

Disability Bill Exposure Draft (October 2005)

Joint Response from the Autistic Family Support Association Inc. & Autism Victoria Inc.

General Comments.

Autism Victoria Inc. (AV) and the Autistic Family Support Association Inc. (AFSA) have previously applauded the Victorian State Government and the Department of Human Services for undertaking to review the Intellectually Disabled Persons' Services Act 1986 and Disability Services Act 1991 with a view to drafting a single act that is more enabling and more inclusive of people with or at risk of diagnosis of an Autism Spectrum Disorder, especially those who are at present excluded because they do not have an intellectual disability, that is, an IQ score less than 70. (see Autism Victoria submission dated 29 August 2003 - <http://www.autismvictoria.org.au/policy/AutismPolicy01.pdf>)

The Disability Bill Exposure Draft is a welcome document, and we wish to acknowledge the amount of work and consultation that has been undertaken in the development of legislation that embraces the input of the disability sector in the context of current trends and philosophies. We are grateful for the opportunity to respond from the perspective of those in the community with an Autism Spectrum Disorder.

This joint response to the Disability Bill Exposure Draft deals with three areas of major concern to families and professionals within the Victorian autism community. Our concerns relate to individuals who are not recognised by the existing legislation and are thus excluded and/or prevented from accessing disability services, as well as the families and carers of individuals with an Autism Spectrum Disorder:

1. Individuals diagnosed with an Autism Spectrum Disorder who do not have a defined intellectual disability. There is concern that the term 'neurological disorder' as used in the definition of disability is not specific enough to embrace these individuals.
2. Reference to age cohorts such as "under 6 years" – will these children remain excluded from disability-funded services?
3. Families and Carers of individuals with or at risk of a diagnosis of an ASD have a significant role and responsibility for finding, creating and providing the supports needed for their family member/s with an ASD. The Disability Bill Exposure Draft makes almost no reference to this role, and does little to acknowledge and validate the responsibilities borne by families.

We note that there are many other areas of the exposure draft that are of concern and we support the detailed submissions of other organizations with whom we liaise, namely:

- ACROD Victoria - <http://www.acrod.org.au/divisions/vic/BillResponseDec05.pdf>
- Victorian Advocacy League for Individuals with Disability (VALID)
http://users.bigpond.net.au/valid/ratified_response.doc
- Association for Children with a Disability (ACD)
- Autism Aspergers Advocacy Australia (A4)
www.a4.org.au/documents/VicDisabilityBill_feedback.doc

Finally, Autism Victoria and the Autistic Family Support Assoc. Inc. call on the government and the department to acknowledge that part of the process of rebuilding the disability support system in the context of this proposed legislation will require additional resources to ensure each individual with a disability receives the supports they require to live a happy, meaningful and inclusive life.

Specific Comments.

1. Individuals with an Autism Spectrum Disorder who do not have a defined intellectual disability.

It is imperative that people of all ages diagnosed with, or at risk of a diagnosis of an Autism Spectrum Disorder who do not have an intellectual disability are equally protected by the new legislation and have equal access to services as those individuals with an intellectual or other disability.

The existing legislation (IDPSA 1986 & DSA 1991) has had a negative impact on a significant number of individuals with an Autism Spectrum Disorder. These life long disorders do not fit neatly into any particular category of disability articulated in existing legislation. Hence individuals with an Autism Spectrum 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 federally funded services and resources, but are deemed 'not disabled' by state legislation.

The proposed legislation uses vague terminology such as “substantially reduced capacity”, and refers to “neurological impairment”, but does not define what this covers. Acquired Brain Injury is specified in the legislation draft, and we believe that Autism Spectrum Disorder should also be specified in the legislation to remove any risk that a person with an Autism Spectrum Disorder will be deemed ineligible for disability supports and services. There are established, internationally recognised guidelines for the diagnosis of Autism Spectrum Disorder – DSM IV TR and ICD 10 – as well as a protocol for assessment and diagnosis developed by Autism Victoria.

We are concerned that interpretation of the term “substantially reduced capacity” is subjective enough that a clinician or officer inexperienced with the nature of Autism Spectrum Disorder will use inappropriate measurement tools and deem an individual more capable than they actually are.

Recommendations

1.1 - The Definitions used in the new legislation, in particular “developmental delay” “disability” and “intellectual disability”, must clearly include and encompass all persons diagnosed with an Autism Spectrum Disorder especially those who do not have a co morbidity with another disorder such as intellectual, sensory or physical.

1.2 - The new legislation must clearly articulate that access to disability supports and services will be based on appropriate measurements of functional ability in respect of social, communication and independent living skills and not on subjective or arbitrary measurement tools that do not capture the core deficits of Autism Spectrum Disorder.

2. Reference to age cohorts such as “under 6 years”

Current legislation disadvantages and prevents families from accessing services because they set apart children under 6 years of age. There is no doubt that some families of children diagnosed with or at risk of a diagnosis of Autism Spectrum Disorder under the age of 6, who may or may not also have an intellectual disability, would benefit from accessing disability services such as the Behaviour Intervention Support Teams (BIST) within the Disability Services division of the Dept. of Human Services.

It is also worth mentioning that people of any age can have a “Developmental Delay” and that such definitions *should not* be tied to any specific age group, nor should access to services be restricted by age.

Apart from standardising definitions, we seek clarification on what impact if any the new Disability Bill will have upon the Government’s Office for Children initiative enacted under the Children, Youth and Families Act 2005.

Recommendation

2.1 - That any reference to age relating to definitions, and restriction to services be removed from the Disability Bill Exposure Draft.

3. - Families and Carers of individuals with or at risk of an Autism Spectrum Disorder who have a significant role and responsibility for finding, creating and providing the supports needed for their family member/s with an ASD.

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 not only acknowledged and but also validated within the legislation when determining who is part of the service system and decision making process.

We concur with the comments contained within the A4 submission that says:

(pg. 14, item No. 8. Families and Carers”

“The draft Bill says ‘Disability services should ... consider and respect the role of families and other people who are significant in the life of the person with a disability’ [see Section 5(3)(g)] yet it fails to do so entirely in the processes it prescribes itself.

The draft Bill should provide services for families and carers who need help that relates both to the person receiving their care and the disability.

People with an Autism Spectrum Disorder should enjoy “normal” family relationships with parents, siblings and family carers. Such relationships are important to the quality of life for all parties. Parents, siblings and others must not be forced to relinquish their family relationships in order to fulfill the role of a carer.”

Recommendation

3.1 - Legislative framework must do more than simply acknowledge the significant support role and expertise of the person’s immediate family – it must make specific provision for families as substitute decision makers.

Other specific areas of concern that we have with the Disability Bill Exposure Draft include:

4. – Accountability. As with other organisations, we are concerned that under the legislation the Dept. of Human Services has the role of enacting, funding, monitoring and providing disability services. We concur with comments made by others that it is critical there be a clear process of consultation articulated in the legislation, especially with regards the development of disability standards and the measurement of performance and quality assurance. The exposure draft notes that ‘all power will rest with the Secretary’, a phrase that does not inspire confidence that a truly consultative model will be developed when the legislation is implemented.

5. - The Review and Complaints process. The replacement of the Intellectual Disability Review Panel (IDRP) with the Disability Services Commission, The Disability Services Board and the Senior Practitioner is welcomed provided the DSC is adequately resourced and has a greater range of powers than IDRP. There is real concern regarding VCAT’s acknowledged “disability skill set deficit ”.

Adopted by Autism Victoria and AFSA, February 2006

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