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JOINT STANDING COMMITTEE INQUIRY INTO NDIS IMPLEMENTATION AND FORECASTING

SUBMISSION FROM THE
MELBOURNE DISABILITY INSTITUTE



Melbourne
Disability
Institute

We welcome the Joint Standing Committee's inquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), including current scheme implementation and forecasting.

The terms of reference for this inquiry are very broad. Each of the points in the terms of reference is worthy of an inquiry in itself. Given the importance of each of the issues raised in terms, we could not provide comprehensive responses to each in this submission, particularly in the short time available. Detailed solutions are required to each of the areas of concern the Committee have outlined. More importantly, each of the detailed solutions must have two features:

1. They must be evidence based
2. They must be co-designed with people with disability, their families and their representative organisations

We therefore cannot propose detailed solutions without each of these conditions being met. For that reason, we have confined our comments in this submission to what needs to be done to build the evidence base for the design and implementation of the scheme and ensure meaningful and genuine codesign.

In this submission we outline a brief 10 Point Plan to ensure both of these conditions are met, and the NDIS is able to realise its original vision of achieving greater social and economic inclusion for people with disability.

The plan outlines five pre-conditions for effective reform and five focus areas which must be addressed. We have included the link between each proposal and the inquiry's terms of reference:

Pre-conditions to ensure the NDIS realises its vision

1. Rebuild trust (TOR H)
2. Full transparency (TOR E, F and H)
3. Co-design (TOR H)
4. Shared governance (TOR B, D, F and H)
5. Sufficient funding of independent advocacy (TOR H)

Priority areas for research and reform

6. Adequate support for people with disability outside the NDIS (TOR A, F and G)
7. Best practice early intervention (TOR F and G)
8. Effective market stewardship (TOR F and H)
9. Improving NDIS operational structures and processes:
 - (i) Changes to the structure of Core, Capacity Building, Assistive Technology and Specialist Disability Accommodation/Supported Independent Living Supports (TOR G)
 - (ii) Draft plans for all participants (TOR C and G)
 - (iii) Empowering control and choice and investing in support coordination (TOR G and H)
 - (iv) Valid eligibility and planning processes (TOR C)
 - (v) Certainty for participants and their families (TOR H)
 - (vi) Local Area Coordination (TOR)
 - (vii) Changes to Section 170 of the National Disability Insurance Scheme Act (2013) (TOR C, G and H)
 - (viii) Adequate Agency resourcing through an NDIA Resourcing Guarantee (TOR C)
 - (ix) Appeals to the AAT (TOR H)
10. Improving interface with mainstream services (TOR B)

1. Rebuilding Trust

The Terms of Reference for this inquiry do not directly address the most fundamental issue at the heart of the current challenges to ensure that the NDIS achieves its vision - trust. Or more specifically, the lack of it.

The actions of the NDIA, particularly in the last eighteen months, demonstrate that that they do not trust anyone. They do not trust people with disability and their families. They do not trust medical professionals or allied health professionals. They do not trust their own staff or their community partners.

And sadly, as a result no one now trusts the NDIA.

But the NDIS only works on trust. To function effectively, people with disability and their families must trust that the scheme will be there for them when they need it, and that it will work in their best interests. In turn the NDIA must trust people with disability and their families to represent their needs and circumstances accurately. On a larger scale it must also trust them and their representative organisations to engage meaningfully on scheme implementation and reform.

Those conditions are not present and have not been for some time. Therefore, the first way to improve the implementation and performance of the NDIS is for the NDIA to rebuild trust. It is essential for the NDIA to regain its social licence with people with disability, their families and carers and the organisations that represent them.

Trust is based on respect and equality. The NDIA needs to engage with the disability community on that level. It must learn to become a servant of the community it is supposed to empower and serve, rather than seeking to assert its power at every turn.

The senior management and board of the NDIA must also start to trust their staff and their community partners. Their unrelenting drive to introduce independent assessments, reflected a deep distrust of their own staff and partners. They showed that they would rather rely on a flawed mathematical formula, effectively enforce robo-planning, rather than place their trust in their own staff. It was clear that the NDIA not only believe that the expert reports from participants exhibit “sympathy bias”, they believe their own staff are incapable of fair and accurate professional judgements. Lived experience is seen as “too much empathy” rather than providing important insight vital to the effective operation of the scheme. They appear to have given up on the task of training and supporting their staff to carry out their important role.

2. Full transparency

The process to introduce greater transparency has commenced with the actuarial review commissioned by Disability Reform Ministers as well as the release of the latest Annual Financial Sustainability Report. These are important and welcome first steps. However, much more still needs to be done.

A full assessment of the sustainability of the NDIS requires access to previous Annual Financial Sustainability Reports, depersonalised data and the underlying actuarial models, so that the assumptions and the drivers of costs can be scrutinised in detail. To be truly transparent, this data and information should be provided in a format that can be independently scrutinised by people with disability, their families and their representative organisations. In particular to test the assumptions behind it against people’s lived experience of the operation of the scheme on the ground. While the release of the recent reports is important, the information has not been provided in a way that disability representative organisations can easily engage with. The opportunity for them to make a vital contribution to the reform of the scheme has therefore been lost.

The NDIA is building one of the best population-based databases on disability in the world. It is publishing more data in different formats. The NDIA has also agreed to contribute data to the development of a National Disability Data Asset (NDDA). The NDDA is aiming to link administrative disability data, including social security, health (MBS, PBS and hospitalisation data), justice, employment and tax data.

These are all welcome improvements. However alone they are insufficient. They also represent a lost opportunity. The NDIS is a very complex piece of social policy. Managing its implementation, sustainability and ongoing reform requires very careful selection of the most appropriate policy levers. To date, the NDIA has largely applied actuarial analysis to drive its management of the NDIS. The actuarial approach to managing social insurance schemes seeks to minimise the five drivers of costs - access, scope of supports, price of supports, volume of supports and administration costs. This approach works well for small accident compensation schemes, where the diversity of disabilities covered is also relatively small. The complexity of the NDIS and the diversity amongst the population it supports means it is not possible to fully understand cost drivers using actuarial analysis alone. Other forms of analysis including, for example, causal analysis need to be applied to genuinely understand what may be happening – and more importantly why it may be happening. Without careful analysis of why change may be occurring it is impossible to respond effectively.

Doing additional analysis is not possible however without access to the data. As a result, many of the questions in the terms of reference for this inquiry cannot be answered accurately or comprehensively.

The Productivity Commission in its Review of NDIS Costs in 2017 recommended that NDIS data should be made available for research by the middle of 2018, in accordance with the “Five Safes” - safe people, safe projects, safe settings, safe data and safe outputs. Immediate access by the disability community and researchers to NDIS data remains an essential priority for the effective implementation and reform of the NDIS. This will require a significant change in mind-set by the NDIA, which continues to act as the owner of NDIS data, rather than the custodian.

This is an important distinction which the NDIA do not always appear to grasp. The NDIA collects and holds an extraordinary amount of personal data on each NDIS participant. This data is collected by the NDIA in order for participants to receive the support they need. Participants “provide” the data not as an end in itself, but in order to secure the support they need. The data belongs to them. While the NDIA should be a careful and considerate custodian, it is also reasonable to allow independent scrutiny of the scheme’s operation and outcomes.

Transparency also needs to extend beyond data availability. It should also include access to NDIS participants who are interested in participating in research, to facilitate qualitative research and longitudinal studies. Transparency would also include access to the staff of NDIA and their community partners so their front-line experiences can also inform research, refinements and improvements in the NDIS.

Transparency would enable the impact of the NDIS operating model to be examined. It would shine a light on changes in the NDIS operating model and their impact over time and how the insurance principles of the NDIS are being operationalised. Without transparency, the NDIA will never be fully accountable for its actions and this is essential, as part of good governance.

3. Codesign

All future changes to the NDIS must be codesigned to ensure they embrace the experiences and perspectives of people with disability, their families and the organisations that represent them. Codesign must be inclusive and representative of the broad and diverse disability community. Codesign of public policy and practices also needs to include researchers and should be based on evidence that is contestable. Codesign therefore requires transparency. It is also based on trust.

In recent times, the NDIA has tried to position the Independent Advisory Council as its source of codesign. Occasionally, the NDIA has also added carefully selected peak bodies to workshops or roundtables. This is not codesign. Codesign processes must include the full disability community, including some of the scheme's strongest critics. It must include processes which not only include representative organisations but also mechanisms to reach the "grassroots". While this takes time and resourcing, the three different sources of information would give the NDIA the broadest possible view on the ways the scheme is working on the ground and the potential impact of reforms.

There are many different mechanisms which codesign could be implemented. Before the scheme's introduction in 2013, for example, a number of working groups were established around particular issues – workforce, safeguarding mechanisms, choice and control. These working groups had a direct line into the COAG working group. In the first few years of the operation of the NDIS, the NDIA board and senior management established a Citizen's Jury which was led by the then President of People with Disability Australia, Craig Wallace, to examine the performance of the NDIS and provide advice on changes. Mr Wallace was well-known for his outspoken views. These are just two examples of the ways genuine codesign have been approached in the past. There are clearly many more. A necessary first step would therefore be to sit down with the disability community to consider the most appropriate mechanisms for the future.

4. Shared governance

The NDIS cannot be delivered successfully without the full support and cooperation of all jurisdictions. The current shared national governance arrangements which underpin the NDIS should therefore be strengthened.

There are three principal reasons why shared governance is essential:

1. The interfaces between the NDIS and mainstream services will not work effectively without the collaboration and active engagement of all jurisdictions
2. Supports for people who are not eligible for the NDIS are a shared responsibility between the Commonwealth, State and territory governments and the NDIA
3. States and territories have operational experience which can and should be drawn on by the Commonwealth Government and the NDIA - and this will only be available when all parties are committed to working effectively together.

The requirement for shared governance contrasts with the proposed changes to the NDIS Act (2013) in the National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Bill 2021 (NDIS Amendment Bill 2021). The proposed changes to Sections 14, 47A (6) and 48(5) introduce Category D rules. These rules would only require the Commonwealth Minister to inform other jurisdictions of any proposed changes. This completely undermines the shared responsibility for the success of the scheme and allows the Minister unfettered discretion in these areas. All of these rules should be Category A rules, cementing shared governance.

The experiences with independent assessments, earlier this year, also highlight the essential nature of shared governance for the NDIS. Checks and balances were deliberately included in the NDIS Act (2013) to protect the integrity of the Scheme. These must be maintained and strengthened.

Neither the role of the Commonwealth as Scheme underwriter nor the rising proportion of NDIS spending which is funded by the Commonwealth Government are reasons to weaken current shared governance arrangements. The Commonwealth is the underwriter and hence responsible for any NDIS cost over-runs because it is the only level of government with the financial resources to perform this role. The share of NDIS spending funded by the Commonwealth was always anticipated to rise and is not a new unexpected phenomenon. This is because the Commonwealth covers the cost of people ageing in the scheme. The Commonwealth is responsible for meeting these costs because the Commonwealth is solely responsible for aged care. This was flagged in the original Productivity Commission report and the report into NDIS costs in 2017.

5. Sufficient funding of independent advocacy

It is essential that independent advocacy is resourced adequately. In recent times, the vital role played by independent advocates has been highlighted through their contributions to the work of the Royal Commission into the Abuse, Neglect, Violence and Exploitation of People with Disability, the Joint Standing Committee on the NDIS, the National Disability Strategy and their advocacy around the impact of the COVID19 pandemic on people with disability and their families. However, it is also clear that independent advocates are overwhelmed, juggling with competing priorities with too few resources. There is a pressing need for an increase in funding for both systemic and individual advocacy. Without sufficiently resourced independent individual advocacy, any new planning processes will not result in the fair delivery of the NDIS, because those unable to advocate for themselves will be left behind. At the moment most organisations providing individual advocacy have extensive waiting lists and are only able to support those in the most dire circumstances. That means many who desperately need help simply go without. This is not equitable or sustainable. It has both a significant human cost as well as a potential financial cost to the scheme – if people do not receive sufficient or appropriate support in a timely way, they may wind up further in crisis and needing additional support.

Similarly, increased funding is needed for representative organisations to genuinely engage in any codesign processes. At the moment, their participation is expected without remuneration. The same expectation is not applied, for example, when the NDIA relies on external consultants to complete discrete pieces of work. Codesign processes which continue without consideration of how they will be adequately resourced are not genuine codesign.

6. Sufficient support for people with disability who are not eligible for the NDIS (Tier 2)

When the Productivity Commission undertook its ground-breaking work in 2010 and 2011, it placed the NDIS inside a three-tiered system. Tier 1 was the total Australian population, all of whom had access to the NDIS should they require it. Tier 2 was all Australians with disability. Tier 3 was those Australians with a disability who required an individual package of supports to meet their day-to-day support needs. It was never intended for the NDIS to become an “oasis” in a desert in which only people in Tier 3 received any form of support. It was expected that more limited support for people with disability would still be available in Tier 2. It was also expected that changes would occur in all other mainstreams systems such as health, justice and transport so that all people with disability had their needs met – not simply their day-to-day support needs funded through an individual package.

The current inequity between those eligible for the NDIS and those who are ineligible is not simply fundamentally unfair. It also creates a very significant risk to the sustainability, culture and equity of the NDIS. Adequate support for people with disability who are not eligible for the NDIS is key to the

success of the scheme. The support received by the last person to qualify for the NDIS must be only a little bit more than the first person who does not qualify. As long as there is an absence of equity between Tiers 2 and 3, there will not only be continuing risks to Scheme sustainability but an on-going source of red tape, as the NDIA seeks to protect the financial viability of the NDIS.

Currently, only \$132 million has been allocated to the Information, Linkages and Capacity Building (ILC) grant funding from the total NDIS funding of \$30 billion (as forecast in the 2021-22 Federal Budget). With an expected number of NDIS participants of 533,000 and approximately 4 million people in Tier 2, it is self-evident that allocating such a small amount of money to all people with disability who are not eligible for the NDIS is grossly inadequate (\$33 per person compared with the average package size of the NDIS of more than \$70,000 per person).

The ILC program has also gone through numerous changes in direction since the scheme began. With the transfer of ILC funding to the Department of Social Services and a fresh round of consultations on a yet another strategy further changes can clearly be expected. But wherever the current consultations and strategy lands it is unlikely to resolve the fundamental flaw of the program – a broad policy brief that does not match the amount of funds allocated. According to the ILC policy, ILC is expected to support people with disability ineligible for the NDIS, provide information, resources, peer support and capacity building for individuals as well as deliver mainstream and community capacity building to support all people with disability. The policy overreach is large and the funding totally inadequate. As a result, while there have been worthy initiatives funded through the current approach, success has been patchy, disconnected and piecemeal. In particular there has been limited attention on practical support for those ineligible for an individual package from the NDIS. In short ILC will never work while there are insufficient supports that actually help to improve the lives of people with disability in Tier 2.

Predictably, the inadequate and poorly directed allocation to Tier 2 is already proving to be self-defeating. It is leading to much greater costs to government as people with disability are forced to find ways to become NDIS participants or alternative while forced to wait experience further deterioration in function and independence and need more significant support as a result. This is just the kind of short sighted thinking the NDIS was expected to overcome. Approaches such as independent assessments, which the NDIA hoped would limit the number of NDIS participants will simply not work, because they do not address the underlying cause of the excess demand.

Another disability system which was deeply inequitable was the support for people with disability in WA, before the introduction of the NDIS. Those most in need qualified for support through a Centralised Access Process (CAP). Those outside the CAP received very little. Over time, the CAP review processes became more and more onerous and demeaning as people with disability and their families were forced to “prove” that they were more in need of support than the next person. Many of the families who missed out on CAP funding were traumatised by the process. The CAP has important lessons for the NDIS and its implementation.

In the *Review of NDIS Costs* in 2017, the Productivity Commission recommended increased funding for ILC/Tier 2, as did the Joint Standing Committee in 2018 and the Productivity Commission in its *Study of the National Disability Agreement* in 2019. So long as there is a “cliff” at the edge of the NDIS, rather than a gentle slope, the NDIS will not be sustainable or equitable. Increased support for those not eligible of the NDIS therefore needs to be addressed as a matter of urgency. However, responsibility for Tier 2 is shared with the Commonwealth, state and territory governments. It will require a coordinated response. It will also be important to design Tier 2 in ways in which one size does not fit all. After almost eight years of operation, there is still very little known about people who sit just outside eligibility for the NDIS – what their support needs are, what services they currently use, what services they miss out on and what would make a difference to their lives. This is an important area for future research in order to implement the most appropriate policy response. Most importantly, the optimal arrangements for children in Tier 2 and who need some early

intervention will be very different to the needs of adults. Therefore, changes to Tier 2 should identify key sub-groups and then align support structures with their needs through co-design and based on the best research and evidence.

7. Early Intervention

The key steps to optimising early intervention are:

- better supports for children not eligible for the NDIS, as noted above in relation to Tier 2
- supporting parents following diagnosis of a child with disability
- ensuring that the best evidence in relation to family-centred practices and key worker models are available for parents from trusted sources to help them make optimal choices
- potentially system changes including possible market interventions to assist with informed choice.

Supporting parents at the time of diagnosis of disability and in the immediate period following is essential for both child and family wellbeing. The immediate phase where parents are grappling with a new diagnosis and what it will mean for their child and their family is also often the same time when early intervention services typically begin. In this period parents are anxious to do the best for their child and can be vulnerable to suggestion, including sometimes effectively looking for a “cure”. In this situation it can be challenging to make decisions, particularly without support. Demand for more and more therapy can often be the result. When parents do not have access to independent evidence and information about what will be in the best long-term interests of their child it is challenging to make genuinely informed decisions about the most appropriate interventions.

Research over many years shows that early intervention is most effective when it utilises family-centred practices delivered in day-to-day settings. Under this approach parents and others involved with the child, including extended family and early childhood workers, are trained in how to incorporate therapy activities into day-to-day life. This is much more effective than the medical model of therapy delivered in short periods in clinical settings. It produces not only better outcomes for the child but promotes family resilience and wellbeing. Unfortunately, the medical model has emerged as the dominant form of early intervention under the NDIS.

The impact of insufficient funding for Tier 2 is clearly evident from the higher than expected number of children entering the NDIS and then remaining as ongoing participants. Typically, children who are eligible for early intervention receive packages of \$10,000 or more and remain eligible for early intervention supports until the age of seven. This may be contrasted with children who are deemed to be ineligible for early intervention. They receive only a few hours support over 6 months and once this support has been exhausted can receive no additional support for a minimum of 12 months.

At the end of the early intervention period those who are deemed ineligible to become ongoing NDIS participants then are exited from the scheme and receive nothing. It is therefore completely unsurprising that when parents face the prospect of very little support for their child who is missing developmental milestones that they fight for ongoing inclusion in the NDIS.

The latest suggestions from the NDIS to introduce support bands for children with a diagnosis of autism will not work. This is evident from earlier experiences with the NDIS. In February 2016, the NDIA introduced the Early Childhood Early Intervention (ECEI) Gateway which tried to classify all children into three levels of early intervention. This policy failed because it was not based on need and did not address the “cliff” at the edge of the NDIS.

Much more work needs to be done to build an evidence base for effective early childhood interventions and ensure they are reflected in both the policies and processes of the NDIS and in the

funding and practices of providers. More support and independent information also needs to be provided to parents to help them to make genuinely informed decisions about interventions for their child. And finally, a great deal more design and implementation work needs to be done to ensure there is an effective and accessible Tier 2 to ensure all children in and out of the scheme are connected to universal services and are genuinely included in the life of the community.

8. Effective market stewardship

While the Productivity Commission Report in 2011 was ground-breaking in its identification of the economic benefits of the NDIS and endorsing participant control and choice, it did not pay sufficient attention to the critical importance of market stewardship to an effective scheme. The implicit assumption which underpinned the report was that if demand grew, good quality supply would follow. It was assumed the market would work efficiently. This was always an unrealistic assumption, for a number of reasons including:

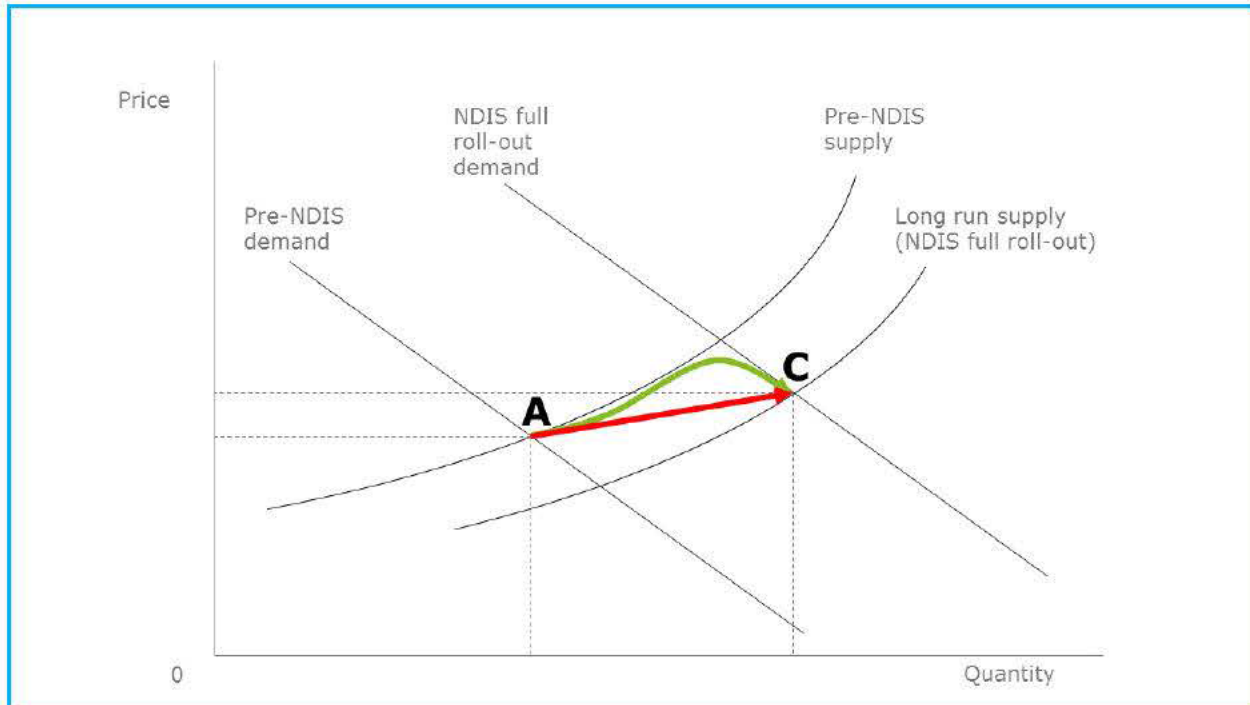
1. the purchasing of disability supports and services is unlike the purchase of other consumer goods or services. For example, there are multiple considerations in selecting a provider and it is not easy to switch – there are high transaction costs
2. the historic underfunding of the sector has distorted the market
3. there is an imbalance of power between providers and consumers that cannot be simply addressed through choice, and
4. the lack of independent information and support for participants to act as informed, resourced consumers

There is also no blueprint for success – the NDIS is unique in the world. While the NDIS draws on aspects of policy and practice internationally and nationally, it is unique in both design and implementation. It is also, in public policy terms, only in its infancy. Given all of these factors, the role of market stewardship is even more critical.

And yet to this point the NDIA has almost exclusively relied up on a single instrument - price - to guide market growth and development. In an effort to control the market and costs, it has set more and more prices over time. It has relied upon more and more detailed actuarial and cost analysis rather than employing different stewardship strategies. This has been a futile pursuit - it is simply impossible to set prices for every service, in every NDIS sub-market and in every location.

In August 2019, the NDIA published the National Disability Insurance Agency Pricing Strategy, which illustrates the shift in the disability market, as a result of the introduction of the NDIS, using the figure below:

Figure 1: Transition from equilibrium prior to the NDIS to the long run NDIS equilibrium



As the figure above illustrates, the introduction of the NDIS created a big demand “shock” in the disability market, from “pre-NDIS demand” to “NDIS full rollout demand”. Effectively, the introduction of the NDIS has led to a doubling of the quantity of demand in a very short period of time, with a similar expected addition to demand for a skilled disability workforce. Both have placed significant upward pressures on the supply curve.

The introduction of the NDIS also coincided with increases in the SCHADS award (over and above Fair Work Commission decisions) of between 29 per cent and 45 per cent in nine instalments between December 2012 and December 2020. It is this increase in wages which has significantly contributed to “cost increases” in recent years. The Productivity Commission Review of NDIS Costs in 2017 noted that the changes in the SCHADS award have permanently added \$6.4 billion to the costs of the NDIS. Wages have only increased further in the years since the Commission conducted its review.

Further, upward pressures on the supply curve from award wage increases have been exacerbated by NDIA service provider “red tape”, reflected in the need for the NDIA to introduce the Temporary Transition Price (TTP) loading.

As a result, it is impossible to believe that the supply curve for the NDIS will shift downwards as forecast by the NDIA. In fact, it is clear supply shortages and market gaps will continue to for some time. It also clear that despite the significant increase in demand, there has been little innovation in service offerings. Participants consistently report difficulty in locating and obtaining services that work for them, particularly in rural, regional and remote areas.

On the demand side of the market, it is essential that demand for individual services is highly elastic. This implies a need for the demand curve to flatten, so that a relatively small rise in prices generates

a large decline in demand. However, this will not happen without participants having access to timely, reliable, independent and accessible information and ability to use that information to inform decisions about purchasing.

In effect, a new and vastly expanded disability marketplace needs to emerge. Participants and their families need support to become the discerning buyers the market assumes they are. They need essential information at their fingertips, enabling them to navigate efficiently and effectively and overcome inherently high transaction costs. Quality support coordination, other effective service navigators such as LACs, standardised easy-to-read service contracts, mechanisms to facilitate NDIS participants trying new services and reduced transaction costs are all important ingredients in creating an effective market and a sustainable NDIS.

It is also important to remember that in the original vision for the NDIS, it was also assumed that people with disability would be able to access both mainstream services and specialist disability services. This assumed an investment in mainstream services and reform to ensure they met the needs of people with disability through the Australian Disability Strategy. An important function of Local Area Coordinators was to help participants link with mainstream services. Where capacity and capability was an issue, LACs were expected to have a community development role. In practice however LACs have been completely consumed by planning.

A re-positioning of LACs is therefore one aspect of an overall strategy to stimulate innovation, build new sources of supply and shift the supply curve downwards. There is a long list of potential market enabling mechanisms which could be trialled and adopted if effective - bulk purchasing of services in thin markets, price deregulation where markets are competitive to name just two – which should become part of a much more sophisticated approach to market stewardship.

Finally, the NDIA, as the dominant player in the NDIS markets, must become much more aware of the consequences of its own actions on the behaviours of participants in order to avoid perverse effects. Every time its actions erode trust, it undermines market effectiveness. “Use it or lose it” policies can add to demand undermining sustainability, while unwritten operating rules can undermine market effectiveness and increase the risk premium for services, such as for Specialist Disability Accommodation.

In summary, much more effective and nuanced market stewardship is essential for the achievement of control and choice for all NDIS participants, efficient allocation of resources, and the sustainability of the NDIS. The implementation of much better market stewardship needs to start with an analysis of experiences to date utilising the NDIS data and then build up an evidence base from which more effective market stewardship can be co-designed.

9. Improving NDIS operational structures and processes

There are a number of key NDIS operational structures and processes which should be improved.

(i) *Changes to the structure of Core, Capacity Building, Assistive Technology and Specialist Disability Accommodation/Supported Independent Living Supports*

One of the few aspects of the NDIA’s plans to introduce independent assessments that had broad support from people with disability and their families was the promise to make NDIS funding more flexible and allow participants greater choice and control over the ways in which they could use their funding. It was not clear why this greater flexibility was tied to the introduction of compulsory assessments- other than an attempt to further control scheme costs.

There should only be three categories of supports: core/capacity building, assistive technology and Specialist Disability Accommodation (SDA)/Supported Independent Living (SIL). This structure should be introduced immediately. Within core/capacity building there should be total flexibility.

(ii) Draft plans for all participants

Despite multiple promises over many years, NDIS plans are still approved and finalised without participants and their families having the opportunity to see a draft.

In addition to the obvious loss of empowerment for participants and their families, there is also no opportunity to ensure that there have been no mistakes or misunderstandings between the planner and the participant and their family or other advocate. This leads to unnecessary requests for reviews. All participants should be immediately provided with a draft plan before finalisation and approval.

(iii) Empowering control and choice/investing in support coordination

The NDIS is complex and difficult to navigate. For many participants it is clear that the “postcode lottery” of the old welfare disability system has been replaced by the lottery of luck: the good fortune of effective advocacy. The promise of “choice and control” has not been realised for too many participants who have not had the support they require to make it meaningful. Too few participants are provided with support coordination. Advocacy remains grossly underfunded. And despite repeated calls for the development of a framework of support for decision making, the NDIA is only now turning its attention to this critical piece of infrastructure.

Therefore, to ensure that the NDIS is equitable, support coordination must be available to all participants but particularly those without strong and effective family support. Currently, it is clear that there is insufficient high quality support coordination available and helping to build this supply is an NDIA responsibility as part of its market stewardship role. In the most significant cases of persistent disadvantage, on-going case management should also be provided. How this should operate should be one of the areas of immediate codesign with disability representative organisations.

(iv) Valid eligibility and planning processes

Valid assessments and processes for both eligibility and the determination of reasonable and necessary supports are the bedrock on which the equity and sustainability of the NDIS must be built.

The planning process must continue to begin with establishing the goals of the participant and then take account of sustainable informal supports. This process of starting with participant goals is absolutely critical to the culture and structure of the NDIS. The focus is, and must continue to be, on what people with disability can do and the support required to exercise their full citizenship - rather than what they cannot do.

The final step is the assessment of reasonable and necessary supports. Valid assessments require the careful assessment of information from multiple sources by appropriately trained staff/assessors/planners. The planning process must also take account of expert reports. Where there are assessment tools which have been validated for NDIS purposes, they should be used. In this context examining tools which directly measure support intensity needs rather than function should be considered.

However, even with improved and targeted assessment tools, there will still be a need for multi-disciplinary teams to exercise professional judgement. This means an appropriately trained and resourced workforce will still be needed. It will take the assessors considerable time to get to know the participant’s needs, goals and informal support arrangements and to have the opportunity to independently assess their capabilities in multiple settings.

(v) Certainty for participants and their families

One of the reasons people with disability and their families fought so hard for the introduction of the NDIS was the promise of certainty. Certainty in the knowledge that the scheme would be there when they needed it. In the case of older parents, certainty in the knowledge the scheme would support their adult child when they were no longer able to. This is an essential part of the trusted relationship between the NDIA and participants and their families. Unfortunately, recent actions by the NDIA have significantly eroded that trust.

Like the Disability Support Pension, the NDIS should have a category of “manifest and lifelong” disability which would mean that the participant is and remains eligible for the NDIS. The proposed powers for the CEO to amend a plan under the NDIS Amendment Bill (2021) would then not apply.

(vi) Local Area Coordination aligned with the original intent

Currently, Local Area Coordinators are spending almost all of their time on planning. This has not changed despite many promises to the contrary. It is now essential to align the duties and responsibilities of LACs with the original intent, with a primary focus on building trusted relationships and assistance with service navigation and community capacity building so that NDIS participants can better access mainstream services and the community becomes more inclusive of people with disability.

(vii) Changes to Section 170 of the National Disability Insurance Scheme Act (2013)

When the National Disability Insurance Scheme Act (2013) was passed by the Parliament in 2013, it was not anticipated that large parts of the functions of the NDIA would be outsourced to non-government community partners. As a result, the current legislation does not allow delegations from the CEO to the staff of community partners.

This leads to needless double handling and, more significantly, means that the majority of NDIS participants and their families never meet the person who is responsible for approving the funding on which they are completely dependent. This leads to simple mistakes and misunderstandings, is deeply disempowering and contributes to inequity.

One way to correct this situation would be to amend Section 170 of the NDIS Act to allow to include the staff of the NDIA’s Community Partners. This would then allow the necessary delegations under the Public Service Act.

This would however result in a significant change in the current operation of the scheme. Given the consequences of the decision, this would be another area which would require significant consultation and codesign with people with disability, their families and their representative organisations.

(viii) Adequate resourcing of the NDIA through an NDIA Resourcing Guarantee

In the original Productivity Commission report on the NDIS, it was estimated that operational costs would be represent about 10 per cent of total scheme costs. This was based on global best practice in managing social insurance schemes. However, before the introduction of the NDIS in 2013, the Department of Finance arbitrarily cut full-scheme operational costs to seven per cent of the total budget. The NDIA was then further subject to an arbitrary staff cap from 2014 onwards.

The Productivity Commission in its Review of NDIS Costs in 2017 recommended that administrative costs should be increased. They argued that artificially constraining administration costs could have perverse effects and undermine the sustainability of the NDIS.

In the 2021-22 Commonwealth Budget, NDIS operational costs are projected to be just four per cent of total scheme costs. While it is important to ensure that the scheme is administered efficiently and that the bulk of funds go to participants, it is also important to ensure the NDIA has the appropriate resources to effectively administer the scheme. To do otherwise will only threaten scheme sustainability and undermining quality service delivery.

It is notable that the Participant Service Guarantee (PSG) in the NDIS Amendment Bill 2021 is framed solely on the basis of time periods in which the NDIA must respond or act. However, timeframes are a very narrow and potentially perverse measure of quality of service. NDIS participants and their families will not be well served by the PSG if all that happens is the NDIA makes poorly considered and ill-informed decisions more quickly.

There are numerous examples of why adequate resourcing is essential: good planning and assessment is best undertaken by multi-disciplinary teams in multiple settings, which takes time and resources; a Participant Service Guarantee based on time frames will not assist if it only leads to poor decisions happening faster; and, LACs need more time to undertake community capacity building and facilitate access to mainstream services. Adequate NDIA resourcing is therefore essential and should be provided through an NDIA Resourcing Guarantee designed to match the Participant Service Guarantee (PSG) and ensure it is realised in practice.

(ix) Appeals to the AAT

The latest Quarterly Report from the NDIA (June Quarter 2021) shows that 4,345 appeals were “resolved before hearing”, many just outside the door of the hearing. Only 99 appeals were actually heard by the AAT. Taking an issue to the AAT requires enormous time and financial resources to obtain the necessary reports, as well as emotional and physical capacity to navigate and persist with the process all while under considerable pressure. The current approach of the NDIA to AAT appeals, in which they push participants to the limit and then agree to a confidential settlement at the last minute, often because they know the case has merit and do not want details to become public, amounts to completely unconscionable behaviour. It must stop immediately.

AAT reviews provide an important guide to the fair operation of the NDIS and so should be welcomed where there is legitimate disagreement about eligibility or reasonable and necessary supports. Where appeals are baseless, they will be quickly dismissed and so should not be feared by the NDIA.

10. Optimising interfaces with mainstream services

The management of the interfaces between the NDIS and mainstream services, including health, education, justice and housing has been a concern since before the introduction of the NDIS. It remains a major challenge, with concerns about cost shifting on all sides. The unfortunate consequence of this squabbling is that people with disability are left without support or inadequate support. Ultimately, this is self-defeating, particularly from an insurance perspective, which seeks to minimise lifetime costs and maximise life outcomes.

There needs to be a major rethink of how these interfaces are managed. The best approach would be to put the person first and provide the optimal supports, with the question of who pays sorted out in the background between government departments and agencies. This would also contribute to better short-term cost outcomes from a taxpayer perspective as, for example, people with disability would not be left in hospital for unnecessarily long periods at high cost and also, potentially, leading to very damaging and therefore expensive long-term outcomes.

One of the most complex interfaces is the interface between the NDIS and health and so this would be a good place to start the codesign process. Any codesign process would also need to take account of jurisdictional differences and therefore needs to involve states and territories as well.

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