Autism Victoria Inc. A14601C
24 Drummond Street, Carlton VIC 3053
Telephone: (03) 9657 1600 Facsimile: (03) 9639 4955
Postal Address: P.O. Box 374, Carlton South VIC 3053
Email: admin@autismvictoria.org.au **ABN 15 600 724 949**

A RESPONSE TO THE DRAFT NDIS REPORT

Introduction

The review provided below is an overview of the draft report and highlights some of the key areas that may impact on individuals with an Autism Spectrum Disorder.

The review should also be read and interpreted within the context that this is the draft report and that following public hearings etc. there may well be a significant rewrite. Although there may be a re-write it is critical that we provide comment and raise the concerns we have identified in the draft report.

Along with a written response Autism Victoria will be attending the public hearing in Melbourne and to present in person to the panel.

There is an ongoing concern by Autism Victoria that the notion of a National Disability Insurance scheme appears to be very much driven by the needs and aspirations of people with an Intellectual and/or physical Disability and many of the unique needs of people on the Autism Spectrum may well be, if not disregarded, not well understood within the context of a National Disability Insurance scheme.

This is potentially a once in a lifetime opportunity for a scheme to be designed and funded that will meet the needs of both individuals and families and the opportunity should not be lost.

COMMENTS

As you would expect there is an exceptional level of detail in the full report and to comment on each area may not at this stage be overly productive.

What may be more helpful is perhaps highlighting the various areas of real interest and to provide a more general overview of the report and how it relates to Autism Spectrum Disorders.

Overall the report does not reflect particularly well the specific issues and concerns of people with an Autism Spectrum Disorder. Rather the report appears to recognize the issues of people with an Intellectual Disability and the issues for people with a Physical Disability but I have struggled to find where in the report there is much reflection on the unique issues or funding needs for people on the spectrum.

It is certainly true that in the section on Early Intervention the writers make reference to children with Autism and the need for funding of early intervention services but they do not, in this report at least, indicate what level of support this should be. That is, should the support be based on something like the 1,000 hours model or something less/more.

Obviously, if early intervention funding is based on an intervention covering 1,000 hours per year then the next question becomes one of eligibility. We know some children may need this level of intervention for a number of years while for others the intervention need may not be obvious until after the early years period. Likewise a further question this raises is, would these children still be eligible or not, if after a year or more/less, their behaviours regressed? If there is a regression how long would it take to access the additional funding required etc.

Of equal concern at this stage is the lack of clarity regarding the definition or eligibility criteria in the report. The writers refer to severe or profound disability but again there is a concern this is based on the criteria that applies in the case of Intellectual or Physical Disability and does not recognize the issues of Autism. For everyone who has battled the Department of Education for funding will attest to the lack of understanding which is often applied to children on the spectrum.

This issue is equally true for adults on the spectrum who may at times function well in society and then in response to a sensory or other issue become severely limited. The NDIS does not at this stage provide an appropriate response.

More broadly, there are also question marks around the capacity of the new model to impose a quality service system to ensure supports are appropriate. There is reference to market forces driving quality but this does not recognize that market forces may work within a private sector environment but experience of Aged Care and the private sector suggests very strongly that there is a critical need to ensure more than market forces are at play.

There is the real possibility that market forces may lead to a two tiered system of support based on the notion of ability to pay with individuals with little or no family support being obliged to utilize the Target service whilst those who can 'top up' payments will be able to access the David Jones model.

It is particularly critical that the NDIS recognizes the right of families to access what would currently be considered a "David Jones" model which is in effect the optimum for Autism Spectrum Disorders. Costings for ASD individuals within an NDIS model must recognize current research that recommends 1000 hours of early intervention per annum in the early years as well as issues around aids and equipment such as the funding of GPS tracking systems for ASD "absconders", fridge and cupboard locks, computers, ipads, trampolines etc. Further support for respite both general as well as after school and school holiday periods must also be included in the NDIS model.

Specific comments on key points include:

Point 4 – Talks about the functions of the NDIS including quality assurance. This also demands a model that ensures quality outcomes and quality service delivery. The notion of a system based on quality assurance is the current model which simply demands administrative responses and does not address the fundamental questions of quality service and quality outcomes.

It suggests a critical component of any new system is a form of accreditation/licencing that assesses the quality of the service system, the quality of service outcomes and the quality of support staff whether via an organization or directly employed.

Point 6 – Talks about an Advisory Council of Key Stakeholders. It will be essential for the key stakeholder group to include an expert voice on Autism Spectrum Disorders to ensure the scheme does not have a bias towards particular disabilities. At this stage there is little comfort the current advice is taking into account the particular issues relevant to Autism Spectrum Disorders

Point 8 – Talks about increasing choice. This of course implies choice is able to be accessed. This raises questions and challenges within the evolution of a service delivery system including access to skilled staff, whether part of or independent from a formal service system. Having identified the need for high quality staff the next question is how to achieve this within the current wage models. Pay rates within the disability sector are historically poor and without a significant investment the risk is that individuals will seek the lower cost model and potentially the lowest quality service and service outcomes.

Point 9 – Talks about access to Specialist and Mainstream services. This is an interesting comment as it suggests the disability service sector is somehow not mainstream or generic enough for people within the NDIS model. If however the suggestion is that people in the NDIS should be able to access neighborhood house, local schools etc then this has always been the case.

In saying that however the major issue has always been the inability of these mainstream services to meet the specific support needs of people with a disability. This is particularly relevant for people on the Spectrum who are often not recognized as having a disability and thus are not given the level of support or assistance they require to access mainstream services.

Point 14 – Talks about State funding obligations. If this is the model to be implemented it is critical that these funding amounts are quarantined immediately or there is the potential for the States to reduce funding in anticipation of the introduction of the NDIS.

In effect why would a state government, in the current climate, increase funding to the disability sector when that funding will ultimately be consumed by the NDIS funding model. Would it not make more sense for the states to reduce their current commitments or at the very least not increase their funding given this role will potentially revert to the Commonwealth. Perhaps a solution would be to indicate to the states that they would receive the funding to implement the NDIS at the State level.

This model would also ensure that there was no loss of employment and no loss of expertise within the State system. It would also encourage states to continue to invest at the State level with the knowledge that the commitment will continue into the future. It suggests that it would also reward the states already heavily investing in Disability services.

Point 16 – Talks about the implementation of the NDIS. Proposing a 1 year trial of a program as significant as this appears to be far too quick for a system to be trialed, modified, trialed again etc. then rolled out across the country. It may be more appropriate to take time in trialing the model and ensure that issues are addressed and tested well before a national scheme is implemented.

Overall Comment.

It should be acknowledged from the outset that the design of a universal support system for people with a disability is an extremely complex process. That the Productivity Commission has managed to develop a model at all should be cause for celebration and we should be careful not to pass criticism of the model for criticism sake.

In saying that it is important that note be made of critical issues that have been in play for significant periods of time and will, most likely, continue after the introduction of the NDIS.

Areas of significant concern for Autism Victoria are:

1. A critical need to clarify the definition of severe or profound disability. These terms appear to be driven by Intellectual and Physical disabilities and do not necessarily recognize the unique needs of individuals with an ASD.
2. The adoption of relevant assessment tools should include DSM 4 and ICD 10 to ensure individuals with an Autism Spectrum Disorder have effective and well recognized assessment tools.
3. Specialist Autism Case managers to complete the initial and ongoing assessment to ensure an understanding of the needs of ASD individuals is not only taken into account but is recognized in the funding regime..
4. The NDIS will need to support and enhance the capacity of the service system to meet the needs of individuals in rural and remote locations.
5. Workforce development will potentially be of greater importance as the current formal support system moves from a structured model to a less formal model.
6. An NDIS should support staffing models that do not encourage the growth in a ‘casualised’ work force. Given the current trend is towards a casual workforce a more individualised model may create even less sustainable employment and eventually a less skilled workforce as job security is lost.
7. The aim of providing choice must also come with a model that addresses quality. In particular it is important specialist areas such as Autism have a service structure that ensures services whether by an individual or an organization meet particular standards via accreditation.
8. It is critical for the NDIS to meet the objective that real choice is offered and real support is achieved.
9. The funding regime must not be limited by a “unit price” that restricts the service system from developing new and innovative services
10. The NDIS bureaucracy must remain hands off and not tie up the system with regulations in a way that restricts the ability of services to meet the needs of individuals.
11. Within the examples provided of current impairments of body function many of the issues facing individuals with an ASD are not included. These areas include danger perception, communication (as distinct from language), indifference to auditory stimuli, sensory processing, understanding concepts of norms and social mores, temperature regulation etc.
12. Likewise when reference is made in Part 2 of the report to Activity Limitations and Participation Restrictions there is no mention of absconding, obsessions, patterns of behavior of injury to self or others.
13. There is a critical need for a National register to identify and plan for service provision.
14. Given the unique nature of ASD’s any advisory body must contain specialist knowledge of ASD’s as a priority.
15. It will be important to develop appropriate principles for adoption of evidence based therapies across the disability sector.