

Submission to Productivity Commission: National Disability Insurance Scheme (NDIS) Costs Position Paper

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1. About Women with Disabilities Victoria

Women with Disabilities Victoria (WDV) is an organisation run by women with disabilities for women with disabilities. Our members, board and staff live across the state and have a range of disabilities, lifestyles and ages. We are united in working towards our vision of a world where all women are respected and can fully experience life.

Our gender perspective allows us to focus on areas of particular inequity to women with disabilities: access to women's health services, engagement with NDIS services, and safety from gender-based violence.

We undertake research and consultation. We provide professional education, representation, information, and leadership programs for women with disabilities.

2. Overview

WDV is a strong supporter of the NDIS. We agree with its fundamental principles, including a human rights approach, choice and control for participants and a clear focus on outcomes for individuals.

WDV supports the NDIS' restructuring of costly, ineffective and at times unjust disability service systems and appreciates that this is a change that will take some time. Over time, elements of the scheme will need review and readjustment. While WDV sees that there are many new opportunities that should be available to women when the scheme is fully operational. The reconfiguration of systems also presents an opportunity to address a number of underlying inequalities that have historically disadvantaged women with disabilities. We are seeking a new system that delivers fairness and justice in outcomes and recognises diversity and disadvantage to ensure positive outcomes for women. WDV is concerned that each review of new systems should give issues of gender due consideration so that inequalities and disadvantages in the old system are not replicated in the new.

An ordinary life should recognise the roles of women with disabilities as working women, parents or carers. Above all, an ordinary life should not be a life that exposes women to violence or discrimination.

WDV agrees that there is widespread commitment to making the scheme successful and sustainable. We are committed to working with our members and a wide range of partners to make the scheme safe and workable for women. Our focus is on ensuring that women can engage with a system that is able to recognise and respond to their individual circumstances. While there are many aspects of the Position Paper that are of interest to us, we will focus commentary on key issues that affect WDV members.



3. Draft Recommendations, findings and information requests

While we acknowledge that costs and sustainability are critical to the success of the NDIS in the long term, WDV is pleased to note the observation by the Commission that costs are 'just one side of the equation' $(p7)^1$.

How is the scheme tracking?

Draft Finding 2.1

WDV endorses this Finding.

WDV agrees that timing of the rollout set in Bilateral Agreements has led to compromise in some areas, as noted in the Position Paper. WDV's view is that some of these compromises are unacceptable leading to inadequate planning, unnecessary use of the appeals process and a level of confusion and dissatisfaction for participants. Processes that use shortcuts - such as an over-reliance on reference packages or telephone planning sessions - to meet the rollout timetable rather than the individual planning needs of participants threaten to undermine the integrity of the scheme.

WDV supports a slowing of the rollout, with a process that allows for a clear point in time for eligibility so that those affected by the slow down are not excluded due to delayed roll out. This should be accompanied by an appropriate system for identifying and addressing high priority people with disabilities in crisis meaning that urgent needs or complex situations will be fast tracked.

Draft Finding 2.4

WDV agrees in principle but feels that this is an ambiguous finding. It would be helpful to emphasise the need for further tracking and analysis of who is benefiting most and least from the scheme. This is noted elsewhere in the Position Paper where reference is made to key findings from trial and transitional data (pp. 16-18). WDV agrees that better reporting on quality is needed (pp 45-46) and suggests that openness to more research and review by others (universities, analysts, participants) will strengthen the NDIS. See, for example, http://socialequity.unimelb.edu.au/ data/assets/pdf file/0010/2364499/Choice-Control-and-the-NDIS-Report-Melbourne-Social-Equity-Institute.pdf

Scheme eligibility

AGE: WDV is concerned about unfairness of the age cut off (under 65) being wholly dependent on criteria such as the location and timing of the rollout into the relevant area. This results in random inclusions and exclusions for WDV members. A much fairer approach would be an agreed commencement date (for example, 1st July 2016) for the purpose of

 $^{^{\}rm 1}$ All page references are from Productivity Commission Position Paper Overview and Recommendations, June 2017 unless otherwise noted.



meeting the age criteria. We are also deeply concerned that people with disabilities over the age of 65 will not have the benefits accorded to those who qualify for the NDIS. This will create a two tier system: some people with disabilities will have adequate resources and some will not.

PARENTING: WDV understands that clarity is needed around current guidelines allowing for support for parents whose disabilities restrict their capacity to care for their child or children.

It is important that NDIS packages that are designed to support participation do not value economic participation (employment) over the other work that women might do, including parenting and caring. Support requirements for parenting, such as assistance with bathing or caring for a child, should be explored in any planning for women with disabilities with family responsibilities.

Scheme supports

Information request 4.1

WDV agrees with a broad approach to defining what is reasonable and necessary, with detail to be shaped by court and tribunal decisions over time. This is because social contexts (what is reasonable and necessary, what is an ordinary life) change over time. Expectations of support for people with disabilities to pursue goals, live independently and participate fully should remain in line with social change, guided by the NDIS Act.

Greater transparency (rather than legislative clarity) is the most effective way of defining and operationalising the concept. It is worth noting that progress on this relies on a system of challenges and appeals being transparent, responsive and timely. For this to be effective, decisions made by the NDIS need to be subjected to scrutiny to ensure that the parameters of what is reasonable and necessary are reviewed and reshaped as needed.

At present, WDV is concerned with the time taken for the internal review of decisions and the potential impact of delays (sometimes months) on the implementation of a 12 month plan.

WDV supports public reporting on reviews and decisions of the NDIA (p45). Further, WDV proposes that a policy unit within the NDIA should ensure that review processes (internal and external) lead to transparent capture and communication of the range of decisions that shape the meaning *and application* of what is reasonable and necessary. Clearly, this should include decisions formalised by a court or tribunal. It is critical that policy application should also take account of NDIS decisions to settle a matter prior to a formal decision being made (by the AAT or a court). In this instance, there is potential to avoid precedent and repeat inconsistent decision-making and implementation approaches that may not be acceptable if subjected to external review.



WDV supports the proposal that the NDIA should adopt a process for amending or adjusting plans to reduce costs and delays associated with a full plan review if that is not needed (p45).

Information request 4.2

WDV believes that LAC providers have been over-used in the rapid 'on-boarding' process and this has diverted resources away from pre-planning, information and capacity building work that was a significant part of the ILC stream under which LACs were to perform a range of important functions. WDV believes, in principle, that LACs should not be involved in planning because it limits their capacity to deliver these other important functions.

If a major change is made to the LAC function so that they have capacity to undertake all of this work *in addition to* significant involvement in planning work, then WDV agrees that it is logical for the NDIA to have the capacity to delegate plan approval functions, where LACs are properly skilled and equipped (see Draft Recomme ndation 4.2).

Draft Recommendation 4.1

WDV endorses this Recommendation.

Draft Recommendation 4.2

WDV strongly endorses the Commission's recommendation that planners should have a sound understanding of disability. We would add to this the need for all planners to recognise and respond to the diversity of individual experience, including culture and sexual identity, for instance.

We agree that in some cases, specialist knowledge and experience is required. While the commission notes psychosocial disability as an example, we would also add that specialisation and skill in areas such as complex communication are essential to a proper planning process. This experience and skill goes beyond knowledge of disability 'types' and diagnostic categories.

WDV also proposes that planners should have a broad understanding of relevant mainstream systems so that they understand areas of complex interface that may be needed to define the scope of each package. Family violence is an example. Recognising and responding appropriately to women experiencing family violence requires a level of skill, experience and knowledge of family violence systems in order to develop an appropriate NDIS plan.

WDV is conscious of the complexity of the interface between NDIS and mainstream service systems and supports further work across a range of areas. We continue to be concerned about access to services for those women who are not eligible for NDIS packages.

Attention is rightly directed to significant work that needs doing around health, education and transport. However, it is critical that attention is paid to the interface with the



developments in prevention and response to violence against women. Women with disabilities are at increased risk and need to be included in all violence prevention and response programs. To date, there has been inadequate work done in this area, given its significance in ensuring that women with disabilities have the opportunity to live an ordinary life.

LACs and support coordinators need experience and clear pathways in order to coordinate between social services and family violence prevention and response services.

WDV agrees that, where expertise is required, this might be leveraged from disability services but notes that careful management would be required to avoid any conflicts. This is particularly the case where there are limited numbers of providers and so WDV agrees, where a disability expert is engaged, the role should be advisory, with decisions made by the participant and a planner. An alternative approach might be to include an advocate in planning processes where expertise is required.

Boundaries and interfaces with the NDIS

Draft Finding 5.1

WDV endorses this Finding.

WDV agrees that it is, 'a false economy to have too few resources for ILC activities in the transition period' (p31) and agrees that the transition period is the critical time for investment in this area.

Draft Recommendation 5.1

WDV partially endorses this Recommendation.

WDV strongly endorses the Commission's view that ILC funding should be accelerated and maintained until the scheme is fully established and a proper review can take place.

This critical element of the NDIS needs more resourcing and it needs to be brought forward to support other elements of the NDIS. Without capacity building of mainstream organisations to include people with disabilities, the scheme cannot function effectively and people with disabilities (those who are participants and those who are ineligible) will not be adequately connected with services.

Further, ILC provides the greatest opportunity for women with disabilities to participate fully in the scheme – not only as participants in receipt of funding packages but as providers of information to peers, as capacity builders for mainstream services, as educators and trainers for service organisations and as service providers.

WDV agrees that ILC funding should be increased to maximise the effectiveness of this stream and that this should occur during transition. Delaying until after a COAG five-yearly



review of scheme costs may miss significant opportunities during the transition period when resources should be maximised.

Draft Recommendation 5.3

WDV endorses this Recommendation.

Provider readiness

Draft Finding 6.1

WDV endorses this Finding.

WDV is pleased to see that thin markets are recognised. Further, WDV considers that women at risk of violence should be considered to have 'complex, specialised or high intensity needs' and therefore we consider that the market is likely to struggle to provide disability specific, gender sensitive responses. In our view, this is likely to lead to poorer participant outcomes.

Training is needed to ensure that workers understand the risks of violence in all settings, with co-residents, family or community.

Information request 6.1

WDV suggests that cross government collaboration would be a useful strategy to prioritise parts of the workforce for immediate attention. In particular, we advise this approach to build the skill of those providing support for participants with complex needs.

WDV advises cross government collaboration to prioritise the capacity of services to deliver gender responsive services. This is key to increasing the quality of NDIS participants' lives and preventing violence and abuse before it occurs. Where women choose to have services delivered by a female provider, providers must have flexibility in scheduling and a sufficiently diverse workforce to respond. Thin markets in this area of complex, specialised and high intensity work risk exposure of women to violence and discrimination.

The Victorian Government has processes in train to target skill development and workforce development within disability services in this state (40). Victorian work on family violence implementation, including workforce readiness, may offer a useful model for consideration. Implementation of the reform includes significant work on provider readiness and the use of hubs to ensure access for women across the state.

Workforce readiness

Information request 7.1

The NDIS has provided a much needed disruption and impetus for change in culture of service provision. While the disability support system is expected to mature over time, in the short term WDV has observed the impact of structural change, mergers, rapid



recruitment of staff, competition to retain staff and the challenge of providing skill training within pricing structures that do not allow for backfill or significant professional development. Staff must now be deployed in systems that are more flexible and respond to individual choice in dispersed locations with less supervision than in onsite services.

Growth required in the workforce to meet NDIS participant demands need not compromise its quality if workforce and skills plans are in place and adequately funded. This can be done in parallel with work in the broader community sector, including aged care and family violence.

Current NDIS pricing model for training and professional development per worker per year is inadequate and needs to be addressed.

WDV proposes efforts from all levels of government to lift the status of the disability workforce and provide skills development and other career incentives such as affordable pre-employment training. It is important to work in tandem with other industry plans (aged care, family violence). It is also important to take an intersectional approach to diversifying the workforce, emphasising recruitment targeting a diverse cohort of workers. For example, people with disabilities are ideally placed to add value to the disability sector from their lived experience. A range of models of service delivery are important to provide flexibility for participants service needs and to build the workforce.

It would be helpful for current and future NDIS participants and other people with disabilities to drive the identification of these skills as well as being considered an important part of the current and future workforce.

Draft Recommendation 7.2

WDV endorses this Recommendation.

Draft Recommendation 7.3

WDV endorses this Recommendation.

The reasons for providing NDIA payments for provision of informal supports are logical but the blurring of paid services and informal care arrangements raises significant issues. There is a risk that women who receive support may be placed in a position of dependence (eg: only the family provides transport) reflecting a power relationship that has potential to isolate women or restrict opportunities for economic or social engagement. WDV proposes that this sort of arrangement should only be considered at the request of the participant and following a confidential conversation with the participant.

While every member of the community can reasonably expect to give and receive care, the NDIS has relied strongly on a pillar of informal care, including informal supports in each participant's plan.



This has significant consequences for women as caregivers and for those receiving support. Women who provide the bulk of informal care are expected to do so as part of someone else's plan, in an unpaid capacity. This significantly restricts their ability to participate in paid work in the community. It would be difficult to place a dollar value on this care for some. This is an area of the NDIS that requires clarification.

Recent research supports the concern that, 'some participants living with disability may be in exploitative, or even abusive, relationships with some carers and that there may be legitimate concerns for their safety and wellbeing. Responding appropriately to these complex situations is even more difficult if NDIS staff have minimal training and preparation for their roles, are overwhelmed by high workloads and lacking previous experience working in the disability sector' (Choice, Control and the NDIS, University of Melbourne, 2017:48).

There is a real risk of creating or worsening power imbalances by assuming that family members are able to provide primary supports which could place women at further risk. It is also worth noting that Quality and Safeguarding measures are only developed to cover formal services rather than for informal or family support which raises complex issues about how to monitor or support quality and safety in informal supports.

Participant readiness

Information request 8.2

WDV agrees that participants 'need more help to make the most of the NDIS' (p41). In addition to the development of targeted information, WDV strongly supports a range of advocacy and information sharing work by peer groups and DPOs (p42).

At present, NDIA specifically rules out the funding of any advocacy work. This should be reconsidered. Advocacy of all kinds – individual, peer, representative, systemic, legal – is needed to support participants and build capacity for healthy and active engage with the NDIS. Advocacy is also needed for participants to make full use of the systems of review and challenge.

In particular, WDV believes that the effective utilisation of the proposed system of Quality and Safeguarding will require involvement of a range of advocates to inform and support participants as they navigate these new pathways and systems.

When reviewing average package cost (p17), it is interesting to note that those people who may be least able to advocate for themselves are receiving packages of lower than expected value while the reverse is the case for participants described as having high ability to advocate for themselves (p17). WDV proposes that there is a need for advocacy – both individual and systemic – to ensure that those people who are less able to advocate for themselves can still be well-served by a consumer driven system that requires participants to be informed and engaged.



WDV would be interested to see data breakdowns by gender to see that women are receiving equal opportunity to benefit from packages and are managing to overcome pervasive gender stereotypes about what women are entitled to ask for and what they are expected to do (housework, childcare) with little or no assistance.

WDV strongly endorses the Commission's investigation of, 'considerable scope for the NDIA to improve transparency and clarity around planning processes' (28). Further, there is scope for a range of agencies to bridge information gaps and build capacity for better understanding of the system and how it works, outside the NDIA bureaucracy. Disabled People's Organisations (DPOs) are well placed to understand the nature and format of accessible information that suits the needs of their members. Further, DPOs are able to provide peer to peer information sharing which is both trusted and targeted to their constituents (young people, women, LGBTIQ, Aboriginal and Torres Strait Islander communities, CALD communities). These organisations do not experience the conflict of interest that may complicate the position of Disability Support Organisations.

WDV proposes increased outsourcing of information provision to targeted groups through DPOs and peer to peer information sharing networks.

Governance

Draft Recommendation 9.3

WDV endorses this Recommendation.

Draft Recommendation 9.4

WDV endorses this Recommendation.

Draft Recommendation 9.5

WDV endorses this Recommendation.

Funding arrangements

Draft Recommendation 10.2

WDV endorses this Recommendation.