

Productivity Commission National Disability Insurance Scheme Costs

Comments against the Issues Paper of February 2017

These are my personal observations of the scheme and are supplied without prejudice.

The main points I wish to raise in my submission are

- 1) The NDIS needs to be totally funded by Federal Government.
- 2) Have a national approach to the operation guidelines
- 3) The speed of the rollout needs to be slowed so ALL issues can be addressed
- 4) Planning sessions need to be attended by professional well trained NDIS staff who understand difference between high and low need participants
- 5) Updating or review of annual plans need to be better organised
- 6) Funding Family Carers
- 7) Funding is required for repair and maintenance of Adaptive Technology equipment
- 8) The NIIS and NDIS need to be combined

These items are not in any order of priority, they are just areas where the NDIS could be improved.

I am aware of the NDIS through people in the industry and have registered as a Provider. I am making this submission as an individual.

The NDIA has to accept the fact **each participant is different** and a general model or set of parameters or new assessment tools will turn into a disappointing and frustrating environment for participants, carers, support people, plan coordinators and administrators.

Thank you for the opportunity to comment on the NDIS.

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24 March 2017

Detailed information on each of the above topics

1. A National Scheme

The NDIA was setup as national scheme but the funding for the scheme is shared between the Commonwealth, State and Territory Governments. As noted on Page 29 of the Issues Paper the Commonwealth Government only contributes 40.6% of costs during the initial stages. The State and Territories cover the rest. When fully operational there will be some funding arrangements, all to be decided at some later stage.

From the NDIS web under Governance

The Australian Government will provide funding of \$11.7 billion to the National Disability Insurance Scheme in 2019-20, the first year after the full national rollout. This is 53 per cent of the \$22.2 billion total cost of running the National Disability Insurance Scheme, with the States and Territories providing the remaining funding. (<https://www.ndis.gov.au/about-us/governance/federal-funding>)

As was seen in the ACT the Territory initially funded for 5075 but 5229 (from NDIS Annual Report 2016) applied to enter the scheme. This has been repeated in other jurisdictions from information in the NDIS Annual report.

If this was a truly federally funded scheme then the States and Territories could close down all the miscellaneous funding they provide now specifically related to NDIS activities. Many of these schemes are winding down but they need to be completely closed. This will cause problems where community groups have had funding either through State or Territory. This would free up staff and resources for other state activities or could easily be transposed to the national scheme.

The Commonwealth needs to take total control of funding the complete NDIS once it is nearing full operational status. An amount needs to be extracted from the State and Territory Governments equivalent to current funding. NO new money is to be given the states and territories to fill this gap. The state and territories do not have to find money to contribute to the NDIS or other activities required for participant need.

On page 30 of the Issues paper the States and Territories can add their contributions in kind. With their own interests at stake I believe the States and Territories will be creative in their accounting. There are many Government funded (supplied) houses that will need replacing over time. The NDIS needs to address this issue for disability participants. The States and Territories need to fund housing for low income or other state residents.

A final point on the National Scheme. Fund the NDIS to the level it was intended. The \$22Billion per year was a guide. It appears with a blowout of costs particular areas are being targeted for drastic cuts, which will in time make some large supportive companies to close down with the loss of knowledge and vast experience base. Once these staff are gone it will extremely difficult to restart with years of talented people in the disability industry gone. The frustration levels of individuals within companies now is disturbing as the NDIA pushes for such small savings.

As the number of participants has been under estimated the sustainability of the scheme is under current and future cost pressures. This was evident with the ACT

government freezing new participants. Accept the funding is inadequate and the Federal Government needs to make hard decisions in collecting more money.

The only way to guarantee funding and have the NDIS costed is to remove the States and Territories from the equation have it totally controlled federally. The Federal government then can decide if more money is required, which it will, then it can levy taxes (unpopular) but there are enough spin doctors in the system to explain where the taxes are going. The Federal Government has to be clear in allocating the money collected into the scheme. (A big ask but is necessary)

On Page 10 the Issues Paper asks about costs. One obvious cost not included in the flowchart is the AT. It is not just the initial purchase price but ongoing maintenance repair. AT will be a \$1Billion expense to the fund each year (NDIA information) More reuse of AT, where practical, has to occur. Occupation Therapists can't keep ordering new equipment, although easier.

The States and Territories need to be responsible for health care, education and these need to be funded from respective budgets. As noted on page 15 of the Issues Paper the boundaries need to be defined so duplication or gaps do not hinder the outcomes required by participants.

With the Federal Government in control it can guide the NDIS. With the State and Territory having to contribute then it becomes a scheme of compromise.

Page 31 question are addressed above.

2. Combing National Injury Insurance Scheme (NIIS) with NDIS

The NIIS was setup to support catastrophic injuries from motor vehicle accidents, workplace accidents, medical treatment or general accident. The funding for these classes of injury is funded through levies and various premiums. It was to be fully and independently funded.

This may have been the correct way forward at the time when the schemes were setup. Having the Schemes operating now for several years and seeing the same activities being performed, eg planning, support and Assistive Technologies (AT) delivered by both Schemes it is time to combine.

In the ACT the functions of managing the few cases are managed through iCARE in NSW.

The collection of money from car insurance and Works Compensation is to remain with any participant that is classified as a catastrophic injured person could be flagged and funding from the State and Territory collection schemes. The funds could be transferred to support these people. Is the initial hospital stay funded by the States and Territories (or Private Health funds)?

The NIIS payment is already compromised in the ACT. Instead of paying the levy to the NIIS fund the ACT government passed legislation covering potential participants driving ACT government owned vehicles like buses, fire trucks and ambulances. The

ACT government should have been a good citizen and paid the NIIS levy. The cost of extending the scheme to cover those catastrophically injured in the ACT as a result of an accident with these ACT government vehicles will be managed through the ACT government's usual insurance arrangements and hence will not affect the determination of the Lifetime Care and Support (LTCS) levy for motor vehicles. (Legislative Assembly for the ACT 2016 Week 5 Hansard (5 May) Page 1566).

There are differences between the two Schemes but with suitable legislation that could be fixed. For example NIIS covers oversea participants whereas NDIS limits support overseas. Supporting participants that move overseas is ridiculous.

Efficiency gains and cost saving can be achieved by combining the function of NIIS and NDIS.

3. Planning Sessions need well trained staff

Planning sessions need to have well trained staff that can judge the level of support required by the participant. It is not difficult if it is a plan review at the anniversary. The NDIS staff can see what was used and not used in the previous plan. New Items could be added and ones not used can be subtracted.

Many participant have English as a second language. They have a different attitude to the access to the NDIS. The Government has sold the idea of participants being fully supported and for life.

Better education and better training for all in writing and reviewing plans to reduce the waste and allocation of resources when there is limited uptake of services.

I have knowledge of high needs participants. Low needs people may find planning session a lot easier and achieve desired outcomes.

It appears participants that have had major plans that run into several hundreds of thousand dollars have only 10 hours to manage this. The normal amount should have been at least 100 hours a year.

To obtain a review is near impossible to get or takes months. The planners have been told to use up the allocated money then reapply. This is non-sense when the initial planning or on going planning session can easily identify the people who need high contact in organising support workers.

Proper levels of support required. I know of companies having planning coordination hours cut from 100 hours a year (2 hours per week) to 10 hours for the complete year. Participants are on packages of around \$300k per annum. There appears to be no reason for the cut and having a review is getting to be a traumatic, frustrating experience, wasting more time than was cut in the first place.

High need participants require massive care hours in having two people to feed three meals each day and support of personal hygiene. Even to manage their daily existence. Many times, although support staff are allocated, sometimes things go wrong then the planner is required to find other people to fill shifts etc.

Many participants are in their own homes. The alternative is removing these participants to nursing homes or worse being forced into group housing where few staff can manage multiple participants. This model is back to the old days of care. All we need now are the fences to go up. This is not the model for inclusion into the community, or giving participants to the live a normal ordinary life. Planning to keep people in the own house, with the required and supportive staff is essential. This only happens through positive planning activities, which unfortunately are not happening enough.

On page 5 of the PC Issue Paper Feb 2017 it states the *NDIS is about ensuring people with disability can get out and about in the community – its about getting them to work, to school and to cafes and restaurants so they can catch up with family and friends. It's also making it possible for them to participate in everyday life with their families*". This maybe an admirable vision for people with mild disability but someone who is bed ridden and is an effort to eat and shower the system is completely failing. The coordination required for these participants is grossly inadequate with the NDIS on, it appears, a mission to limit coordination planning hours to support these people to reduce overall NDIS costs.

It appears that cost overruns are driving the funding and level of care already. As a tax payer I do not want to see waste in the system but we have the NDIS so fund it adequately.

The planning sessions need much improvement with more face to face commitment from NDIS staff.

4. Updating Plans

All plans need to have the default annual review. Having said that each plan needs to be able to be reviewed and changed through a convenient and proper process. A complaint is annual plans being reviewed early and other plans having to rollover for months. This is totally unsatisfactory.

When a new plan is approved by NDIS there needs to be an easy and quick review turn around if participant, family carer or support planner coordinator have an issue with what is being offered. Words like "live with it" have been heard when support and coordination hours have been drastically reduced. In one case a quadriplegic person needing many support people and coordination hours had a plan that was to cost over \$200,000 reduced by more than half. A review could not be easily scheduled with NDIS and it is expected that the review could be in the system for 6 months. This is appalling when the issues could be resolved if all parties were able to sit down and discuss the reasons why such a big reduction at the time of the plan approval.

More to the point the NDIS staff obviously had little understanding of the needs of the participant. Maybe the participant's goals and objectives and aspirations were not articulated to the satisfaction of the NDIS reviewer and it did not meet the tick and flick template.

To review and rework a plan takes time and money both for the participant (or coordinator/family) and the NDIS. The NDIS needs to lift its game in this area to minimise any reviews. When plans get underfunded frustrations with NDIS are happening. If the NDIS thinks participants are gaming the system then visiting the participant and having concerned people around could easily solve the issue in one meeting.

When new information comes to light with the participants plan during the plan period then an amendment needs to occur. It appears now that the complete plan needs to be addressed when only a small component needs modifying. This wastes participants, planners and NDIS staff time and costs the money in doing so. If a plan needs modification due to changed circumstances then and the Plan manager believes that it is generally a minor change then only this component needs to be reviewed. The complete plan needs to be read by all parties to confirm relevance but only the new component needs to be accessed in detail with either an approval or rejection. Examples of quick plan reviews are needed when no money has been set aside for repairs for Assistive Technologies (AT), like beds and wheel chairs. A quick response is need from the NDIA staff. As more plans are developed and better understanding of the equipment in use funds for repairs will be included. This will include the hire of replacement AT while the original equipment is repaired.

As noted above Plans should only be update on their anniversary, plus and minus a week or two. This is not happening at present with various plan reviews having to be hurriedly assembled due to NDIS wanting to bring forward the review.

What is included in a participants plan In Box 2 of the Issues Paper on page 18 states ‘The reasonable and necessary supports that will be funded under the NDIS and information about the review and management of supports and the plan’ It also states that the plan is prepared with the participant, which I believe NOT to be true. The participant prepares their first plan with supporting evidence forwards to NDIS. If accepted then a further planning session is undertaken with participants, coordinators and NDIS. The NDIS goes away and presents the plan with no further discussion. The last step is flawed especially for high needs people.

Support staff need more certainty in their working lives. Either through being a Provider (which many do not want) or if employed through a company these people need to have job security in becoming permanent part time rather just casual. This will only be achieved through the NDIS approving plans without the frustration of having to return for review. The example given in this submission where an extreme high needs person had their well costed plan halved in value. With activities like this support staff can’t be paid. In this instance it was a failure of NDIS.

To answer the question on Page 18 as to ‘Is the planning process valid, cost effective, reliable, clear and accessible’ is a resounding NO from knowledge I have. My comments are based for high needs participants. The system may work for easy low needs participants.

6. Assistive Technology – Repair and Provision

Funding as available for purchase of AT under the various funding structures but little is found for the repair of this equipment. If a plan does not include repairs then a review is needed through the NDIA. The Plan Review is a miserable time wasting task to undertake for a small value item a better process is required. The NDIS needs to be able to respond to simple requests for funding increases to support the repair. As time progresses and participants become more aware and Support Reference Item Numbers are added then these will be included in the annual participant plans.

There is a lack of funding, with no known Support Item Reference Number for home maintenance eg repair of ramps or repair of other property damaged due to beds and wheel chairs being moved. In government housing it is assumed that the local government will repair on a needs basis but home owners supporting participants need some way to recover some money to repair then make good the areas so the repairs are not needed again. Eg gyprock walls where beds and wheel chair destroy the wall need to be repaired then more substantial skirting boards of metal needs to be added. If Government housing can be fixed then individual property owners need to be able to claim through the NDIS.

There are some rental and repair Support Item Reference Numbers scattered through the pricing guides for AT but a majority of AT is not covered.

6. Different Funding and Operational Arrangement in each State and Territory

Each State and territory has its own guidelines and operational policies for becoming a Provider. There are several payment structures for different regions. Typically a company operating the ACT has to apply for a complete review of their operations to operate with participants in NSW.

Maybe when the NDIS is fully funded nationally then some of these barriers can and will be removed. This needs to be addressed where major cities adjoin each other over a border. This will be more of an issue in remote regions.

7. Funding Family (Informal) Carers

At present funding for family cares is non existent through the NDIS. A substantial amount of unpaid care is proved by family members. This is touched on Page 22 of the Issue Paper.

Some family members can not cope or want to be involved with managing family participants. It is a hard and difficult task especially if a high needs person. These family members allow the government (NDIS) to supply the support workers and plan managers, which is direct cost to the NDIS. If a family, on the other hand, decides to look after the participant then these people need some compensation.

The degree of Informal Carer funding would depend on each individual circumstance. Like the NDIS one size DOES NOT fit all. Many low need participants may not qualify for any informal funding.

There are many older parents, now into their 70 and 80s looking after very mature disabled children. As the parents lives are near an end and they also can not cope

physically with rigours of support. More and more these people will be turning to the NDIS for support carers. It is also an issue with housing as many of these participants now live in family homes. Depending on the financial situation of current living arrangements many of these participants will be forced onto the open housing market, or placed in institutional care via nursing home, hospital or group housing.

Housing is addressed through SDA.

8. The NDIS Web site

The web site has too much information available and it is difficult to find specific information. There have been improvements over time. There are many hyperlinks that do not go anywhere.

This is a minor criticism and I am sure the web developers and maintainers are performing a great job with the amount of information they have to publish and in removing outdated pages. An improvement could be to have an email address where web addresses or hyperlinks that are in error could be sent to aid in removal or repair.

A few more dates need to be added to web sites and pages. When searching for information one never knows if you are looking at old information or data. Dates appear on printable material but not browsed pages.

9. Training Sessions

The NDIS in Canberra (and other locations) run training/information sessions on various activities.

I have attended one of these sessions and the information provided was valuable with helpful staff.

Additional Information posed by questions in the PC Issues Paper

The page numbers refer to where the question was raised.

Page 12 Participants joining and leaving the NDIS

Would you want to leave a completely funded package when the NDIS is providing support? Would you give up house cleaning when the NDIS is paying informal carers in the own home? Some of these instances are of low financial value but they exist. The Government sold the idea that the NDIA will look after you and have a lifetime of support. Once a participant or family carer understand that all their costs and have care provided by the Government there is no incentive to exit the scheme. The LAC will guide new participants into the scheme - not how to exit. There is an expectation that the money is there and it is their right now to be looked after. I believe it required the staff at NDIS evaluating the plans to be realistic about the plans in front of them.

The old State and Territory schemes were only supporting limited numbers of people that knew the schemes existed. There was limited funding and limited support people to cope with the disabled people. Many companies spent a lot of time juggling where disabled people could be placed or supported. Possibly many were turned away due the lack of resources. With the NDIS being widely advertised as support for life these people now had access to the support they required. There are people who need to be covered under health in the States and Territories are being included under the NDIS.

There are many families that have lower education, have in lower economic strata or come from non English speaking backgrounds. These people do not want to understand and feel the Government said they would be looked after. So leaving the NDIS is not an option.

Exiting the NDIS for low needs participants needs to be reviewed. This would only be valid for lower cost participants needing little input from NDIS. Maybe some of these participants need follow up action but not be a continuing participant of the NDIS. During the planning phase low need participants need to have their goals and aspirations addressed in a more practical sense to allow for exiting the system.

The ACT, and possibly other regions, have reach its number of participants with only very young people still to be diagnosed (possibly through ECEI) or through vehicle or work place injuries (which will be funded through NIIS). There maybe movement across the borders if participants change their abode.

To guide low dependant participants out of the NDIS better and more focused plans need to be developed and implemented. The participant's goals and aspirations need to be written so there is an end date. Again NOT all participants will fall into this group of people. The more focused exit plan may only come at the first anniversary planning meeting when the goals for the second year are discussed and planned for.

High needs participants will only leave the NDIS on death.

Page 12 Utilisation rates in plans

The NDIS is new with planners and NDIS staff wanting to be all encompassing. It should not have been an issue that utilisation rates are not high in the participant's first plan. These issues could have been resolved in the annual review and developing the follow on plan. Plans need to be reassessed annually and possibly areas need to be dropped or new activities added. If a participant deteriorates during the year a completely different care support package maybe needed. Different AT maybe required.

Something that is not being addressed now effectively is the reviewing of annual plans.

This is a steep learning curve for all new people involved with disabled people. It is only the older people that have been in the old State and Territory companies like Disability ACT (in the ACT) that understand the needs and requirements of participants.

Page 15 Speed of rollout

The speed of the rollout, I believe, has been a major issue in the NDIS system so far. The speed has generated issues with Provider interface to the payment system, not well trained NDIS staff, and multiple changes to the Support Item Reference Numbers. The NDIA has been learning 'on the run'. The NDIA created major frustrations within the Provider community with the continual changes and problems with computer and payment systems. Most of these issues are slowly being addressed.

The training, or even finding suitable support workers has been an issue due to the speed of the rollout. This will still be a major problem in regions that have not been included into the NDIS at present. This will improve over time.

The Support Item Reference Number are a good idea to be able various funding areas to be tracked. It has taken several years to have a system that may work. The problem now is to have planer and coordinators use the item numbering system correctly. Various plans now have previous Item numbers and all this needs cross referencing and changed.

In the ACT nearly all participants have been identified but still has issues in access to suitable NDIA staff and payment systems Access through the Portal still an issue.

The rollout to new areas needs to be slowed. Get the current system as right as it can be. There are enough participants now to who are actually using the system to understand where the effort needs to be applied. The NDIS has to listen to people and Providers. This is completely different and possibly alien to the NDIS Managers who want to impress the Government.

If time is taken now then the balance of the participants not on board the NDIS will find the process far less challenging. I am not sure why the Minister needs impressing. They keep changing.

Page 19 Assessment tools

It is unclear what Assessment tool means here.

There appears to be internal tick and flick document where plans are finalised at the NDIA. This is an internal document used to access the support and final plan funding. When high dependency participants only receive 10 hours per year for a plan coordinator to manage a participant, with the NDIA not wishing to review the plan the assessment tool is inaccurate and waste in resources.

Any assessment tool has to be accurate.

Having models that participants fit is useless as every participant is different and require different needs. The data maybe worthwhile collecting but not as a means to drive the cost base a participant is funnelled into.

Page 22 An ageing population increasing demands on the system

We are in an aging population. There are many older family members caring for participants now. As these older people become infirmed or unable to properly care for family members there will be an increase in demand for NDIS services.

Many of these high need participant are their own or family homes. This is obviously preferable given the reduced cost in not supplying housing or pushing people into nursing homes or hospitals. Once these older family members can no longer look after children there will be an increase demand for housing. There was a move away from group housing or estates where multiple disable people are together. It is against the ethos of allowing participant gain a normal life in the community.

Funding will have to increase for the next 10 to 15 years to cater for the old parents leaving their children in other care.

Page 24 Numbers of Carers

In the ACT there appears to be limited support workers available. This adds to work loads to high demand participants for plan coordinators. For example these high demand participants require two people to prepare and feed participants three times a day, two people to look after personal hygiene, there are further support people required to support home maintenance and including cleaning and gardening. On top of this visits to doctors requires further support carers. There is not enough support carers in the system. As an individual Provider the money is satisfactory but if the support person is employed through an agency the agency has to take their percentage. My support people do not want to set up business and be bothered with ABNs etc.

Page 27 How well equipped are individuals to understand and interact with NDIS

There is a massive amount of reading and understanding required to enable a reasonable outcome for the participants from the NDIS. If there are very specific requirements and for very low need participants then families and cares would able to

navigate to receive a satisfactory outcome. Once the participant is beyond low needs then most families and carers will miss out or have support activities not relevant to the participant. If the low take up of activated is as noted on page 12 of the Issue Paper is correct then this is evidence that there is not as much understanding as is required from the plans.

With the information on the scheme changing it is difficult to keep up. Now new item codes and the payment portal have being changed a few more people may find the experience less daunting.

I believe the question also needs to be are the NDIS staff capable of making reasonable decisions on the needs of participants. Given the sharp cut in plan managers hours for extremely high needs participants it is obvious they are not well trained and do not understand the specific needs. They could be following the rules to reduce overall costs.

For low need participants then the LCA maybe be able to help guide new participants into the NDIS system. Once the participant is beyond low needs then a different company or plan coordinator is required to support these people.

There are many families and participants from non-English speaking countries who have a different take on the NDIS. These families need a lot of support in guiding them through the NDIS. This is making sure the plan that they have been given meets the needs of the participant. It appears that this is not well understood by NDIS staff.

Page 28 Finance capability of the scheme

What ever reporting is done it has to be accurate and honest, not what the minister wants to hear or the management of the NDIS wants to communicate.

If using standard bench marks in the Insurance industry for administrative cost then the NDIA needs to be below these figures. Commercial Insurance companies are there to make money, therefore a comparison would be very difficult. NDIS needs to be efficient and below the industry levels. Governments can run efficient organisations.

Summary and recommendation

The below are not in any order of importance.

1. Remove the States and Territories from the system and have Federal Government fund the complete scheme.
2. Slow the rollout to new regions and get the process right (almost there). If the system is not functioning correctly for 60,000 participants how will it work for 460,000 participants? Don't listen to the internal hype
3. Accept the fact the NDIS was under funded and support the scheme.
4. Within the NDIS employee staff that can understand participant's needs and approve decent plans that are funded correctly in one attempt, ie have trained staff
5. Have an easier review process for NDIS screw-ups. Have an easier change process within the plan if things change.
6. Combine the NIIS and NDIS
7. Support family member carers, before all the participants are pushed into the NDIS for complete care.
8. Need to plan for low needs participants to be able to exit the NDIS