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Productivity Commission Inquiry Submission

NDIS Costs 2017

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INTRODUCTION

Sotica is a boutique consultancy service through which it's Principal, Dr Leighton Jay works with organisations, many of which are in the Human Services sector. Over the past three years, Sotica has completed numerous strategic projects assisting disability sector organisations to adjust to the sector reforms being driven by the National Disability Strategy and the National Disability Insurance Scheme. Sotica has also worked directly with the NDIA on selected projects. Through these, I have met with and discussed operational issues with several hundred NDIA employees and participants spread across the Perth Hills, Barkly, Barwon, ACT and Hunter Trial Sites.

I am also a member of the NDIA's Intellectual Disability Reference Group (IDRG) through which I have some awareness of both strategic and operational issues confronting the Scheme. I have also been able to contribute to the Scheme's development at a strategic level through these roles.

As the parent of an adult WA NDIS participant with complex support needs, my view of the NDIS is also grounded in day-to-day practical realities faced by people entering and engaging with the NDIS (both in WA and in the National Scheme).

I am an NDIS optimist. The creation of the NDIS has the potential to be a watershed development for Australia, especially for people with intellectual disability who continue to be the most marginalised and silenced of an already marginalised population. If we can get this 'right', the NDIS will shine as a beacon to the world and truly position Australia at the forefront of upholding and championing the human and citizenship rights of people with disability by building a sustainable structure that upholds and champions those rights as a default position. In my opinion, the value and importance of such a development cannot be overstated.

Following some opening remarks in the next section, this paper addresses a number of the issues identified in the Commission's Issues paper. I have clearly identified these for ease of cross-referencing.

OPENING REMARKS

In the context of this Inquiry, I must start by stating my dismay with the way that the NDIS has been politicised by Federal politicians. Recent statements to the House of Representatives and the media by Hon Christian Porter and Hon Scott Morrison demonstrate that they still seem to think of the NDIS as a 'welfare system', something that is deeply troubling to me. Kurt Fearnley's response to their comments succinctly summarises many of the benefits that are already accruing from the Scheme but remain largely absent from the political debate (http://www.abc.net.au/news/2017-02-14/paralympian-kurt-fearnley-confused-and/8268750). The NDIS is an **INVESTMENT** in Australia's present and future. It must not be seen simply as a cost which is what currently seems to be happening!

A primary concern for me is that politicians seem keen to try and score political points by talking about ‘cost blowouts’ and ‘funding black holes’. Conversely, I hear very few talking about the potentially significant financial benefits that the Scheme’s success will deliver to the Federal budget year on year. It is false economics to discuss Scheme costs in isolation from the pay-offs that will be delivered in other areas. These include (at the very least):

- reduced health system costs as people with disability are able to do things that prevent and reduce hospital admissions;
- reduced welfare expenses as carers and people with disability enter the employment market; and
- increased income tax revenue as more people with disability and carers enter the workforce and become taxpayers.

SCHEME COSTS

Cost Drivers (Issues Paper p10)

The current arrangements in which the NDIA is setting prices is, in my opinion, a realistic and reasonable approach. However, it seems to be causing many service providers to position and agitate for higher prices rather than look at ways they can be truly innovative in their approaches. However, to be fair to service providers, the Federal Government has provided precious little funding to enable them to explore and develop such innovative approaches. By comparison, Federal and State government funding is frequently made available to other industries when sector-wide reforms of such scale are implemented (e.g. dairy industry deregulation).

Given the sheer size of the disability sector, the scale of the reforms being implemented and the relatively limited financial reserves that many service providers have, this has been a major oversight by Government. It has seriously hampered service providers’ capacity to be more innovative and has driven numerous organisations to merge, perhaps with a “we’re now too big to be allowed to fail” risk mitigation strategy in mind. Ironically, larger organisations by their nature are generally far less able to be responsive to policy and market changes. And it is virtually impossible for them to reinvent themselves to the degree that they eventually may need to in this situation.

In WA, the Disability Services Commission has for the past three years made modest funding available to WA Individualised Services (WAiS) to run a ‘Provider Program’ that assists Service Providers to identify their particular strategic and operational challenges and to make necessary adjustments. This has proved to be money well spent, and similar strategic investments on a larger scale need to be made nationally. It may well be that had such investments been made earlier, more service providers would now have lower overheads.

Another issue that I am aware of is a tendency for some providers to inflate their prices for NDIS participants. There have been many social media posts about Allied Health Services doing this, with some rebuttal suggesting that they are simply reversing historic practices of subsidising their services from other income sources. Consistent with this, I have heard of providers giving potential customers two quotes, with the higher quote applying to NDIS participants! While this cost driver may diminish when the Scheme reaches maturity and 'market forces' operate, it does seem that this is an issue worthy of closer examination.

I am also aware that allied health services are sometimes/often included in participants' plans even when that is not requested by the participant or their family members/carers. In our family member's situation, OT and Physiotherapy services are included in his WA NDIS Plan even though he has only infrequently used these services in previous years. One service provider (understandably) tried to secure a service plan that effectively guaranteed that all of the planned hours would be delivered. The 'OT assessment' that was included resulted in a recommendation that a bidet be retro-fitted in the place where he lives. For a range of reasons, he did not proceed with this. We view it as something that is neither necessary nor unlikely to effectively address the presenting issue identified by the OT. A peer to peer support organisation's CEO commented to me that: "we're seeing OT assessments included in SO many plans! And bidets are also being frequently recommended." While this is anecdotal and may be a local issue, I suspect it reflects a wider trend, in which case such decisions and actions will be a cost driver for the Scheme.

Finally on this point I must note that the paltry amount set aside for ILC funding will soon be seen for what it is – highly inadequate! This in itself will become a cost driver for the Scheme. There is no way known that $132M per annum can deliver what the ILC is supposed to deliver, even in combination with the idealised expectations of Local Area Coordinators (LAC). Unless communities, schools, local governments, businesses, employers etc can genuinely become more inclusive as a default position, there is a risk that other Scheme costs will increase to offset this shortfall.

For example, consider a person with disability who could easily and meaningfully make a positive contribution as an employee but is unable to gain employment because the ILC and other initiatives don't result in changed employer attitudes. Instead of being gainfully employed, they are more likely to engage with more professional support services, so contributing to higher Scheme costs (along with continuing to receive the DSP and not pay income tax).

Utilisation Rates (Issues Paper p12)

From my work with the NDIA and my connection to individuals and families it seems that there are many reasons why utilisation rates are low. In some areas, there is a 'thin market' of services (e.g. Barkly). There are also cultural and language issues that are acting as barriers for some people. Looking closely at the utilisation rates of indigenous participants could provide some useful insights to causative factors.

My own experience as the parent of a participant entering the Scheme was that the process of changing from a state-based, familiar system to something new created anxiety. This seems to be a very widespread experience for participants and family members and is understandable. The degree to which participants had control over their services pre-NDIS undoubtedly influences their ability to put their plan into action. We have several years of ‘share managing’ my son’s arrangement prior to the NDIS and I am well educated and familiar with the machinery of government. Even so, it was an anxious experience and not all of his funded services are fully used.

For some participants and families, navigating the new landscape is overwhelming. I had a phone conversation with one mum who confidently told me that her son’s plan had been approved. When I asked who was now providing his services, she replied that he wasn’t receiving any services. When I asked ‘why not?’ she said that the NDIA hadn’t told her which providers to use. I explained that as a government agency, the NDIA had to be impartial so was unable to provide such advice. The effect for her had been paralysis. She had no idea how to choose service providers when confronted with a list of 100+ provider names on a website.

For participants and families whose pre-NDIS service experience was one of ‘don’t rock the boat’, disempowerment and passive acceptance, it will take time to unlearn embedded behaviours and take up an empowered self-leading role in their lives. This necessarily translates to some services not being used to the full.

There are also people whose plans include services that they choose not to use to the full for various reasons. In my son’s case, we’re pleased that they are included in his plan and will use them if required. But we feel no compulsion to use them simply because they’ve been included. I hear similar comments from many others.

SCHEME BOUNDARIES

Eligibility (Issues Paper p15)

A critical issue in this area is the widely varied methodologies being used to diagnose children on the Autism Spectrum. Prof Andrew Whitehouse (UWA, Telethon Kids Institute) is acknowledged as a world expert in this area and is on the record as stating that this is a problem. How children are diagnosed differs in every jurisdiction with the methodology used in WA identified as the ‘gold standard’ in Australia. There absolutely needs to be ONE consistent approach used across Australia and that approach should be demonstrably evidence-based and verified as valid.

The current inconsistent approach results in desperate parents (understandably) trying various ways to get the diagnosis they want. Without an ASD diagnosis, most are left without the support they feel they need to manage a challenging situation. I have little doubt that this already means that some children in some jurisdictions have been diagnosed as being autistic when they aren’t and are accessing NDIS funding when they probably aren’t truly eligible. The ECEI is a positive initiative should help to address this issue over the longterm.

Intersection with Scheme Boundaries (Issues Paper p16)

In my opinion, this is likely to persist as a problematic issue for some considerable time to come. I have no doubt that other sectors and agencies are attempting to ‘cost shift’ some costs and services to the NDIS (e.g. health, education). On some points, it will be possible and beneficial to set clear guidelines and boundaries that will apply in all circumstances. At other times, the highly individualised nature of some participants’ needs will make this much more difficult to determine. In an ideal world, discussion and negotiation of where cost liabilities should fall would centre on the participant’s needs and would be negotiated in good faith to achieve the best outcome for the participant. The reality however, is vastly different to that with bureaucrats and senior decision makers frequently having little direct contact with participants and their grassroots issues. They are also increasingly held accountable for how they manage scarce resources in constrained funding environments. The siloed approach that often prevails will not help achieve best outcomes and at present I can’t see what the solution to this will be. It is and remains an issue.

Mental Health (Issues Paper p16)

In my opinion, people living with mental health challenges have not been included in the Scheme very well to date. The decision to include people with ‘psychosocial disability’ was an eleventh hour decision that has been problematic for many people with lived experience of mental distress and MH sector advocates. The legislative eligibility requirement that a participant’s disability be permanent sits uneasily with the widely adopted ‘recovery’ language and approach that characterises the vast majority of contemporary community MH services. It would also be fair to say that by making an eleventh hour decision to include people with psychosocial disability, the estimates of eligible participants from this population are unlikely to be very accurate and probably underestimate the size of this cohort.

I am also aware that the cost of support packages for participants with psychosocial disability will vary considerably and that many potential participants may be hard to reach due to homelessness, drug and alcohol issues and/or because they live in hostels or locked facilities. In 2016, the Perth Hills Trial Site undertook a specific project related to planning with and for participants living in hostels. A great deal that can be applied across similar situations elsewhere in Australia was learned from this project and should be noted and incorporated. Key informants who can provide the Commission with more specific information about what was learned from this project are Ms Marita Walker (NDIA Perth Hills Trial Site Manager) and Ms Denise Hughes (consultant). I am fairly confident that what they learned from the project can usefully inform your considerations of Scheme costs related to this cohort.

Information, Linkages and Capacity Building (Issues Paper p17)

Please see comments above in section ‘Cost Drivers’.

PLANNING PROCESSES (ISSUES PAPER SECTION 4)

In 2015, I heard David Bowen say that ‘people need to understand that the first plan is just about getting into the Scheme’. I bore that comment in mind as my family member entered the WA NDIS in 2015. For me, this statement was incredibly useful in helping me to take a longer term view and to lower my expectations of what the Scheme could/would deliver. I think this should be a major headline that is broadly, loudly and repeatedly stated and I have expressed this personal view to the NDIA.

Among people with disability and their family members, expectations of what the NDIS will deliver to and for them are generally very high. The Every Australian Counts campaign, along with the NDIA’s own publicity and promotion fuels such expectations. In many instances, this has contributed to disappointment and frustration when participants finally engage with the Scheme and begin their planning process. Social media is replete with many, many such stories and experiences.

With the Scheme now having entered the ‘rollout’ phase, the planning process is has been shortened and is seemingly impersonal to many people. Some people’s experience of the planning process has bewildered them when it seems that their voice has not been heard and reflected in their plans. This has been underwhelming given the expectations that were promoted. Given that most people are understandably focused on THEIR entry into the Scheme and their experience and plan, it is not surprising that they have little idea of the sheer scale of what the Agency is attempting and needing to do to transition hundreds of thousands of people into the Scheme over the next three years.

As someone who understands this challenge, I think the Agency has adopted a necessarily pragmatic approach to planning that utilises defensible, evidence-based reference packages as a starting point. However, I think they could have done a better job of selling the need for such an approach or raising awareness of how it will work for incoming participants. This has contributed to issues arising for both participants and the Agency. Incoming participants who get to participate in well run pre-planning workshops, report that these are highly valuable and usually helpful.

My own realisation during my son’s first year as a WA NDIS participant was that he and we could take control of his plan and the planning process for Year 2. Indeed, given that he has complex communication support needs and we explicitly want him to have his own say about his plan (separate to what my wife and I might want and think), it was imperative that we did so. The planning process simply could not accommodate him having the time and communication support he would need to have his voice heard and reflected in the plan. As such, we virtually had the Year 2 plan written prior to the first review and planning meeting. I know that many other participants and families would similarly take control of their plan and reduce the time and costs associated with planning if they were adequately resourced to do so. It is also true that for many people, their plans do not need to be reviewed and rewritten on an annual basis. Providing participants with the option of having two or three year plans would be a welcome development and I know is under consideration. That will assist in reducing Scheme costs associated with planning.

It is also necessary to note that there are wide variations between plans within regions and certainly across regions. It is important that as the Scheme rolls out and the Agency matures, these discrepancies are identified and addressed. While some variation is inevitable and likely to be an accurate reflection of differences in participant requirements, wide variations should be the exception rather than a norm.

It seems that to date, the performance of planners has largely been assessed on the basis of 'number of plans completed' and a somewhat subjective assessment of the quality of plans. The relentless focus on the number of completed plans has been extraordinarily burdensome for some staff and alongside the average package cost seems to be the primary measure of Scheme performance at the political level. This is a great disappointment. Senior politicians need to also see the more grounded evidence of the difference the NDIS is making for participants (and directly hear of their frustrations too). The focus on these two quantitative measures to the exclusion of all else is unhealthy and undesirable.

GOVERNANCE AND ADMINISTRATION OF THE NDIS (ISSUES PAPER P28)

I, like most people outside the political sphere, have limited knowledge of how well the Agency's governance operates or what the associated costs are. However, one thing that the Agency initially got right was to ensure that the development of the Scheme was overseen by people with lived experience of disability. The recent change in the composition of the Board away from this criterion marks a genuine issue of concern to many people with disability and their carers. I am encouraged to hear that the new Board members so far seem keen to learn about the lived experience of disability and the issues that people confront on a daily basis.

I think that political influences, inadequate resources and ineffective authorisation severely limited the capacity of the previous Board to do their job properly (see following paragraphs for additional remarks on this point). Bruce Bonyhady's departing letter which identified the challenges confronting the Agency was spot on. For example, the NDIA received a great deal of public criticism for the failure of the ICT system last June. Without question, some of that criticism was justified. But from what I have been told, key decisions about the ICT system design, oversight and management were made by senior DHS bureaucrats, yet DHS wore virtually none of the scathing public criticism. This sort of de-authorising those governing the Scheme has the potential to seriously compromise its success. Politicians and bureaucrats from other Commonwealth Departments need to properly authorise the Board to do its work and then trust the Board get on with it.

The governance arrangements include the Independent Advisory Council and the Reference groups (such as the IDRG) which report to it. These are excellent, value-for-money contributors that enable important issues to be identified, analysed and possible solutions developed by representatives of those most affected. In the case of the IDRG, we have developed several position papers, for example how Support for Decision Making might work best for participants within the Scheme. This paper addresses a critical issue for highly marginalised and often silenced participants.

Both the UN CRPD and the NDIS Act explicitly preference the right of ALL people to make decisions in their own lives, which is a substantial departure from how services have largely been designed and delivered to most people with intellectual disability prior to the NDIS. Given the more urgent priorities that the Agency has dealt with (and will continue to deal with for some time yet), it is not yet apparent to me how support for decision making will be included in the Scheme's core elements.

Building support for decision making capacity requires dedicated focus. Knowledge about how to do this well and what it requires when participants have limited conventional communication is uneven and generally low across the disability sector and in the broader community. In the long run, it is both desirable and entirely possible that this function will be done by people in informal support roles. But for that to happen, there needs to be some early, strategic and specific investment made to build capacity for this. If that is not done, it is possible that people will argue for paid advocacy support to be included in their plans as a surrogate for this, and that will ultimately cost a great deal more and miss a golden opportunity to build more inclusive communities. The current level of ILC funding (where some might argue such capacity building belongs) is simply inadequate to cover this investment.

In short, please ensure that both the IAC and its various reference groups are resourced to continue their functions. They are a cost-effective way of tapping into diverse, grounded and fabulous expertise from across the country.

I think that Bruce Bonyhady's comments about the 7% target for operating costs need to be heard. I have a very strong opinion about this based on the projects I have done with the Agency. I have been surprised by what seems to be low levels of resourcing for the work needing to be done. The Agency and its staff have done a magnificent job to date despite being inadequately resourced to run the Scheme while they are concurrently developing it.

It seems to me that the 7% target is a somewhat arbitrary figure that derives from political desires to keep costs down. While this is an understandable concern, it needs to be a realistic, evidence-based target or it will pose a major threat to the viability and success of the Scheme as a whole. If 10% is a widely used benchmark then that would be a more evidence based measure. The narrow concern with Scheme costs isolated from benefits that will flow to other areas of the Federal budget represents a blinkered view that fails to see the Scheme as an investment!!

PAYING FOR THE NDIS (ISSUES PAPER P31)

In addressing this issue, I will start by asking "how do any of us pay for our insurances?" Answer – we pay premiums that enable us to purchase specific insurance as standalone products. The NDIS is an insurance Scheme. In my opinion, it should be funded accordingly. This means that there could and should be a specific NDIS levy (similar to the Medicare levy) that all eligible taxpayers contribute to. At present, that levy is set at 0.5% and has been rolled into the Medicare levy. It should be a separate levy, and it should NOT apply to people residing in Australia who are not eligible to be participants in the Scheme.

It seems that a 0.5% levy may be inadequate to cover the cost of the Scheme. In that case, the premium needs to increase, and politicians need to get past their reluctance to do this. If we continue to talk about and treat the Scheme as a welfare Scheme, we will not get this right. It is not welfare! It is an insurance Scheme and as such it is an entitlement Scheme. Having a separate NDIS levy will help make this clear. As an entitlement Scheme, the NDIS should not be funded on a year by year basis or out of general revenue. It is the primary initiative Australia has undertaken to put our UNCRPD commitment into action. No-one made us sign the Convention. If we believe in it, which we absolutely ought to, then this is our collective undertaking and commitment to the citizens that we have ignored and marginalised for far too long.

There is also little doubt in my mind that the current Bilateral Agreements (by and large) are resulting in cost-shifting from the States to the Scheme. The haste and manner with which the NSW government is exiting from the disability services landscape is almost scandalous in some respects. It is unquestioningly having negative effects for many participants who are finding themselves indefinitely ‘captured’ by certain providers due to the ‘in kind’ arrangements that have been agreed. This ‘capturing’ of participants by services contravenes their rights under the Act and its indefinite nature is already proving to be stressful for some participants.

The in-kind arrangements are a risk to the Scheme’s integrity, especially around the provision of accommodation services for people with disability. In NSW, government provided accommodation has been outsourced to selected service providers who now have ongoing contracts to provide accommodation to the residents of those facilities as part of the NSW government’s financial contribution to the Scheme. However, this has the effect of removing the elements of choice and control from resident participants who may wish to move to different accommodation or receive their accommodation (or indeed other) services from a different provider.

There also seems to have been significant underestimating of likely participant numbers in most jurisdictions, with both the ACT and South Australia being well documented examples. With the Commonwealth committed to picking up the cost of overruns, this has added a potentially significant cost. It is yet another example of how the political decisions associated with the Scheme are one of the most significant threats to the Scheme’s success, something that has been a consistent storyline from day 1 and continues to be the case.

Thank you for the opportunity to contribute to this Inquiry. I wish you well in your endeavours and hope that my humble contribution is of some value and use. I sincerely hope that in time, we will be able to look at the NDIS as a major social policy achievement that lights a path for many nations to follow.