

Summary of NDIS Costs Position Paper and AASS submission response

It is encouraging to seek such a thorough and comprehensive document that has not shied away from highlighting the issues present within the current NDIS system.

LINK - http://www.pc.gov.au/inquiries/current/ndis-costs/position/ndis-costs-position-overview.pdf?utm_source=DSC+Contacts&utm_campaign=e9823461c4-EMAIL_CAMPAIGN_2017_02_20&utm_medium=email&utm_term=0_153f43591e-e9823461c4-

How the Scheme is tracking	
	AASS Comment
<p>DRAFT FINDING 2.1 The scale and pace of the National Disability Insurance Scheme (NDIS) rollout to full scheme is highly ambitious. It risks the National Disability Insurance Agency (NDIA) not being able to implement the NDIS as intended and it poses risks to the financial sustainability of the scheme. The NDIA is cognisant of these risks.</p>	<p>All states in Australia are rolling the scheme out over 2 years, except for NSW who are rushing to roll out in 1 year. Due to the capture of unreliable and incorrect data, many regions in NSW have seen a budget blowout within the first 2 months of NDIS implementation. SW Sydney is a perfect example of this. NDIS planners in this region, especially in Liverpool run the risk of offering plans that contradict the legislation , opening up potential litigious claims by participants.</p> <p>With the impartial nature of plans, and questions that are aimed towards participants with a physical disability and not an invisible disability, plans are subjective and offer either too much or too little funds.</p> <p>The best alternative is to offer a lump sum to families to spend within the NDIS boundaries. This will allow a quicker and more partial roll out for the first plan.</p>
	AASS Comment
<p>DRAFT FINDING 2.4 Early evidence suggests that the National Disability Insurance Scheme is improving the lives of many participants and their families and carers. Many participants report more choice and control over the supports they receive and an increase in the amount of support provided. However, not all participants are benefiting from the scheme. Participants with psychosocial disability, and those who struggle to navigate the scheme, are most at risk of experiencing poor outcomes.</p>	<p>Sadly the data collected does not reflect the experiences of families in SW Sydney. These families are from CALD backgrounds where English is not their first language and are from low socio economic communities. Many parents have a disability themselves. AASS have clients who requested a translator to assist in understanding NDIS questions. Most translators and planners do not understand the range and complex nature of disabilities and as a result the questions were not asked in context and participants received a poorly funded plan.</p> <p>We have examples of plans that do not reflect the needs of the participant.</p>

	<p>EG participant who is 16 years old with Autism, Developmental delay, sensory processing disorder, non verbal, increasing violence and aggression towards his single Mum and school where he is continually suspended. His plan offered \$16,000 in core supports so he can “engage in the community” and \$5,000 for therapies. <u>This young boy does not have the functional behavior to engage in the community.</u> The plan is suggesting that there is no hope for him to learn functional behavior yet this is not the case and it contradicts everything the NDIS stands for.</p> <p>After appealing this plan as instructed by the planner back in April, I was informed this morning (19.7.17) by “Christine” from the NDIS that the plan appeal has been rejected because:</p> <ul style="list-style-type: none"> * \$1700 has already be spent on in therapies – why? * why is the participant not accessing Medicare items? * when reminded the participant has been suspended from school (the last time for 20 days) the NDIS worker said the participant needs to access the school councilor for behavior management, not the NDIS plan. <p>THIS INFORMATION CONTRAVENES THE LEGISLATION AND EVERYTHING THE NDIS STANDS FOR. This situation is common, especially for families who access the Liverpool NDIS office.</p>
AASS Suggestions	
<p>INFORMATION REQUEST 3.1</p> <p>The Commission is seeking feedback on the advantages and disadvantages of maintaining ‘List D — Permanent Impairment/Early Intervention, Under 7 years — No Further Assessment Required’ in the National Disability Insurance Agency’s operational guidelines on access. Feedback is sought on the extent to which the list:</p> <p><input checked="" type="checkbox"/> reduces the burden on families to demonstrate that their child will benefit from early intervention and/or provides certainty that support will be provided</p> <p><input checked="" type="checkbox"/> reduces the burden on the National Disability Insurance Agency of assessing whether children are eligible for early intervention support under the National Disability Insurance Scheme Act 2013 (Cwlth)</p>	<p>An automatic right for children to access early intervention therapies (EIT) without the need is welcomed.</p> <p>The cultural barriers already faced by parents with children in need of EIT (ie stigma from within their community) often mean active avoidance of an official diagnosis resulting in loss of critical time and intervention therapies that are crucial to setting children up for success.</p> <p>Adding bureaucratic barriers for families already facing crisis compounded by cultural barriers, especially those prevalent in lower socio-economic areas will see scheme avoidance resulting in untreated individuals needing welfare support later in life and in many cases entering the criminal justice system</p>

<p>☐ may be contributing to supports being provided to children who are unlikely to benefit from such supports</p> <p>☐ may be discouraging or inhibiting exit from the scheme</p>	<p>Doctors and allied health professionals are best placed to identify the intervention needs of 0-7yo. Empowering doctors to continue through the GP medical plan program and that plan is a “deemed” NDIS plan, means NDIA will have no need to make ill informed medical guesstimations.</p> <p>As a minimum this GP Plan could be used as an interim NDIS planning process</p>
AASS Suggestions	
<p>INFORMATION REQUEST 3.2</p> <p>The Commission is seeking feedback on the benefits and risks of maintaining ‘List A — Conditions which are Likely to Meet the Disability Requirements in section 24 of the NDIS Act’. In particular:</p> <p>☐ to what extent does List A reduce the burden for people with permanent and significant disability of entering the National Disability Insurance Scheme under the disability requirements?</p> <p>☐ is there any evidence that people who do not meet the disability requirements are entering the scheme under List A?</p>	<p>For Autism, list A conditions state;</p> <ol style="list-style-type: none"> 1. Autism diagnosed by a specialist multi-disciplinary team, pediatrician, psychiatrist or clinical psychologist experienced in the assessment of Pervasive Developmental Disorders, and assessed using the current Diagnostic and Statistical Manual of Mental Disorders (DSM-V) diagnostic criteria as having severity of Level 2 (Requiring substantial support) or Level 3 (Requiring very substantial support) <p>Prior to 2013, most individuals diagnosed with autism do not have this severity level. People and families who come from CALD backgrounds will be at a disadvantage in gaining access to the NDIS if they can’t produce this document. No, list A does not necessarily reduce the burden of people with permanent or significant disability.</p> <p>Most people who are diagnosed with autism are diagnosed with co-morbid conditions. How will this affect NDIS entry for people who are Autism Level 1?</p>

SCHEME SUPPORTS	AASS Suggestion
<p>INFORMATION REQUEST 4.1</p> <p>Is the National Disability Insurance Scheme Act 2013 (Cwlth) sufficiently clear about how or whether the ‘reasonable and necessary’ criterion should be applied?</p> <p>Is there sufficient clarity around how the section 34(1) criteria relate to the consideration of what is reasonable and necessary?</p> <p>Is better legislative direction about what is reasonable and necessary required?</p> <p>If so, what improvements should be made?</p> <p>What would be the implications of these changes for the financial sustainability of the scheme?</p>	<p>No. Most planners come from an administrative background and have no educational experience or lived experience of what disabilities are (we are often asked what is Autism by planners) nor understand relevant questions to ask in order to extract meaningful data from participants or their families.</p> <p>No and NDIA don’t provide any advice or guidance. LAC are actively misleading claimants eg LACS in planning meeting telling parents “you won’t get that Im not going to put that in? How I that empowering client centric decision-making? Planners in the Liverpool office are telling participants you cannot receive music therapy as we don’t have enough money. This contravenes the legislation as well as takes choice and control AWAY from the participant. The NDIS should have a clear and transparent definition of reasonable and necessary and not leave this to the opinion of planners who have no understanding of disabilities.</p> <p>More rules is NOT the answer, practical application of how the scheme work, with consistent messaging from the regulator- who monitors LACs not parents is the key.</p> <p>Offer participants a sum of funding (eg \$20,000) from which they can purchase NDIS approved therapies. THIS is the definition of choice and</p>

	<p>control. Participants understanding they have financial boundaries can then best work out for their own needs where to allocate the funds.</p> <p>Given this, there should be a minimum amount of funds allocated to service providers to provide meaningful and substantial support to participants. This will also support the sustainability of organizations.</p> <p>Self assessment guidance materials, case studies of what the threshold benchmarks are, monthly information sessions/ workshops where parents can go – like a ‘study centre’ model lead by a facilitator that understands NDIS planning and can workshop through the forms and have interpreters present.</p> <p>Lack of support will mean no uptake and greater burden on health care and justice systems in the long term.</p>
AASS suggestion	
<p>INFORMATION REQUEST 4.2</p> <p>Should the National Disability Insurance Agency have the ability to delegate plan approval functions to Local Area Coordinators?</p> <p>What are the costs, benefits and risks of doing so?</p> <p>How can these be managed?</p>	<p>Why create a whole new level of bureaucracy. Drs know what is wrong with patients, why can't they fill out the plans? Having LACS both creators, facilitator and approver, creates conflicts of interest and exposes the system for backdoor deals especially given we are already dealing with vulnerable community. (similar to the VET fee help dilemmas)</p> <p>AASS have LAC's contacting us to offer advice on where supports can be found and even advice on Autism. It is not sustainable to AASS to have staff productivity focused on providing a free service to a very well funded LAC.</p>
AASS Comment	
<p>DRAFT RECOMMENDATION 4.1</p> <p>The National Disability Insurance Agency should:</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review <input checked="" type="checkbox"/> review its protocols relating to how phone planning is used 	<p>Agree, in fact phone planning should only be used;</p> <ol style="list-style-type: none"> 1. When the participant agrees to it as an initial planning meeting; or 2. used to clarify information after an in-house scheduled session has already been held <p>The main issue is not the planning process. The issue arises in planners who do not take up all the relevant information provided in the plan, their lack of</p>

<p>☑ provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants’ rights and options</p> <p>☑ ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants.</p>	<p>understanding and knowledge of disabilities and, as a result, plans that are poorly funded, funding allocation in clusters that are restrictive to the needs of the participant and non reflective of the participants daily needs.</p> <p>Review protocols are not clear and different people that you speak to on the 1800 800 110 numbers provide different information where, at times, planners have said that “you have been given the wrong information” or “you are in between the old system and the new system”.</p> <p>Providing this information in general would be helpful for participants, families and service providers.</p>
<p>DRAFT RECOMMENDATION 4.2</p> <p>The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise</p>	<p>Yes. All planning teams should have consultant experts that deliver continual training programs, and be called on to triage matters, or LACS should specialise in different areas to build expertise faster</p>
<p>Boundaries and interfaces with the NDIS</p>	
<p>AASS Response to Draft Recommendation</p>	
<p>DRAFT FINDING 5.1</p> <p>It is a false economy to have too few resources for Information Linkages and Capacity Building, particularly during the transition period when it is critical to have structures in place to ensure people with disability (both inside and outside the National Disability Insurance Scheme) are adequately connected with appropriate services.</p> <p>DRAFT RECOMMENDATION 5.1</p>	<p>Why is the government throwing good money after bad? This is bandaiding a skills and knowledge gap.</p> <p>The infrastructure and governance framework necessary to assess an individual’s medical needs and connect them with services already exist- use them.</p> <p>Doctors are best placed to program a patients needs.</p>

<p>Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount (of \$131 million) for each year during the transition. The funds that are required beyond the amounts already allocated to ILC to reach \$131 million should be made available from the National Disability Insurance Agency’s program delivery budget. The effectiveness of the ILC program in improving outcomes for people with disability and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed five-yearly review of scheme costs. The ILC budget should be maintained at a minimum of \$131 million per annum until results from this review are available.</p>	<p>Redirect the \$131M into the medicare scheme with a medicare line item allowing doctors to spend time with patients to prepare proper plan and refer them to relevant services.</p> <p>GPs have a broad network of relevant service providers they are already referring to. They do similar work for disability and carers pensions already. How would I change the NDIS?</p> <p>More medicare funded assessment teams led by a pediatrician to provide assessments. Once a participant is deemed to have a lifelong disability (there is no cure for Autism), they then get NDIS funding based on the Dr’s assessment of need (this can be based on level of severity and family need) Eg level 1 \$15,000 p/a, level 2 \$25,000 p/a etc</p> <p>The participant is then free to spend the funding with NDIS approved therapies and items.</p> <p>If modifications, equipment, or extra funding for respite is required then a review takes place with experienced staff who have had either working or lived experience with disabilities.</p>
AASS Suggestion	
<p>INFORMATION REQUEST 5.1 The Commission is seeking feedback on a mechanism to ensure that the States and Territories bear the cost of participants who were intended to be covered by the National Injury Insurance Scheme.</p>	<p>States and Territories have already stopped services for NDIS areas that have rolled out. The issue is that there are people with disabilities that are not able to access services under state and NDIS.</p>
Provider Readiness	
AASS Response to Draft Finding	
<p>DRAFT FINDING 6.1 In a market-based model for disability supports, thin markets will persist for some groups, including some participants:</p> <p>☑ living in outer regional, remote and very remote areas</p>	<p>Given Australia is a multicultural nation and highest prevalence of Autism is within western Sydney, suggesting CALD representing a thin market is concerning and goes to the core of fundamental issues with the funded client centric model.</p>

<ul style="list-style-type: none"> ☑ with complex, specialised or high intensity needs, or very challenging behaviours ☑ from culturally and linguistically diverse backgrounds ☑ who are Aboriginal and Torres Strait Islander Australians ☑ who have an acute and immediate need (crisis care and accommodation). <p>In the absence of effective government intervention, such market failure is likely to result in greater shortages, less competition and poorer participant outcomes.</p>	<p>Holding certified NGOs accountable is easier than tracking and managing a multitude of CALD participants that don't speak the language and in many cases lack the education and intellectual capacity to understand the decision they need to make.</p>
AASS Suggestion	
<p>INFORMATION REQUEST 6.1 In what circumstances are measures such as:</p> <ul style="list-style-type: none"> ☑ cross-government collaboration ☑ leveraging established community organisations ☑ using hub and spoke (scaffolding) models ☑ relying on other mainstream providers appropriate to meet the needs of participants in thin markets? <p>What effects do each have on scheme costs and participant outcomes? Are there barriers to adopting these approaches? Under what conditions should block-funding or direct commissioning of disability supports (including under 'provider of last resort' arrangements) occur in thin markets, and how should these conditions be measured? Are there any other measures to address thin markets?</p>	<p>Fund NGO/agencies that are servicing these thin market areas to build the business supports necessary to help client's access services.</p> <p>Current funding mode simply encourages collusion between provider and client, eg use us and we will do xyz or sign off on abc</p> <p>Money needs to go the sources that can support the clients getting the service.</p> <p>Thin market NGO could receive 'set client allocations' based on predetermined standards and the NGO can work for the client and receive payment structure similar to Perpetual trustee method or as a % loading based on client complexity.</p> <p>The 'user choice' component is still satisfied as the NGO will prequalify through the NDIS accreditation process and is a provider of choice services.</p>
AASS Suggestion	
<p>INFORMATION REQUEST 6.2 What changes would be necessary to encourage a greater supply of disability supports over the transition period? Are there any approaches from other consumer-directed care sectors — such as aged care — that could be adopted to make supplying services more attractive.</p>	<p>If not funding the NGO administrative costs , then provide infrastructure-policies frameworks, corporate services and co-operative models necessary to deliver to thin markets.</p>
Workforce Readiness	

<p>INFORMATION REQUEST 7.1 What is the best way for governments and the National Disability Insurance Agency to work together to develop a holistic workforce strategy to meet the workforce needs of the National Disability Insurance Scheme?</p>	<p>AASS Suggestion Dissolve the NDIA- redirect planning to GPs and other health professionals and leave the administration of claims to the health funds. Redirect all the money used in the current complex government regime to fund NGO administration in thin market areas and cover some cost for health insurers now overseeing claim payments.</p>
<p>INFORMATION REQUEST 7.2 How has the introduction of the National Disability Insurance Scheme affected the supply and demand for respite services? Are there policy changes that should be made to allow for more effective provision of respite services, and how would these affect the net costs of the scheme and net costs to the community?</p>	<p>AASS Suggestion NDIs does not recognize the word “respite” and for younger participants, planners have stated that this is the responsibility of the family. Under Social and community participation- respite providers in the SW area of Sydney have a very long waiting list and are not able to meet the demand of participants wanting services. NDIS need to recognize that Respite is a necessary tool that enables families to cope and continue to provide to care for their loved ones rather than face the possibility of relinquishing care altogether, which would be more costly for the government.</p>
<p>Participant Readiness</p>	
<p>INFORMATION REQUEST 8.1 Is support coordination being appropriately targeted to meet the aims for which it was designed?</p>	<p>AASS Suggestion Support Coordination has been very helpful for families who don’t know how to navigate the system. The only issue is that not all Support Coordinators are aware of what is required of them and therefore participants may wait a long period of time before they are even contacted. The NDIA and LAC have different processes- sometimes services are sent Request for Support Coordination and sometimes not. It needs to be consistent.</p>

	AASS Suggestion
<p>INFORMATION REQUEST 8.2</p> <p>Is there scope for Disability Support Organisations and private intermediaries to play a greater role in supporting participants? If so, how? How would their role compare to Local Area Coordinators and other support coordinators?</p> <p>Are there any barriers to entry for intermediaries?</p> <p>Should intermediaries be able to provide supports when they also manage a participant’s plan?</p> <p>Are there sufficient safeguards for the operation of intermediaries to protect participants?</p>	<p>Yes</p> <p>Yes – costs of establishing a business, and attracting and retaining talent</p> <p>No,</p> <p>No – see earlier comments</p>
Governance	AASS Suggestion
<p>INFORMATION REQUEST 9.1</p> <p>The Commission is seeking feedback on the most effective way to operationalise slowing down the rollout of the National Disability Insurance Scheme in the event it is required. Possible options include:</p> <ul style="list-style-type: none"> ☐ prioritising potential participants with more urgent and complex needs ☐ delaying the transition in some areas ☐ an across-the-board slowdown in the rate that participants are added to the scheme. <p>The Commission is also seeking feedback on the implications of slowing down the rollout.</p>	<p>See earlier comments about using GPs/other health professionals and having their plans as a minimum sitting as a defacto or interim NDIS plan.</p>

Funding Arrangements	
	AASS Suggestion
<p>INFORMATION REQUEST 10.2 The Commission is seeking information on the best way to align the ability to control cost overruns with the liability to fund cost overruns.</p> <p>Possible options include:</p> <ul style="list-style-type: none"> ☐ estimating the proportion of cost overruns that the Australian and State and Territory Governments are responsible for and allocating funding responsibility accordingly ☐ altering the governance arrangements of the National Disability Insurance Scheme to give the Australian Government greater authority to manage the risk of cost overruns, to better reflect their funding liability. 	
<p>INFORMATION REQUEST 10.3 The Commission seeks feedback on the level of a future contingency reserve that would enable the National Disability Insurance Agency to operate like an insurance scheme, and how this would best be implemented, including any transitional arrangements.</p>	<p>10.3 Currently there is a disparity around Australia with plans, understanding of phrases such as “reasonable and necessary” and even basic understanding by planners of various disabilities and the level of need required by participants.</p> <p>In order for an insurance scheme to be successfully implemented, one would require specific and clear policy and/or guidelines that stipulates what is required for the participant. This may be acceptable for individuals with a physical disability, however for those with invisible disabilities, the needs are varied and can be quite complex given comorbid diagnoses.</p> <p>EG 2 participants with ASD level 2 can have differing needs due to differing comorbidities. One may be verbal and the other may be non verbal. One may have violent/aggressive behaviours where the other may not.</p>

	<p>I propose a two pronged scheme.</p> <ol style="list-style-type: none"><li data-bbox="1060 110 1974 248">1. Keep the current format for participants with a physical disability. Ensure the process is clear with no room for subjectivity. There may need to be a cap to items such as modifications however therapies and support staff MUST be uncapped and in accordance to need.<li data-bbox="1060 256 1974 673">2. For participants with an invisible disability. There needs to be a different approach as their needs are different to those with a physical disability. The current questions n the planning process are aimed at physical disabilities making it difficult to get a clear picture of the participants needs. At the very worst, I would like to see a lump sum awarded to each participant for use in any NDIS approved cluster of supports. Currently participants are restricted to the poor amounts awarded in each cluster that do not reflect the individual needs. This means that more plans are being reviewed unnecessarily. Perhaps have levels of funding eg lvl 1 , \$15,000 Lvl 2 \$20,000 and Lvl 3 \$25,000 The only time these need to be reviewed are if the funding has been used. Given the restriction on therapists and respite places it will be difficult to spend these funds frivolously. This way participants really do have choice and control and are not being dictated to in line with legislation and rhetoric.
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