

AUTISM VICTORIA - SUBMISSION RE DISCUSSION PAPER FOR REVIEW OF THE DISABILITY LEGISLATIVE FRAMEWORK

INTRODUCTION – the situation for individuals in Victoria with an Autism Spectrum Disorder.

Autism Victoria represents individuals diagnosed, or at risk of diagnosis of an Autism Spectrum Disorder – Autistic Disorder, Asperger’s Disorder or Pervasive Developmental Disorder Not Otherwise Specified. The criteria used for a diagnosis of these disorders can be found in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revised*, pp. 69 – 86. Autism Victoria also represents the primary carers of these individuals – parents, spouses, extended family, direct care staff, and professionals engaged in providing therapy, education and training, disability and family support, health care and similar.

The Autism Victoria Executive Officer, Mrs Amanda Golding, has prepared this submission after extensive consultation with representatives of the above groups. We also support the submissions made by other key disability groups, particularly those representing service providers and advocacy groups. Our submission does not cover every aspect of the discussion paper. Rather, it focuses on issues of concern to our constituency because they are not adequately addressed by the existing legislation, or necessarily articulated in the submissions of others.

Autism Victoria applauds government and the department for undertaking to review the existing Disability Legislation with a view to drafting a single act that is more enabling and, we trust, more inclusive.

The existing disability legislation has a negative impact on a significant number of individuals with an Autism Spectrum Disorder. These disorders do not fit neatly into any particular category of disability articulated in the existing legislation. This means that individuals severely affected by an autistic disorder will not qualify for disability supports mandated by the existing legislation unless they also have an intellectual disability, mental illness or other physical or sensory disability.

It is incongruous that these same individuals are acknowledged by Centrelink and other federal offices and are eligible for services and resources, but are deemed ‘not disabled’ by state legislation.

The existing legislation disenfranchises a significant group of people who are not able to access much needed disability supports. The current incidence for Autism Spectrum Disorder is **conservatively** estimated to be between 20 and 40 per 10,000 (see Appendix One).

Autism Victoria strongly recommends that the new Disability Legislation enables access to a range of disability supports based on functional need and not on arbitrary cut off points.

Finally, Autism Victoria calls on the government and the department to acknowledge that part of the process of rebuilding the disability support system in the context of new legislation will require additional resources to ensure previously excluded individuals receive the supports that they are entitled to.

SPECIFIC RESPONSES TO THE DISCUSSION PAPER

1. Principles

- 1.1. We agree that Disability Legislation should contain principles and that the four guiding principles articulated in the State Disability Plan form the basis of a set of principles that should be part of the proposed legislation. We would, however, add a further principle:
 - The **Principle of Equitable Access**, which would ensure that people with a disability are equally able to access services relative to their **functional** needs, not according to arbitrary rationale that is put in place primarily to exclude access.

2. Access

- 2.1. This is absolutely critical for those diagnosed with an Autism Spectrum Disorder. Time and again people with a diagnosis of Autistic Disorder, Aspergers Disorder and Pervasive Developmental Disorder Not Otherwise Specified are excluded from disability services because they do not have an IQ score less than 70. These people have significant, often complex needs and are shunted between programs because they 'do not meet the eligibility criteria'. Inevitably they fall into giant chasm entitled 'no service'. The proposed Disability Legislation **must be based on needs** and not on arbitrary and irrelevant cut off criteria such as IQ scores or diagnostic tags.
- 2.2. As well as the existing widely accepted criteria relating to permanency, reduced capacity, need for ongoing support and variable chronic/episodic nature, the criteria for determining eligibility for disability supports must also include reference to:
 - A reduced capacity for **social** interaction
 - Impaired **pragmatic** communication skills
 - **Maladaptive** behaviours
 - Impaired **executive** function
- 2.3. We totally agree with the statement in the discussion paper "that determining whether a person has an intellectual, physical or sensory disability, an acquired brain injury or neurological impairment is less relevant than is their capacity to perform daily activities or to participate in the community." (page 15). There are several readily available methodologies that can be used to ascertain a person's functional abilities and the legislation must allow for selection of a methodology **most appropriate** to the individual seeking services.
- 2.4. Criteria for determining the target group for disability supports will need to embrace the rights of people with disabilities and impairments, as expressed in the guiding principles of the proposed draft legislation. If a person's disability or impairment prevents them from participating in the life of the community they should become part of the target group for disability supports.
- 2.5. The establishment and regular review of guidelines to determine who is to be part of a target group for specific disability support services is one of the most challenging tasks for the disability sector. The discussion paper is correct to suggest that these

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guidelines should not be articulated in the legislation, that they **better reside in the policy arena**. Such positioning does enable greater flexibility and responsiveness by government and the community. However, there is also a risk - the more powerful lobby groups could diminish the access of those in the more marginalised groups – this has been the experience of those representing Autism Spectrum Disorders in the past.

3. Priority

- 3.1. The new legislation and accompanying policies and regulations must focus on building a comprehensive disability support system from the ground up. The current fragmented approach to disability supports, so often crisis driven, is not acceptable.
- 3.2. A service model that takes into account **different levels of need at different points in an individual's life** is essential. Transition between service levels should be easily effected, without the need for excessive 'reassessment', especially diagnostic reassessment. Transition between the different life stages should be as seamless as possible, and recognise that additional supports may be necessary during a transition phase. The service model should also enable clients to easily re-access disability supports if an attempt (or attempts) to achieve self-sufficiency should break down.
- 3.3. Resources need to be allocated to services targeting all levels of need, not just the highest levels. Establishing the level of support an individual needs at any point in time should be determined at the local level – by the professionals and carers who know the individual and their local community the best. Prioritising the allocation of support packages would more appropriately reside at a regional level. Part of the process for prioritising should take into account the consequences for the individual if the determined level of support is not provided.

4. Individualised Planning and Funding

- 4.1. As the discussion paper highlights there are many approaches and considerations in relation to individualised planning and funding. We have long advocated that an individualised approach is best for people with an Autism Spectrum Disorder because of the pervasive nature of these disorders. **One size does not fit all**. The proposed legislation must acknowledge that a range of planning and funding models must be established, especially to ensure the current culture of service 'exclusion' and 'ineligibility' is not retained.
- 4.2. In addition, care must be taken to ensure that the individualised approach, particularly to funding, does not impose an **additional burden on individuals and primary carers** in relation to 'shopping around for services'. Provision of an individualised package is of no value if there is not a strong network of agencies with an adequate administrative infrastructure to enable them to provide the required supports. Competition between agencies for the 'higher value' packages, or conversely for the clients with the 'cheaper' support needs must not be allowed to impact negatively on people with disabilities and their carers.

5. Tenancy Rights

- 5.1. The discussion paper correctly highlights the inadequacy of the current legislation in relation to the range of accommodation supports, tenancy rights and management of

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client finances. We concur with the need for protections and safeguards appropriate to the needs of the individual and the type of accommodation supports in place.

- 5.2. Many individuals with an Autism Spectrum Disorder are excluded from accommodation and housing services because they do not have an intellectual disability. We trust the new legislation will rectify this anomaly.

6. Standards and Quality Assurance

- 6.1. The discussion paper provides a good overview of the range of issues relating to Disability Standards and measurement of Quality Services. Autism Victoria believes that there should be two levels to this discussion.

- 6.1.1. The 'macro' level should define general disability standards and a process of measuring service compliance with these standards. Measuring service compliance should not reside totally with the department. An independent process should be established to measure and monitor services in relation to standards and service quality and we support the idea of implementing a rating scale.

- 6.1.2. At the 'micro' level, services offering expertise with a particular condition, such as Autism Spectrum Disorder, should also be required to meet, monitor and review a set of standards **specific to the expertise required** to offer a specialised service or services. The National Autistic Society in the UK has developed an Autism Spectrum Disorder Service Accreditation Model. In essence, a service must be accredited by the NAS as being able to provide specialist Autism Spectrum Disorder services before Local Government Authorities can allocate eligible clients with an individualised funding package to that service. A feature of the NAS Accreditation Program is a system of triennial peer-based review in order for a service to maintain accreditation.

- 6.2. The discussion paper clearly advocates legislation that is enabling rather than prescriptive. It is important that the legislation requires **Strategic Planning** to be undertaken on a regular basis, but the format should not be prescribed. This will allow for strategic planning that is more responsive to the most up to date principles and practices in the disability field.

- 6.3. The legislation should require that there be a Disability Advisory Council, but the composition and specific Terms of Reference should not be prescribed. Such prescription would restrict the ability of the council to be responsive to current policy and practice.

7. Independent Complaints Mechanism

- 7.1. The State Plan is all about building inclusive communities for people with disabilities. There should therefore be an 'office' that would be empowered to **address all impediments to the successful inclusion of people with disabilities**. This would include, for example, abuse, service provision, service quality, privacy, exclusion, discrimination and such. The 'office' should also provide supports necessary for aggrieved persons to pursue complaints in relevant non-disability jurisdictions, such as Equal Opportunity, Tenancy Rights and Discrimination. The 'office' should be accountable to Parliament, not the department. This office would

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best be styled the 'Disability Commissioner' and have the power to seek prosecution if all viable avenues of resolution are unsuccessful.

- 7.2. Community Visitors play a vital role and should be retained. We see them as being part of the 'Office of the Disability Commissioner'.
- 7.3. **Families and primary carers** play a major role in the disability support system. They arguably know the person with a disability – the impact of their disability, their needs, aspirations, and value systems – better than any one else. It is paramount that the carer's knowledge and expertise is acknowledged and taken into account when determining who is able to be a substitute decision maker.
- 7.4. The legislative framework needs to make provision for substitute decision makers, and needs to acknowledge the support role and expertise of the person's immediate family. However, the immediate family is not always able to make these decisions, for a variety of reasons. In these cases, a range of appropriate alternative substitute decision makers needs to be articulated. Alternative decision makers should be able to demonstrate a good understanding of the individual's circumstances, and also expertise in the area in which the decision is to be made, eg. Financial, Medical, Accommodation etc.
- 7.5. There are many informal support and decision-making arrangements currently in place. Whilst many work very well without any control mechanisms, there is the potential for exploitation or inappropriate decisions. If existing legislation such as the Guardianship and Administration Act is not able to provide these controls, then the Disability Legislation should develop these, perhaps to be administered under the domain of the Office of the Disability Commissioner.
- 7.6. The guiding principles, if interpreted in the spirit intended, would preclude the use of restrictive practices that were incompatible with community opinion and current policy. However, there are members of the community who would advocate that the legislation should clearly define allowable and unallowable practices. In the specific case of Autism Spectrum Disorders, there are a small number of affected people who have very severe maladaptive behaviour, often due to a 'cocktail' of co morbidities. These people need a high level of protection to ensure they are treated with care and respect, whilst acknowledging that some forms of restraint, especially chemical, may need to be used. If Departmental Guidelines are to be used, their authority should be confirmed but not necessarily articulated by the legislation. The legislation could mandate for specific monitoring and review of the guidelines

8. Reviewable Decisions

8.1. It is essential that decisions relating to

- an individual's eligibility for disability supports,
- the level of disability supports provided, and the
- equity and appropriateness of such disability supports

can be challenged. If the new legislation adopts the 'enabling' approach, leaving the service detail to regulation, guideline and policy, it is imperative that an independent review process is mandated by the legislation. A model for the conduct and outcome

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of a review should allow for enforceable decisions in relation to provision of service supports appropriate to the needs of the individual concerned.

9. Privacy

9.1. The privacy of an individual with a disability should be protected in the same way as any other individual in the community. The proposed legislation should take into account the need by some people with a disability to have a substitute decision maker. It is also important that the legislation allows for the collection of data in a non identifying way that will only be used for the qualitative and quantitative improvement of disability service supports.

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APPENDIX

AUTISM SERVICES COORDINATING COMMITTEE

Report on the prevalence and incidence of Autism Spectrum Disorders

Prepared by Richard Eisenmajer PhD

The prevalence and incidence rate of autism have always been an area of conjecture and contention. The 'prevalence rate' is the number of affected "individuals in the specified age range living in a specified area at the time the count was made". The 'incidence rate' actually refers to the "number of *new* cases in a specified time" (Wing, 1996). The incidence rate has been difficult to study in autism due to the problem of not being able to diagnose the disorder at, or soon after birth. A review of the literature by Fombonne (1996), found that recently reported higher estimates of autism have probably not occurred as a result of the *incidence* of autism increasing. Fluctuations in rates are probably related to differences in each study's methodology. Fombonne states that if autism is indeed increasing, it would be difficult to detect with the current survey techniques employed by researchers.

Doubts have surfaced over the prevalence rate with each edition of DSM and ICD, and follow-up studies have been completed. Up until the publication of DSM IV, these studies have usually shown prevalence rates of 4-6 individuals in 10,000. With the re-emergence of Aspergers Syndrome and its recognition as a variant of autism, the concept of the *Autism Spectrum* has garnered widespread support. Individuals that have in the past not usually been considered to have autism are now being identified as having "Aspergers" or "autistic spectrum". It is fair to say that the prevalence studies that found the figure of 4-6 in 10,000 did not usually consider these 'higher functioning' individuals, usually because of the difficulty in detecting them in the community. These individuals were either not taking part in any outpatient service, misdiagnosed, or sometimes not included in studies due to their 'higher functioning' status. That is, some studies chose specifically to consider only moderate/severe cases.

The most well known study examining the prevalence rate of autism spectrum disorder was conducted by Wing and Gould (1979). This study was before its time as it attempted to identify all of the children in Camberwell, England using a much broader definition of autism that had previously been used. The broader definition allowed for children who may have exhibited the *triad of impairments*, which included many children who had not been thought of as having 'autism' before. The study was broader, but it also had limitations. Only children with a mild, moderate or severe learning impairment were identified. This included the 'Kanner-type' autistic group, as defined by DSM 111. The authors acknowledged that they could not identify the 'high functioning' end of the spectrum as they would not show up in their screening protocol. This study found a prevalence rate of 22 per 10,000. A similar study completed in Sweden by Steffenburg and Gillberg (1986) supported Wing and Gould's rate finding a rate of 20 per 10,000. A more recent study by Nordin and Gillberg (1996) found a lower rate of 14 per 10,000 and argued that the differences in rates were as a result of different methodologies. Importantly, the rate of the 'core' autism group in all three studies was similar, suggesting that the differences in rate were caused by detection factors in the 'higher functioning' end of the spectrum.

An epidemiological study examining the prevalence rate of Aspergers Syndrome was completed by Ehlers and Gillberg (1993). They used their own criteria for Aspergers Syndrome that is based on Wing's (1981) description and their own clinical experience. The children identified in the study suffered no cognitive impairment and were considered 'high functioning'. For children aged between 7 and 16 years of age they produced four different prevalence rates:

1. *Definite* diagnosis of Aspergers = 36 per 10,000.
2. *Suspected* Aspergers = 29 per 10,000; and,
3. *Possible* Aspergers = 7 per 10,000.

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4. The sum of these estimates gives the figure of 71 per 10,000.

A study by Bryson, Clark and Smith (1989) also examined prevalence rates in Asperger and found a lower figure of 24 per 10,000. Methodological issues are probably the cause of this difference. Ehlers and Gillberg (1993) persuasively argue that the lower numbers in the Bryson et al (1989) study was a result of their less rigorous methodology.

Three conclusions could be made from this literature review:

1. Prevalence estimates are problematic due to the difficulties of case detection for those individuals who are not dependent on services, and the lack of clear diagnostic standards.
2. In order to determine a 'guesstimate' of the prevalence of autism across the spectrum, it is possible to sum the figures provided by Wing and Gould (1979) for cases with a cognitive impairment and those of Ehlers and Gillberg (1993) who were free of any cognitive impairment. Using Ehlers and Gillberg's (1993) conservative estimate, a figure of $36 + 22 = 58$ per 10,000 is derived, or *almost 6 per 1000 individuals*. It is also conceivable however, that the figure is as high as $71 + 22 = 93$ per 10,000, or little more than *9 in 1000 individuals*.
3. It would appear that autism is a more prevalent condition that was previously recognised as a result of widening the definition by adopting the Wing and Gould (1979) model of the Autistic Spectrum.

Though it is acknowledged that the process of summing the rates derived from different studies is less than ideal, it should only be considered an approximation until a new generation of studies are completed on the 'entire' spectrum.

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