

# **VALID**

**Victorian Advocacy League for Individuals with Disability**

**Submission in response to the Productivity Commission Inquiry into  
NDIS Costs Position Paper**

**19 July 2017**

## **About VALID**

The Victorian Advocacy League for Individuals with Disability (VALID) is the peak organisation in the Victorian disability sector representing people with an intellectual disability. VALID is run by and for people with disability and their families. VALID has particular expertise in networking and providing information to people with disability and families across the state. VALID is committed to the vision of an Australian nation in which people with a disability are empowered to exercise their rights – as human beings and as citizens – in accordance with the United Nations Convention on the Rights of Persons with Disabilities. VALID strives to realise its vision through a range of strategies that work to empower people with disabilities to become the leaders of their own lives.

VALID works collaboratively within a range of networks, alliances, advisory groups and representative bodies and is:

- The Victorian agency member of Inclusion Australia (National Council on Intellectual Disability / NCID)
- An active member of the Disability Advocacy Network of Australia
- A member of the Victorian Government National Disability Insurance Scheme (NDIS) Implementation Taskforce
- A member of the National Disability Insurance Agency (NDIA) Intellectual Disability Reference Group
- Represented on the Future Social Service Institute Steering Committee
- Appointed to the Registration and Accreditation for Victoria's Disability Workforce Project Advisory Group

VALID actively campaigned for the introduction of the National Disability Insurance Scheme and remains a committed and active supporter. Our members, directly and via Inclusion Australia (NCID), have always driven our constructive feedback to the NDIA, Commonwealth and Victorian governments, and to inquiries such as this. VALID's comments should not be interpreted as any reduction of support for this vital reform that is fundamental to improving life outcomes for people with disabilities.

### **How is the scheme tracking?**

VALID would like to start by articulating its ongoing support for and commitment to the National Disability Insurance Scheme (NDIS). VALID was an early and unwavering supporter of the campaign for the introduction of the NDIS and remains convinced it is the only model able to deliver outcomes for people with disability in a sustainable manner. VALID remains dedicated to the original vision of the NDIS and strongly opposes any attempt to control costs by deviating from this vision or by undermining the principles on which it is founded. VALID's comments and suggestions are intended as constructive feedback offered in the spirit of co-design to help the scheme achieve its full potential and should not be misinterpreted as any reduction in support for the scheme.

From the very beginning the NDIS has brought huge improvements to the lives of many people with disabilities, especially people who have never received sufficient support and people who are able to

navigate the new system well. To date, it has also been largely on time and on budget; laying the groundwork of its ongoing sustainability.

Given the youth, size and complexity of the NDIS, it is not surprising that there have been implementation issues during such an important reform. VALID's experience is that the NDIS has brought positive changes for the majority of scheme participants, however, for many of the people that VALID spends significant time supporting – people with intellectual disability, autism and challenging behaviours – the NDIS has ushered in a period of greater bureaucracy and negative consequences. A focus on improving outcomes for this particularly vulnerable group of people is urgently required. For example, positive behaviour support seems to be incorrectly viewed as one distinct product or service rather than facilitation of a network of services that enable a person with disabilities to effectively engage, participate and belong. This network of service commonly requires focus on both building the capability of the participant and on sustained support to the persons delivering supports (formal and informal) to the participant and intensive coordination over an extended period.

VALID would also suggest that the under-utilisation of approved funding reflects a lack of investment in capacity building of participants and families, not just supply issues.

VALID also notes that the scheme cannot substitute for or achieve its intended outcomes without persistent implementation of the National Disability Strategy 2010-2020.

### **Scheme eligibility**

To date VALID is not aware of any instances of people who do not meet the disability requirements entering the scheme under List A.

### **Scheme supports**

#### *Information Request 4.1*

VALID does not support making changes to sections of the National Disability Insurance Scheme Act (2013) (Cwlth) relating to reasonable and necessary. VALID is concerned that any changes to reasonable and necessary in legislation will reduce scheme flexibility and the ability to respond effectively and efficiently to individual circumstances. It is important that the principle of individual responsiveness within the scheme is maintained. This is of particular relevance to the 18% of participants whose package size of over \$100,000 indicates complex circumstances that require detailed and individual responses.

Nonetheless, VALID has observed a level of inconsistency, and in some cases inequity, in the ways in which the guidelines around reasonable and necessary have been interpreted and implemented by staff involved in planning.

It is of particular concern that a high number of people receiving packages of over \$100,000 have never even met an NDIA representative at any stage of the planning process. This lack of direct contact helps explain the experience of a number of people with very complex supports needs whose otherwise appropriately funded package still excludes specific critical supports because of an interpretation of reasonable and necessary that does not fully take into account their specific

circumstances. For example, many people who exhibit behaviours of concern have been traumatised in their early lives. Planning their support takes time, and requires great patience and expertise. It is also extremely unlikely that they will ever be in a position to meet NDIS expectations to share supports such as SDA and SIL with other participants.

VALID encourages the NDIA to make greater use of the experience and expertise contained within community organisations and the community of people with disability and families to improve understanding of complex supports. And while we do not support tightening legislative definitions, we would be in favour of attempts to provide improved training for planners – whether Local Area Coordinators (LAC) or National Disability Insurance Agency (NDIA) staff.

#### *Draft Recommendation 4.1*

The transition to the full NDIS is a challenging moment in time and VALID recognises that the rollout is a complex and difficult task. However, the experience of our members and many of the people we support shows that there continue to be serious implementation issues that need to be addressed to ensure that the lives of people with disability and their families are improved or, at the very least, not left worse off.

VALID acknowledges that the bilateral agreements include targets that are very difficult to meet given the limited resources of the NDIS. The structure of these targets has meant that processes have been specifically designed to manage the requirement to meet the volume objectives, rather than maintain the quality developed during the trial phase. This correlates with the current decline in confidence in the scheme by VALID's members.

VALID supports the vision of the NDIS and advocates that quality outcomes for people with disability always remain the primary focus. We do not accept that getting it right and getting it done on time are mutually exclusive. We believe that with the appropriate support and resources a quality scheme can be delivered in a timely and sustainable manner – and that the role of government and the NDIA is to ensure that the appropriate support and resources are made available and used well.

VALID therefore supports the Commission's recommendations regarding planning. We agree that an alternative to a full plan review is needed for minor plan amendments; that a review of phone planning is required; and that clear, comprehensive, up-to-date and accessible information on planning is required. We believe that telephone planning is possible only for a small proportion of participants and their families, and only after the scheme is well understood and established.

VALID agrees with the Commission that greater resources need to be made available for pre-planning; however we do not agree that having LACs on the ground six months in advance is necessarily the best solution. While clearer communication with participants about what to expect from NDIS processes is sorely needed, it must come from trusted independent sources and be in plain language that everyone can understand, and be available in accessible formats. Organisations with specialist expertise could be of assistance to the NDIA in each of these areas.

Attention also needs to be paid to the important role of advocacy agencies. For people with intellectual disabilities the system is difficult to use, relying on skills that they may not have, particularly literacy, insight, and communication. It is crucial that people with cognitive impairment who have complex support needs have access to an advocate or support person to assist with the

NDIS processes so the individual's wishes are communicated – noting that not all people with intellectual disability have family or a legal guardian to assist them. While advocacy is funded externally to the NDIS, it must be secure to enable its vital contribution to the overall success of the scheme.

#### *Draft Recommendation 4.2*

VALID has long advocated for and supported the creation of teams of planners with specialist expertise. NDIS rollout requires skilled, competent planners that have additional information regarding complex needs available to them. As identified by the Commission, significantly improved knowledge to undertake such a pivotal role is needed by much of the planning staff.

Quality training of planners is a critical element in ensuring improved outcomes for people with complex support needs. VALID encourages increased use of industry knowledge and expertise to achieve this, noting that this expertise not only resides within specialist disability providers, but also in disability specific support organisations, advocacy agencies, and people with disability and families.

The NDIA has not made full use of consumer-led organisations in the sector with specialised expertise. The NDIA should draw on this experience in both the development and implementation of training for planners. But beyond planning, this experience could be invaluable in implementation issues more generally – such as the development of reference packages, in the development guidelines for reasonable and necessary, or in effective communication to particular groups of participants.

### **Boundaries and Interfaces with the NDIS**

#### *Draft Finding 5.1*

Tier 2 was a key recommendation from the Productivity Commission in its original report on the NDIS. VALID agrees that an effective Tier 2 is key to good outcomes for people with disability and their families, as well as being vital to the sustainability of the scheme.

VALID agrees that it is a false economy to ration Information Linkages and Capacity Building (ILC) through the transition period.

#### *Draft Recommendation 5.1, 5.2 and 5.3*

VALID agrees with the Commission that the full amount of funding for ILC should be made immediately available to support the transition to full scheme.

However, we would also table our concerns that the intent of the ILC policy far surpasses the budget allocated and that therefore there are insufficient funds for ILC to meet all its objectives. VALID supports allowing the NDIA greater flexibility in how to use the total budget allocated to the scheme. This would allow the NDIA to determine the most effective and efficient use of resources allocated and ensure an appropriate balance between package costs and ILC.

VALID recommends that the focus of ILC be the development of community rather than the purchasing of projects. Investment in the evidence based long-term community development work of Disability Support Organisations (DSOs) with community engagement expertise.

VALID agrees that the outcomes from ILC should be monitored over time. Evidence and transparency are particularly important, especially in the event that the NDIA were given greater budgetary control and were able to exercise greater flexibility in how it manages its budget allocation.

In addition, VALID reiterates our position that the under-utilized expertise of DSOs could also be harnessed in the area of ILC. DSOs are in a strong position to partner with the NDIS to resolve cost issues. Evidence about and experience with specific groups of people with disability may be invaluable in determining the support needs of particular populations and how they may be best met.

VALID agrees that there should be greater transparency around continuity of support. Some of our members are vulnerable to being left without support due to the lack of clarity about which programs are to be transitioned into the scheme. Existing specialist organisations, including advocacy organisations, are in jeopardy because of confusion about which needs should be met through ILC and which remain outside the scheme and need to be met by federal or state and territory governments. We are further concerned that any attempt to slow down transition will exacerbate these issues and leave even more people without support. This would be completely unacceptable.

VALID agrees that state and territory governments should be transparent about support for people with disability outside the NDIS. Reporting on this should not just be reported at COAG but should be more transparent public reporting around progress towards goals identified in the National Disability Strategy (NDS). VALID would also like to take the opportunity to observe that the greatest issue with the NDS is lack of action and joins with calls for a renewed commitment by all three levels of government to achievement of the NDS goals.

## **Provider Readiness**

### *Draft Recommendation 6.1*

VALID agrees with the Commission's recommendation to establish an independent body responsible for price regulation given there is an inherent conflict of interest in allowing the NDIA to continue to set prices.

VALID is concerned that some unit prices are too low. The assumptions underpinning the unit price rationale need to account for the professional development and ongoing supervision of staff in order to create a skilled workforce trained in multiple and overlapping areas (for example specific disabilities, mental health, cultural and gender awareness and sensitivity). Investment in these areas is necessary to establish, embed and maintain supports for persons with complex needs.

### *Draft Finding 6.1*

VALID agrees with the Commission's finding that thin markets will persist for people with complex, specialised or high intensity needs, or very challenging behaviours. It is already apparent that market failure in these areas has resulted in poorer participant outcomes.

VALID has particular expertise in supporting many people with disability who are included in the 18% of people who are provided with 56% of scheme funds. It is imperative, both for the wellbeing of this group of people with disability and their families and the overall sustainability of the scheme to ensure that this group is well supported. However, not only is the current market of supports for people with complex needs and challenging behaviours thin, but it is under threat of shrinkage, with existing specialist organisations in jeopardy.

Specialist supports take years to develop the required level of expertise as well as the trust of people with disabilities and families. The current underutilisation of a number of highly specialised providers (e.g. for previously mentioned reasons associated with the implementation of the reasonable and necessary guidelines and lack of understanding and expertise of this cohort within the NDIA) has undermined their sustainability and is a threat to an already thin market.

### *Information Request 6.1*

There has been a lack of coordination between state governments and the NDIA for the considerable proportion of people whose complex support needs include mainstream supports (e.g. health, justice). Significant gaps are emerging because of the dismantling of case management expertise within state systems with an unrealistic expectation that this will all be picked up by the NDIS. VALID therefore strongly supports cross-government collaboration and consideration of provider of last resort arrangements.

The compilation of specialised evidence based reports spanning a range of domains to underpin the development of highly individualised plans has resulted in good outcomes for a number of scheme participants with highly challenging behaviour. However, because of their broad scope, there is a lack of clarity where the responsibility for funding such reports lies.

Because of the potential risk of block funding and direct commissioning arrangements, VALID would recommend the development of expert steering committees to maximise participant outcomes and scheme sustainability. Allowing experts drawn from specialist service providers, people with disability and families, disability specific support organisations and independent advocates to work together is the best way to find solutions to complex problems.

Clearly a high level of transparency and appropriate funding of independent advocacy organisations would also be required.

It is imperative that state governments and the NDIA work closely together to ensure that:

- Adequate supports, including 'providers of last resort' are available to participants and their families
- Case management that includes coordination of mainstream supports (health, justice etc.) is maintained at a state level when people with disability transition into the NDIS

- The expense of detailed specialist reports for people with very complex support arrangements (especially people that will continue to need supports beyond the scope of the NDIS) does not have to be borne by the person with disability and/or their family

#### *Information Request 6.2*

The development of the support market for people with complex needs requires scaffolding and an interim safety net structure and arrangements that provide a level of continuity and security across the sector given families continue to experience lack of access to requisite specialist services and support and/or reliable delivery of supports. If anything, there seems to be a reduction in the quantity of quality complex needs and behaviour support personnel in the sector.

VALID recommends that the NDIA develops evidence based market building incentives for providers willing to actively build the capability and capacity to provide supports for people presenting with complex support needs.

#### **Workforce Readiness**

##### *Information Request 7.1*

##### *Draft Recommendation 7.1*

VALID is a Victorian organisation and is pleased to participate in the development and implementation of the Victorian Government's comprehensive disability workforce development strategy. Never the less, we agree that the workforce needs of the NDIS require a holistic national workforce strategy and that this has been hindered by the fragmented nature of roles and responsibilities for market stewardship and workforce development between governments and the NDIA.

VALID recommends that any holistic strategy must include an evidence-based, best practice approach to registration and accreditation of disability support workers. This approach must:

- Provide protection for the majority of participants in the scheme who rely heavily on quality systems to keep them safe- such as people with intellectual disability and autism
- Include the flexibility for people with disability, such as those who self-manage and/or plan manage their own NDIS plans, to employ the support workers of their own choosing, regardless of formal training and registration
- Be consistent nationally. State initiatives such as the Victorian Registration and Accreditation scheme currently in development should be adopted nationally

VALID has long promoted the link between quality staff and quality outcomes for people with disabilities and support investment in workforce development. We therefore recommend an evidence-based, best practice approach to the training of disability support workers. We direct the Commission to the work of the Future Social Services Institute and the Victorian Skills Commission and urge the NDIA to be guided by the work findings.



### *Draft Recommendation 7.2*

VALID strongly agrees that detailed data and information about the NDIS as proposed by the Commission should be gathered by the appropriate agencies and made publically available.

### *Draft Recommendation 7.3*

Through its advocacy and representation work, VALID is aware of a high number of reports from families, especially those with responsibility for service coordination, that are becoming increasingly fatigued or overwhelmed in managing to provide the level of informal support deemed reasonable by the NDIS. Nonetheless, VALID has concerns about the proposal to pay informal carers who live at the same residence as a participant as a way of addressing workforce shortages. VALID recommends that such an approach be an option of last resort and that the NDIA takes a proactive approach to resolving the lack of available expert staff.

VALID believes that payment of informal carers who live at the same residence, as a participant requires robust assessment to ensure safeguarding of the participant from abuse and neglect. VALID would recommend that this approach should only ever be considered as a last resort in very specific circumstances – for example when a family member is the only trusted provider of specific supports (maybe gender related or particularly personal in nature) or in remote communities with limited resources or for cultural reasons.

### *Information Request 7.2*

VALID agrees with the Commission's identification of respite as an area requiring particular attention. However, our concerns are more focussed on issues such as the fact that shared care arrangements (e.g. for children with behaviours of concern / risk of relinquishment) seem to be categorised by NDIA as respite - and therefore not approved as reasonable and necessary – when in fact they should be regarded as both appropriate supports for people with disability, and also a mechanism that increased the resilience of informal supports.

## **Participant Readiness**

### *Information Request 8.1*

In VALID's experience, support coordination is provided to a variable standard and is dependent on the practitioner. Some perspectives from our advocacy work include:

- Support coordination needs to be kept person-centred
- It is common for insufficient hours of support coordination to be approved – our experience is that many people use up their entire annual allocation in the first week of the plan
- The families of people with complex support report an over-reliance on informal supports to 'complement' support coordination, in some cases to an extent that borders on exploitation.
- Support coordination should not be provided by services that also deliver direct supports to a participant. Very few providers manage this conflict of interest appropriately.

VALID reiterates its concern about the significant gaps that are emerging because of the dismantling of case management expertise within state systems with an unrealistic expectation that this will all be picked up by the NDIS, the person with disability or their family.

### *Draft Recommendation 8.1*

#### *Information Request 8.2*

VALID welcome the Commission's focus on participant readiness and welcomes the recommendation regarding the e-market. However this initiative will be insufficient to ensure that the majority of scheme participants - people with intellectual disability – will have the capacity to make the most of opportunities presented by the NDIS and drive change in the market.

Effective and efficient implementation of the NDIS is dependent on well-informed, well-resourced and highly engaged consumers, able to clearly articulate their needs, search for appropriate services and negotiate the terms of engagement. Given the striking lack of opportunity for choice and control in the past, it will take significant investment and a considerable period of time for the capacity of people with disability, as well as their families to have the knowledge, skills and resources to become those consumers.

VALID strongly agrees with the suggestion that Disability Support Organisations could play a greater role in developing the capacity of participants. People with disability and their families value the independence of organisations with specific experience and expertise and see them as a trusted source of information and support in the formats that people need and value. VALID's work clearly demonstrates the important role peers can play in working alongside people with disability and their families to imagine new possibilities and to make the most of new opportunities.

The Commission also highlights the important role advocacy organisations could play in capacity building. Given that advocacy is also a significant safeguard for people with disability, it is disappointing that the future of the National Disability Advocacy Program remains unresolved. The current uncertainty over the future of the program has undermined forward planning and damaged the sector at a time when the investment in advocacy should be growing at the same rate as other parts of the sector.

VALID commends the Victorian government for its ongoing commitment to independent advocacy but notes with concern that this is not the case in other jurisdictions.

#### **Governance**

VALID supports the current COAG arrangements and agrees that Western Australia should be fully included in the national scheme.

#### *Information Request 9.1*

VALID does not agree that slowing down the roll out is the only response to the current implementation issues. VALID's preferred response would be to identify the issues that require resolution, prioritise their resolution, look at proposed solutions and then decide if slow down is the only way to appropriate resolution and the only way to achieve agreed goals.

Other methods – such as greater resourcing and boosting staff training – may resolve the issue without slowing down the roll out. Alternatives such as changes to resourcing could be addressed in more detail by the Commission.

Nonetheless VALID suggests that prioritising potential participants with more urgent and complex needs with an increased period of crossover of joint responsibility between the Commonwealth and the states for a designated period may be an appropriate strategy.

### **Funding Arrangements**

VALID supports the NDIA's status as an independent statutory authority. The independence of the agency responsible for administering the scheme was one of the key issues during the campaign for the introduction of the NDIS. An independent agency with its own board (including board members with disability and family members) helps to ensure the vision of the scheme is realised and it is not subject to the changing priorities of successive governments.

VALID does not agree with the suggestion that the Commonwealth assumes greater control of the scheme because it bears the risk of cost overruns. The scheme is a shared enterprise with the State and Territory governments and we believe this is a source of strength. It would seem appropriate that a method of sharing the risk of overruns be developed.

VALID's strong preference is for the NDIA Board to be given greater control over policy and budget direction as the evidence base builds and the scheme matures.

#### *Draft Recommendation 10.1*

VALID is concerned that the NDIA currently has significant limitations in both capability and capacity. Both need to be addressed as a matter of priority. VALID supports the Commission's recommendation to broaden the unrealistic operating budget limit of 7% during the roll out period.

#### *Draft Recommendation 10.2*

The current capping of staff numbers seems particularly short-sighted given the size and complexity of the roll out of the NDIS. VALID agrees that the development of internal capability and expertise is of vital importance and that reconsidering the staffing cap would assist this.

#### *Draft Recommendation 10.3*

VALID supports the Commission's recommendation that in-kind arrangements should cease during transition and should not be a feature of full scheme. VALID agrees that in-kind arrangements with State and Territory governments have compromised scheme flexibility, are inequitable for providers and have reduced choice and control for participants.