



## **DISABILITY CARE AND SUPPORT DRAFT REPORT**

### **RESPONSE FROM THE**

### **AUTISM ASSOCIATION OF WESTERN AUSTRALIA (INC)**

#### **1. OVERVIEW**

The Autism Association of Western Australia welcomes the Draft Report on Disability Care and Support by the Productivity Commission. In particular, we congratulate the Commission's findings regarding the major shortcomings and gaps in current disability provision Australia wide.

While supporting many of the Commission's major recommendations, we wish to ensure that the needs of people with an Autism Spectrum Disorder are understood and met in the final strategy. Consequently, our following comments are both general in terms of the NDIS concept and specific in terms of the Autism population.

#### **2. THE PROPOSED NDIS: THE BROAD CONCEPT**

The Autism Association of Western Australia supports an NDIS based on a federated model with the State disability apparatus fully involved and contributing to the management, planning, policy setting and administration of the program i.e. we support an approach based on local management and decision-making.

The Autism Association of Western Australia has concerns regarding the establishment of any new system that bypasses State responsibility and the achievements of States such as Western Australia. In our view, the further people with disabilities are from those who ultimately make decisions about matters that impact on their lives, the more likely they are to be disempowered and disadvantaged. We also have concern that a federally managed system will compromise and undermine the flexibility that we currently have in the State system in Western Australia and that this will negatively impact on the quality of services and the manner in which services are delivered to families.

In our view, an appropriately resourced State managed system based on local knowledge can best meet the needs of vulnerable people. This is particularly critical in a system that is based on the use of "reasonable and necessary" in determining support-needs. Good outcomes are more likely to be achieved and safeguarded through decision making close to the circumstances being deliberated upon.

**We support a strategy that generates additional federal funding, that collaborates with the States to establish national benchmarks and is administered through State disability bodies such as Disability Services Commission.**



### **3. COMPETITION AND MARKET RELIANCE**

The Autism Association of Western Australia is concerned that the Report is overly confident in the creation of a competitive market to address the needs of people with disabilities. This confidence may be justified for those people with disabilities who can self-advocate and whose needs are not complex or challenging. However, in our experience, markets do not develop to provide appropriate quality care and choice to those whose needs are challenging and complex and who are unable to self-advocate. Services to these individuals are largely met through mission-driven organisations who step in to compensate for “market-failure”. The social value created by these organisations in responding to the needs of vulnerable and marginalised individuals are largely ignored in the proposed map for the future market-driven landscape for disability services contained in the draft report.

### **4. ELIGIBILITY AND AVAILABLE SUPPORTS: AUTISM SPECTRUM DISORDER**

The Autism Association of Western Australia is concerned that many individuals with an Autism Spectrum Disorder could miss out in the framework elaborated on in Tier 3. While a functional assessment tool may address some of the potential risks for the Autism population, in our experience many functional-based assessment tools are based on, and informed by, intellectual and physical disability. Consequently, they frequently fail to measure the severity of the impact of Autism on daily functioning.

The Autism Association also has some concern regarding the lack of breakdown in the report on how the final number of eligible people has been arrived at. This is important as much of the intent of the proposal centres around creating a more responsive and more adequate system than is currently the case. It is also not clear that all individuals currently receiving funded support will continue to receive the same or an improved level of support under the proposed NDIS. The Commission reports that most people currently receiving disability services will receive more support under NDIS. Without knowing the criteria on which this claim is made, it is difficult for the reader to assess.

### **5. ASSESSMENT ISSUES**

#### **5.1 People with an Autism Spectrum Disorder**

Many in the Autism population frequently experience problems with assessment instruments that overestimate their abilities and underestimate their need for assistance. This is largely because measures of mobility and communication that form the basis of many tools do not pick up (and are not designed to measure) the severe and disabling impact of Autism on daily functioning. There are many people with Autism who have no problems with mobility or spoken language (have a normal IQ) but are severely impaired in their ability to synthesise information, to understand their social environment or to make informed decisions.

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They remain very vulnerable individuals in need of continuing support to function in daily life. The Autism Association is greatly concerned at the potential for an assessment tool that will under-estimate the needs of the Autism population or, indeed, exclude them from eligibility for support.

## **5.2 Assessment Tools**

Currently, there is no single assessment tool that is equipped to measure the functional needs of the diverse population of people with disabilities.

Work will need to be undertaken to develop tools that are sensitive to measuring functional need across a diverse population. In particular, any new tool should be piloted with people with an Autism Spectrum Disorder prior to adoption to ensure reliability and validity of results.

## **5.3 Assessment Process**

People with an Autism Spectrum Disorder have complex needs. To understand the level of their support-needs, an assessor must be experienced in working with this population. In addition, due to the complexity of the issues, assessment needs to be over a period of time rather than one based on a one-off relatively short meeting. Likewise, the needs of the person with an Autism Spectrum Disorder can change quickly, requiring additional supports. We are unclear as to how an NDIS process will address these issues.

The Commission states that the assessment process “must be fair, rigorous and safeguarded against exaggerated claims of support needs”. While the Autism Association of Western Australia supports these sentiments, we are concerned that the proposed process is erring too far in the other direction i.e. of a rigid approach that will deliver unintended outcomes. In particular, the Autism Association of Western Australia is concerned about the extreme emphasis on an “independent” assessment process to deliver the fair and rigorous desired result. While we understand the intent is to ensure fairness and equity, the outcome may be quite the opposite for the following reasons:

- i) When assessing a person with an intellectual disability or Autism, it frequently requires a professional experienced in working with that individual to make an informed assessment of their needs. The full extent of the person’s needs will not be established from a de-contextualised assessment process undertaken in a short period of time.
- ii) Where families contribute to the assessment process (due to the person with a disability being unable to respond to the assessor), more skilled families may be better able to represent the person’s needs to an independent assessor compared with more disadvantaged families. Consequently, a professional with knowledge of the person with a disability will be better able to offset any skewing towards those better able to articulate needs i.e. will ensure greater equity and fairness.

The Autism Association of Western Australia supports a process that:

- Includes knowledgeable informants.
- Includes information already in existence.
- Is minimally intrusive.
- Ensures a reliable tool sensitive to measuring the disabling impact of Autism Spectrum Disorder.
- Includes information provided by the person with disability and their family,
- Provides a mechanism for changed-need/review/and appeal.
- Assessors must be knowledgeable and experienced in the population of people with disabilities they are assessing. In particular, those disabilities that are complex such as Autism Spectrum Disorder.

## **6. SERVICE ISSUES**

### **6.1 Service Options**

The Autism Association of Western Australia supports individualised funding for people with disabilities based on the West Australian model. This model ensures portability of funding, consumer choice to select or change services, while at the same time there are mechanisms in the model to ensure service-provider viability.

While many people with a disability will support self-directed services, not all will want, or be able, to become employers of support workers with all that this entails. People with decision making disabilities, challenging behaviour, especially those with aging carers are less likely to choose this option. Consequently, a National Disability Insurance Scheme should recognise diversity of choice for people with disabilities and provide them with options around the level of involvement they wish with planning, service-supports, and funding.

### **6.2 Family Members as Paid Carers**

The Autism Association of Western Australia believes that family members should be eligible to be employed as paid carers in some clearly defined circumstances. In particular, this should be considered as the preferred option where a sibling or relative takes on the long term care of an adult who would otherwise require out-of-home full time care in a congregate care facility; and where this arrangement is the choice of the person (or their advocate, where they are unable to represent themselves). While we understand concerns regarding conflict of interest etc., at every juncture decisions should be made on what the person with a disability wishes. For many individuals, if given the choice between their home and congregate care, the person will choose their own home. It would be to great disadvantage of people with disabilities to rule this choice out of bounds because of some paradigm concerns.

### **6.3 Sustainability and Choice**

A sustainable disability service system is essential to support people with significant disability to lead lives in the community. This requires service funding that reflects the cost of service delivery and investment in workforce development. It should also ensure that people with disabilities continue to have meaningful choice through the maintenance of a diverse range of services and organisations.

### **6.4 Early Intervention**

The Autism Association of Western Australia supports the commitment to early intervention contained in the draft report. We particularly congratulate the Commission on recommending that early intervention be viewed as encompassing the significant periods or events beyond those of early childhood. We do, however, strongly support the need to intervene early, especially with children who have an Autism Spectrum Disorder. Research clearly demonstrates the importance of early intervention in maximizing skill development and minimizing the development of secondary sequelae.

## **7. NDIS GOVERNANCE**

In relation to the proposed arrangements, the Autism Association makes the following recommendations:

- i) At first glance, the governance structure appears to establish a massive new disability industry providing a new marketplace of employment opportunities to those without disabilities. The structure needs to be reviewed to minimize spending on the national framework proposed. In this context, we believe our earlier comments regarding a state based system could prove more efficient, in addition to being a more empowering option for the person with a disability.
- ii) The assessment process is too complex and de-contextualised i.e. the issue of “independent” needs to be reviewed. Professional neutrality does not require that the professional has no knowledge of the person with a disability.
- iii) The assessment process proposed could be intrusive and highly stressing for many families. The periodic reviews proposed would be extremely upsetting for aging parents looking after an adult son or daughter with high support needs. Inevitable concerns will arise of “what if my son or daughter’s support is reduced after I am gone”.
- iv) Funding needs to be indexed to maintain its purchasing power. Without adequate indexation of funding, services will reduce in quantum and/or in quality over time. This is a critically important issue for those who require full time care.

## **8. CONCLUSIONS**

The Autism Association of Western Australia strongly supports:

- i)** A nationally resourced entitlement service scheme to provide support and assurance to people with disabilities and their families.
- ii)** A scheme based on a federated model with the State disability apparatus fully involved in the management, planning, policy setting and administration of the program.
- iii)** A review of the proposed assessment process to reduce intrusiveness, excessive bureaucracy, and to remove unintended consequences resulting from “independent” is being used to ensure professional neutrality (see above).
- iv)** Any assessment tool must be able to measure the complex needs of people with an Autism Spectrum Disorder (many current tools are informed by intellectual and physical disability and do not measure the disabling impact of Autism on daily living).
- v)** Clarity is required regarding the eligible number of recipients cited in the Commission’s report.
- vi)** An NDIS should build on what is clearly working in different jurisdictions. We would not wish to lose some of the very good systems, programs, funding arrangements, infrastructure and collaborative processes that currently exist in Western Australia.
- vii)** An NDIS must formally include a mechanism for annual indexation of funds based on a transparent methodology that maintains the purchasing power of funds over time.

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