

QUESTIONS AND RESPONSES

- ***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?***

Participants and Families are ill equipped to implement their plans due to decades of the system disempowering them. Just because the system has now changed does not mean we will instantly see people being able to understand the new system and become empowered customers buying the supports they need. This all requires time and the right facilitation.

The information sessions being provided are far too often being run by NDIA or other peak bodies who have little or no practical experience of the scheme and how it works on the ground for participants and families and are therefore very theoretical and often confuse people further.

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

Numbers were probably underestimated in the first instance and also the automatic transfer of people from State funded disability supports to NDIS who may not be truly eligible when we look at the fact that the scheme was supposed to support the most severely, profoundly and permanently disabled.

By the Commonwealth and States/Territories not being discerning enough about what “programs” ensured automatic passage into the NDIS then many people who could have continued to be supported by State block funded options are now NDIS individualised funding participants

- ***Why are lower than expected participants exiting the scheme?***

The NDIS was always supposed to be a lifetime care and support scheme for the most significantly, profoundly and permanently disabled Australians. If this is our starting point then scheme exit is highly improbable. These people need lifetime care and support.

Also little or no understanding of the Progressive Neurological disease populations which will generally see peoples support needs increasing over time means that scheme exit for this cohort is also highly unlikely.

The fully inclusive, accessible Australia required for the NDIS to be able to do its job does not currently exist and is probably still decades away. The fact that State/Territory governments are still, for example, building segregated specialist school settings will continue to delay us having a fully inclusive, accessible country where people get the majority of the services and supports they require from mainstream systems. The lack of adequate fully accessible housing, transport etc. all play a part in people requiring specialist funded disability supports.

- ***What factors are contributing to increasing package costs?***

The NDIS is dealing with decades of unmet need and also now crises because of aging parents and aging participants who have not been supported adequately previously and will now be requiring more supports and therefore being higher cost

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

The original PC report urged us to move away from diagnosis to need for supports and this approach is being abandoned with the benchmark package costs. To try and benchmark a package using diagnosis as one of the indicators is fundamentally flawed. Cerebral Palsy and its implications and manifestations for each individual is as unique as the individual him/herself. The NDIS is supposed to be truly person centred and individualised.

- ***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?***

I think it was not and is still not well understood by the general population that the NDIS was not going to provide Individual Funding Support to every Australian with a disability label. The notion that it was our most severely and profoundly disabled Australians that would be supported for their lifetimes has been lost.

We need to get back to explaining Tier 1, 2 & 3 as proposed by the PC.

The lack of effective Tier 2 establishment and work being done before Tier 3 became a reality has also impacted in this space.

- ***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?***

The Bi-Laterals signed up to across the Nation as severely impacting on the eligibility and access. The early intervention section of the NDIS legislation is not being utilised well enough.

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

In Victoria, the proposed speed of the rollout in combination with the epic failure of the new IT system from 1/6/19 is creating a shambolic implementation both for some of the new participants attempting to enter the scheme and some of the existing participants in the Barwon.

- ***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?***

Too early to tell just yet, but theoretically yes.

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

Hopefully those children who ought to be supported in the mainstream systems will be supported there and via Tier 2 and therefore not require Tier 3 supports. Universal services must be further enabled to respond to children with additional needs.

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

Yes, getting in early and being much more active in a walk beside model and providing assistive technology (aids and equipment) to people living with a progressive neurological disease will enable independence for longer.

Yes, getting in early and being much more active in a walk beside model and providing assistive technology (aids and equipment) and supports and therapy to people living with an acquired disability i.e. acquired brain injury and spinal cord injury once their journey in the health system is finished will also reduce long-term scheme costs.

- ***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?***

NO – particularly for younger people with very high and complex care needs where there is a perceived Health/Disability issue. NDIA staff need to better understand when we are talking about the support of a functional issue for a participant and the management of a health issue, (not the treatment of said health issue), which requires supports due to the persons disability not because of the health issue itself.

- ***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?***

YES – people are having to be admitted in to hospitals unnecessarily due to NDIS not funding things they should/could due to the lack of understanding I have described above.

- ***How has the interface between the NDIS and mainstream services been working?***

NO – people are falling through gaps.

- ***Can the way the NDIS interacts with mainstream services be improved?***

YES – if NDIS is funding the majority of a person's supports then they should fund all the supports required (even if that means cost recovery behind the scenes) to prevent us returning to the 'confusopoly' described in the original PC report and to prevent participants becoming casualties of the system.

- ***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?***

We must ensure that we have both Tier 2 and Tier 3 supports available for NDIS eligible participants and for those who are not eligible in particular.

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

Same as above for health interface

We also need to ensure that "block funded" supports for those not eligible for Tier 3 Individualised Funding are still available for people requiring Tier 2 specialised support that is currently not available via the mainstream systems. "Throwing the baby out with the bath water or taking a scorched earth approach" is not at all useful to those people who need some support but will never be eligible for NDIS individualised funding

- ***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?***

Yes, theoretically.

- ***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 current funding envelope for Tier 2 ILC is totally inadequate and will not prevent people tipping in to Tier 3.

The targets for LAC's are not achievable in any quality way the understanding of the geographical communities within they work is imperative as is disability experience.

- ***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?***

In my experience on the ground NO, people simply get a letter advising them they are ineligible and they are then left with nothing.

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

NO – many people in NEMA Melbourne are completely surprised that the phone call they receive is their planning conversation and then a plan arrive sin the mail and they don't know what to do with it.

- ***How should the performance of planners be monitored and evaluated?***

360 degree feedback including participants and families should be core to this.

- ***Are the criteria for participant supports clear and effective?***

NO

- ***Is there sufficient guidance for assessors about how these criteria should be applied?***

By assessors I assume you mean planners, if so NO it is still being too subjectively applied. The operational guidelines have certainly helped but they are still being subjectively applied and many participants and their needs are not black and white but many shades of grey.

- ***Are there any improvements that can be made, including where modifications to plans are required?***

To have a system which automatically end dates a plan the moment any change is made to that plan is causing complete chaos in the ground for participants, family members, service providers and the NDIA staff. This practice needs to stop. A plan and its start and end dates ought to stay intact when some minor modifications/amendments are required. A plan start and end dates should only change if a full plan review occurs.

The communication to participants and families via varying systems e.g. My Gov, secure emails via DHS, postal mail arriving really late or even no communication and you just happen to find out you have a new plan via the participant portal a few days or weeks after it went live is also causing inaccessibility issue for many people and causing major issues on the ground re. access to support services and all of this adds increase pressure on NDIA staff who are constantly being asked to help sort out the messes being made by this approach.

- ***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?***

Having funded supports and budgets clearly aligned with participant goals is essential. Assisting participants and families to understand how this is all interlinked is critical to getting equitable outcomes for participants. Planners need greater understanding of what they can and cannot fund.

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

NO, the process for getting an outcome from an internal review is far too lengthy and then an external review via AAT is also too lengthy and at times the persons plan review occurs before the review process is complete sending the participant and family right back to square 1 again. This system is simply adding to peoples stress levels and is completely unacceptable.

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

Better supporting "informal carers" will always reduce the need for "formal" support workers. Most people are proud and independent and want to do what they can for their loved one and generally speaking only ask for help when they are not coping/managing on their own due to a lack of supports for themselves including access to adequate respite. Increasing our use of assistive technology options that informal carers can monitor (if they so choose) would also reduce the need for formal support workers.

We need to have an early intervention approach to supporting informal carers so that crisis point is not reached thereby requiring a high cost intervention

- ***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?***

Improved pay rates for all caring professions is essential in this space.

- ***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?***

The lack of job security due to the casualization of this workforce is certainly playing a role in not being able to attract and retain a quality workforce. Having permanent part-time and full time roles would certainly assist with this as would staff still being paid if/when cancellations occur. When my child does not attend school his/her teachers' pay is not docked yet we have formal support workers having very unpredictable pay packets due to shift cancellations etc. this is an area that must be addressed if we want a quality workforce.

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

Significant opportunities here to reduce having staff on site "hovering over" people. We can and must make better use of assistive technology to reduce care 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?***

YES, fully federally funded out of general revenue as proposed by PC originally and operated by a separate statutory authority.

- ***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 Bilateral agreements and the lack of having the NDIS fully Federally funded out of general revenue and fully Federally managed and controlled has weakened and diluted the schemes capacity from the start and it continues to do so. This is simply perpetuating the Commonwealth/State argy bargy that has plagued disability for decades and it is now further complicated by the NDIS/Mainstream argy bargy that is seeing people fall through gaps. The scorched earth approach in Barwon Victoria has also left ineligible participants at risk.

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

YES

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

YES – take it out of the government and public service arena

The NDIA needs to be removed from the government bureaucracy and become a statutory body in its own right as proposed by the original PC report. Having is enmeshed in and being interfered with and hamstrung by government and Commonwealth Public Service processes etc. is rendering it ineffectual.

- ***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?***

Participants and Families are ill equipped to implement their plans due to decades of the system disempowering them. Just because the system has now changed does not mean we will instantly see people being able to understand the new system and become empowered customers buying the supports they need. This all requires time and the right facilitation.

The information sessions being provided are far too often being run by NDIA or other peak bodies who have little or no practical experience of the scheme and how it works on the ground for participants and families and are therefore very theoretical and often confuse people further.

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

Unfortunately YES. There will always be a need for a crisis response and a “provider of last resort” because there will always be individuals who are failed by the system and therefore deemed “too difficult” and generally speaking the market will not respond to these people. This needs urgent work now. The NDIA may not be in a position to deliver this service but they must contract the services to deliver it.