The NDIA's plan is that about 2 million Australians with disability can only access the new, as yet untested, ILC services ... which are not actual disability services.

- The mostly online Information services may do a better job than what already exists on the internet. The quality and effectiveness of the new ILC's *information* is yet to be seen.
- The ILC's *linkage* effort for non-participants can link people with disability to for-profit businesses, to mainstream services that may help people with disability, and to charities that provide service and support for people with disability. There won't be many block-funded disability services to link people with disability to.

Already, the NDIS shut down *Autism Asperger ACT* in the first full NDIS rollout area (see [Autism Asperger ACT merger with Marymead prompted by NDIS funding limbo](#) – note, many “merged” services simply disappeared). And SHOUT is [at risk of shutting](#) as well.

What are the barriers to entry for new providers, how significant are they, and what can be done about them?

A4 is not about starting businesses so this is not our area of expertise.

A new disability service provider has the usual challenges of getting a business up and running. However, in this sector there are extra hurdles/barriers: the service needs to register with the NDIA which is a serious risk and adds delay.

A4 is cannot see why the NDIS has a PDF list of registered providers – but we could not find an online database. There are separate lists for each state/territory – but there is no list of providers who offer services online, such as for people in remote locations.

Some smaller service providers feel registration with the NDIA is expensive and time consuming. They choose not to register which means they only service self-managed NDIS participants. These outcomes affect the level of participant “choice and control”.

What are the best mechanisms for supplying thin markets, particularly rural/ remote areas and scheme participants with costly, complex, specialised or high intensity needs? Will providers also be able to deliver supports that meet the culturally and linguistically diverse needs of scheme participants, and Aboriginal and Torres Strait Islander Australians?

As mentioned immediately above, processes/mechanisms should be developed and encouraged that let people access service providers remotely.

The NDIA could be pro-active in developing and funding some more portable service provision.

A4 recognises challenges but does not have specific expertise in disability services for CALD and/or ATSLA communities. A4 notes that ASD diagnosis rates are extremely low in the Northern Territory which suggests that the most basic services are not available to its indigenous communities.

How will the changed market design affect the degree of collaboration or co-operation between providers? How will the full scheme rollout affect their fundraising and volunteering activities? How might this affect the costs of the scheme?

From the outset, state/territory governments and the NDIA have challenged service providers to be more “business-like”. That is, focussing purely on their bottom line and prioritise shareholders’ interests.

Collaboration or co-operation with others is not profitable; typically, it diverts effort from profitable activity.

People with disability will expect reliable services under the NDIS. Volunteer services are rarely reliable.

People with disability prefer a normal life, not a life that is sometimes supported by voluntary help if and when it is available.

The NDIS promised a better life for people with disability. It will cost money to deliver on that promise.

The NDIS has to pay for some things that in the past some people with disability were able to access when volunteers decided to provide it.

In the case of ASD, there is very little fundraising or volunteer service provision ... so the NDIS won’t make much difference for the autistic part of disability sector.

- *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?

The scheme is a major change. NDIS-eligible autistic people (and their families and carers) have a spectrum of readiness for the NDIS. A few can read the material and understand the change. Most cannot; they struggle with the available material that does not answer their specific questions.

People in the ASD sector struggle to “interact with the scheme, negotiate plans, and find and negotiate supports with providers”. That is part of the diagnosis. The NDIA does not recognise the distinct difficulties associated with ASD. Many service providers have little or no knowledge or experience of ASD; they have not provided services for the rapidly growing number of people diagnosed with ASD. Providers prefer to focus on their traditional (non-ASD related) services so autistic people cannot negotiate for services and supports with disability service providers.

The NDIA has no discernible plan to develop or improve service provision for autistic people.

The NDIA does not fund advocacy services for autistic people. Governments do not fund advocacy services for autistic people. Autistic people often have difficulty getting the help they need to negotiate services and supports with disability service providers.

- *Do existing administrative and governance arrangements affect (or have the potential to affect) the provision of services or scheme costs? What changes, if any, would improve the arrangements?*
- *To what extent do the reporting arrangements help to achieve the financial sustainability of the scheme? Are they too onerous or do they need to be expanded?*
- *Does the way that the NDIA measures its performance affect the delivery of the NDIS?*
- *To what extent do the existing regulations provide the appropriate safeguards and quality controls? Can these arrangements be improved?*
- *Are there appropriate and effective mechanisms for dealing with disputes with the NDIA?*

Do existing administrative and governance arrangements affect (or have the potential to affect) the provision of services or scheme costs? What changes, if any, would improve the arrangements?

The White Paper says “oversight of the NDIS is comprehensive”. But much of how the NDIA operates is hidden from the disability sector. The NDIA is extremely reluctant even to provide information when it’s required through Freedom of Information requests. So it is difficult for A4 to answer these questions.

Service providers suggest that the NDIS has increased administrative burden ... which will increase costs.

The NDIA could focus more on whether services meet participants needs ahead of the financial controls. Get participants focussed on the services they receive rather than costs. Costs are between the NDIA and the service provider; the participant should not be involved.

To what extent do the reporting arrangements help to achieve the financial sustainability of the scheme? Are they too onerous or do they need to be expanded?

The measurement and reporting of service quality and quantity are essential.

The current level of reporting to the public is insufficient; it needs to improve. It is definitely not too onerous. Reports can be easily generated out of the administrative databases for the NDIS.

We have no idea what reporting will be required for the ILC. We anticipate that it will need to improve.

Does the way that the NDIA measures its performance affect the delivery of the NDIS?

Absolutely. That is how bureaucracies work.

To what extent do the existing regulations provide the appropriate safeguards and quality controls? Can these arrangements be improved?

Regulations do not provide safeguards – they are advisory. Laws provide safeguards.

Australia needs national OH&S legislation that protects people with disability, that is clients, when they are in disability services.

Are there appropriate and effective mechanisms for dealing with disputes with the NDIA?

No. Australia has a legal system, not a justice system. Australia's legal system has very little understanding of people with disability. Few Australia legal practitioners have knowledge, understanding, and/or experience of disability ... and fewer have sufficient humility to actually listen to lay people who can help them understand. Australia's legal system protects most people who engage in disability discrimination; Australian law defines and promotes "lawful discrimination".

Is the NDIA's target for operating costs (as a percentage of total costs) achievable? Is it practical? Should it vary over the life of the scheme?

The expectation (mentioned in the White Paper) that the NDIA's administration costs should be restricted to just 7% of expenditure rather than the 10% average (or even more) shows that those who are implementing the NDIS simply don't understand the challenges of the very diverse disability sector. Effort to realise this goal may be the biggest risk to the NDIS.

Cost goals are easiest to understand and measure so they get priority.

- *How appropriate, effective and efficient are the market stewardship initiatives?*
- *Is there likely to be a need for a provider of last resort? If so, should it be the NDIA? How would this work?*

How appropriate, effective and efficient are the market stewardship initiatives?

A4 sees very few “market stewardship initiatives”. The NDIA registers disability service providers. The disability sector has [an extremely poor track record](#) in service stewardship. A4 sees no sign that this is changing.

Is there likely to be a need for a provider of last resort? If so, should it be the NDIA? How would this work?

A provider of last resort is necessary; it is not a *likely* need. Yes, it should be the NDIA.

Currently, there are thousands of children and young adults with disability in inappropriate settings such as prisons and aged care facilities. The issue of young people in aged care was raised in COAG over 10 years ago, there was a short burst of reporting then there is been little discernible progress since then.

The NDIA is the only national agency in a position to address this gross national failure.

Autistic people with challenging behaviour are often denied services. Too often, the family is the provider of last resort ... and sometimes they cannot survive.

When the health and education systems cannot provide essential services for people with disability, the NDIA needs to step in to ensure people with disability get the health and education services that are their right under international law (even though it is **not** their right under Australian law).

- *Does the current funding split between the Commonwealth and the States and Territories have implications for the scheme’s sustainability? Does it affect the NDIA’s capacity to deliver disability care to scheme participants at the lowest cost? Are there any changes that could be made to the funding split that would either improve the financial sustainability or the efficiency of the scheme?*
- *What proportion of a state or territory’s contribution to the NDIS are in-kind services? Are there risks associated with in-kind service*

contributions?

- *What are the implications of the current risk sharing arrangements? Do they encourage either cost shifting or overruns? What, if any, improvements could be made to the current risk sharing arrangements?*
- *How is the 3.5 per cent increase in a state or territory's contribution to the full scheme calculated? Is this reasonable? Will it skew the balance of the funding over time? If so, what are the implications? Is there a better way to index contributions?*
- *How will Western Australia's agreement with the Commonwealth Government affect scheme costs?*
- *Is there a better way of paying for the NDIS? For example, would it be better to fully fund the NDIS out of general revenue?*

Does the current funding split between the Commonwealth and the States and Territories have implications for the scheme's sustainability? Does it affect the NDIA's capacity to deliver disability care to scheme participants at the lowest cost? Are there any changes that could be made to the funding split that would either improve the financial sustainability or the efficiency of the scheme?

Yes, the current funding split puts the NDIS at enormous risk. Each separate funder of the NDIS is a separate point-of-failure.

What proportion of a state or territory's contribution to the NDIS are in-kind services? Are there risks associated with in-kind service contributions?

A4 is not aware of any "in-kind services" from states or territories that are regarded as NDIS contributions.

Often, the Commonwealth "privatise regardless" approach does not meet state/territory governments' "doing it my way" approach. For example, the ACT Governments attempts to provide its own service along-side HCWA funded services was a shambles.

What are the implications of the current risk sharing arrangements? Do they encourage either cost shifting or overruns? What, if any, improvements could be made to the current risk sharing arrangements?

"Risk sharing" is a bureaucratic euphemism. Splitting responsibilities between federal and state/territory government results in service gaps, not in "cost shifting and overruns". For example, both states/territories and the NDIA refuse to accept/recognise responsibility for accommodation for children with disability who cannot live at home with their family. This

issue emerged over 10 years ago but little progress was made since. The NDIS ignores the accommodation needs for these vulnerable NDIS participants.

With the arrival of the NDIS, the intersection between education, health, etc. and disability services and supports is confused, to say the least.

For example, states seem to have shifted responsibility for transporting students with disability who travel to specialist education settings from being “access to appropriate education” (education responsibility) to “disability transport” (NDIS responsibility).

How is the 3.5 per cent increase in a state or territory’s contribution to the full scheme calculated? Is this reasonable? Will it skew the balance of the funding over time? If so, what are the implications? Is there a better way to index contributions?

A4 cannot answer about this.

How will Western Australia’s agreement with the Commonwealth Government affect scheme costs?

A4 is disappointed that Western Australia refused to participate in a national scheme to improve the lives of people with disability. The NDIS should be a national scheme; it should be the same in all states and territories.

Is there a better way of paying for the NDIS? For example, would it be better to fully fund the NDIS out of general revenue?

A4 does not have expertise in government funding mechanisms.

From what little we know, it would seem that it would be better to fund the NDIS from general revenue.

- *How should the financial sustainability of the NDIS be defined and measured?*
- *What are the major risks to the scheme’s financial sustainability? What insights do the experiences from the trial sites provide on potential risks in the context of financial sustainability? How might the NDIA address these risks?*
- *Does the NDIA’s definition of financial sustainability have implications for its management of risk? Are there risks that are beyond the NDIA’s remit?*
- *How does the NDIA progress from identifying a risk to managing it through changes in the delivery of the scheme? Are there any barriers to the NDIA doing this effectively?*
- *Are there changes that could be made to improve the NDIA’s management of risk? Should more details about the NDIA’s risk management practices be publicly available?*
- *Does funding the NDIA on an annual basis affect its management of*

risk?

- *Are there other ways the scheme could be modified to achieve efficiency gains and reduce costs?*
- *What are the likely longer-term impacts of any cost overruns? How should any cost overruns be funded?*

How should the financial sustainability of the NDIS be defined and measured?

Maybe “sustainability” is the wrong notion. It is more about benefit versus cost, and people having a reasonable standard of living in our community.

What are the major risks to the scheme’s financial sustainability? What insights do the experiences from the trial sites provide on potential risks in the context of financial sustainability? How might the NDIA address these risks?

The biggest risk is politicians, bureaucrats, journalists and people generally who think everyone with disability is a bludger and a rorter. The actual amounts of money is not the issue.

The NDIA could respect its clients far more. Currently, it believes there is a large proportion of families whose child has an incorrect autism diagnosis. It expects that there are massive efforts to rort the system.

It could engage with ASD stakeholders to develop better policy and systems for autistic participants.

Does the NDIA’s definition of financial sustainability have implications for its management of risk? Are there risks that are beyond the NDIA’s remit?

The negative views of politicians and journalists are outside the NDIA’s remit.

How does the NDIA progress from identifying a risk to managing it through changes in the delivery of the scheme? Are there any barriers to the NDIA doing this effectively?

The view of political masters and its senior bureaucrats are barriers to the NDIA effectively minimising risk.

Are there changes that could be made to improve the NDIA’s management of risk? Should more details about the NDIA’s risk management practices be publicly available?

Yes and Yes.

Does funding the NDIA on an annual basis affect its management of risk?

We have been told that the funding is uncapped. This may be untrue.

In any case, annual funding is common practice for Government agencies; it should be manageable.

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

Almost certainly. A4 is happy to engage with the NDIA or anyone else if they actually wants to discuss such matters.

What are the likely longer-term impacts of any cost overruns? How should any cost overruns be funded?

There would need to be honest disclosure of reasons for any cost overruns. Currently, the NDIA refuses to admit there is even a risk of cost overrun ... due to variations from initial estimates of numbers and costs.

Governments that ignored advice on numbers and costs should pay for the mistakes they made.

Governments should not make people with disability pay through having funding for their plans cut.

Conclusion

Previously, we said that the NDIS has substantial potential to improve the lives of autistic people. They may have access to more services and supports. They more have more choice and control of the services and supports they access.

The hyperbole associated with the introduction of the NDIS is enormous: people's expectations of what the NDIS will deliver is often excessive. The NDIS does not deliver all that people hope.

The reality is that many people, including some autistic people, are better off as NDIS participants than they were previously.

Regrettably, the NDIS is well short of the best it could be for autistic people mainly because the NDIA has failed to appreciate

- the distinct nature of ASD,
- the growing number of autistic people who need services and supports,
- the need for behavioural support for autistic adults and teenagers,

- the gaps in accommodation services for autistic people who cannot/do not live with their parents,
- the value of engagement with ASD-related stakeholder, and
- the nature and value of effective early intervention for ASD.

The NDIA can easily address some of these issues. A4 also appreciates that growth in the number of autistic people is a serious political challenge for the NDIA.

The submission above was prepared quickly and with insufficient resources. We apologise that it is poorly written and often unclear.

We hope A4's submission helps your study.