



**REVIEW OF DISABILITY LEGISLATION IN VICTORIA:
A POSITION PAPER**

August 2003

**Australasian Society for the Study of Intellectual Disability (ASSID)
Victorian Regional Association**

Submission to:

**Legislation Policy and Review Team
Disability Services Division
Department of Human Services Victoria**

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***A Submission to the Legislation Policy and Review Team,
Disability Services Division, Department of Human Services***

Prepared by:

Ms Alex Phillips, Victorian Regional Association, ASSID. President.
With Assistance from Mr Murray Couch, Social Research Consultant.

From the Contributions of:

Dr John Annison Ph.D.
Ms Kathy Arentz
Professor Robert Cummins
Associate Professor Robert Davis
Dr Karen Nankervis Ph.D.
Mr Bill Taylor
Professor Bruce Tonge
Dr Jane Tracy
Professor Jeff Walkley

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For copies of this paper please contact ASSID Victorian Region on email:
Alex.Phillips@rmit.edu.au

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Preamble

In September 2002, the Victorian Government released the *Victorian State Disability Plan: 2002-2012*, which outlined the Government's vision for the future and some strategies for realising this vision. As part of the release of the State Disability Plan, the Government announced its intention to review the legislation for disability in Victoria (Department of Human Services Victoria [DHS], 2002), that is:

- Intellectually Disabled Persons' Services Act 1986
- Disability Services Act 1991.

This review of the legislation aims to develop a legislative framework for disability that supports the principles and objectives of the State Disability Plan (DHS, 2002). The Government issued a discussion paper, *Review of Disability Legislation in Victoria: Discussion Paper (May 2003)* and, as part of Phase One of a four phase review process¹, and this position paper is a response to it.

The Discussion Paper (DHS, 2003) addressed three of the Priority Strategies in the State Disability Plan (DHS, 2002) and considers the legislative issues relating to those priorities. These priorities are:

1. Reorienting disability supports.
2. Developing strong foundations for disability supports.
3. Promoting and protecting people's rights.

This position paper will set out responses under these headings, after some introductory comments and a reflection on principles.

¹ These phases are:

- Phase One—Developing the Discussion Paper and undertaking public consultation
- Phase Two—Developing recommendations for the future legislative framework and obtaining public feedback
- Phase Three—Drafting the legislative framework and the Parliamentary process
- Phase Four—Implementation

(DHS, 2003)

Australasian Society for the Study of Intellectual Disability (ASSID)

The Australasian Society for the Study of Intellectual Disability (ASSID) is a not-for-profit organisation for people who work in the intellectual disability field or have an interest in the area. A Board of Management, comprising elected members, coordinates Regional Associations that represent members from each Australian State and New Zealand. Membership consists of people with disabilities, academics and professionals from a range of disciplines, disability support workers, families, service organisations, students and others with an interest.

Since its inception in 1964, ASSID has provided an avenue for regional associations to respond to changing trends in the treatment of people with an intellectual disability (Sheather, 2002). The aims of ASSID are to provide a network of people to promote the study and dissemination of research into intellectual disability as well as promote the rights of people with intellectual disabilities (Appendix A). Activities of the society are driven by the contributions of its members and include the promotion of quality service provision through conferences, seminars, an electronic discussion list, quarterly journal and magazine. Established by professionals who recognised the need for an organisation that advanced discussion and learning in intellectual disability to improve conditions for this group, ASSID continues to advocate for the rights of people with intellectual disability by contributing to debates and discussion surrounding policy and legislation (Sheather, 2002). The current position paper is a response from the Victorian Regional Association of ASSID to the State Government review of disability legislation and more specifically, the Discussion Paper (DHS, 2003).

Introductory Comments

The focus of the position paper

This position paper reflects the views of an association with a particular interest in, and commitment to, those people who have an intellectual disability. Its focus, then, is on the manner in which this review and any resultant legislative change will affect this population and services directed toward them, within the broader disability field. ASSID has further taken the position that any legislative review and subsequent change needs to incorporate a vision for the future and be proactive rather than address the current situation only.

Position on legislation for persons with intellectual disabilities

It is the view of ASSID that there be continuation of specific legislation that addresses the particular needs of people with an intellectual disability who may require temporary or life-long disability services.

Government and service providers cannot assume that all the needs of this population will be met by generic services and ASSID believes that there is a Government responsibility to ensure that quality services are available where the general community is unable and often unwilling to meet the needs of the service user. While ASSID recognises that community integration has been successful for many people with intellectual disabilities, there are those who will always need specialist services to remain living in the community (American Association on Mental Retardation [AAMR] 2002, p.152; Cummins & Lau, 2003), and there is a need for a legislative framework to ensure continuity and standards of service.

At the same time ASSID agrees that it would not be appropriate for new legislation to attempt to cover areas that already exist under current legislation. For example, the Intellectually Disabled Persons' Services Act 1986 was designed primarily to enable service provision for people with intellectual disabilities and as such did not overlap with the protective function of the Disability Discrimination Act 1992. The usefulness and

relevance of legislation developed for the wider community, including people with disabilities, means that ASSID does not hold the view that people with intellectual disabilities require separate legislation for those issues covered elsewhere.

ASSID strongly recommends that the specific service needs of people with intellectual disabilities, where they have not been provided for in other Acts, continue to be addressed through legislative means (i.e., a new Act or amended Intellectually Disabled Persons' Services Act 1986). As a consequence of cognitive impairment, people with intellectual disabilities usually have problems with communication and hence, in advocating for themselves. This leaves the majority of service users at heightened risk of having fundamental service needs overlooked and neglected in the face of increased competition without the safeguard of mandated service requirements.

The need for legislative review

ASSID strongly agrees that the existing legislation needs review and welcomes the initiative of the Government in this regard. As the Discussion Paper recognises, “there have been significant advances in recognising people’s rights and in delivering supports and services to people with a disability in Victoria” (DHS, 2003 p. x) since the Intellectually Disabled Persons' Services Act 1986 and the Disability Services Act 1991 were introduced.

There are consequences of the different approaches of the Intellectually Disabled Persons' Services Act 1986 (which takes a highly regulated approach) and the Disability Services Act 1991 (which contains few added rights or protections for the wider disability sector). ASSID can appreciate the conclusion in the Discussion Paper that “these different styles and scopes have made the administration of these two Acts more difficult, and have at times created confusion and inconsistency in the application of the Acts” (DHS, 2003 p. x). There is recognition, too, that in recent years, a number of reports have highlighted some of the difficulties with the current legislative framework. For example, the Auditor-General's Report on services for people with an intellectual disability (Deloitte Touche Tohmatsu, 2000) and the review of the operation of the Statewide Forensic Service (Victorian Law Reform Commission, 2002).

One of the particular strengths of the Intellectually Disabled Persons' Services Act 1986 is that it provided the shape of service provision for an extended period, offering facilitation, direction, and a predictable framework for service planning. Any new legislative framework should provide this same sustaining vision for the values, conditions and direction for the service system.

In comments that follow, ASSID will attempt to identify areas where the legislation appears redundant, and areas where the legislation need to be improved and strengthened. Further to identifying areas, any new proposed legislative framework needs to engage with the issue of the efficient and effective distribution of resources across the disability sector.

State Disability Plan 2002–2012, Discussion Paper & Legislation

A fundamental concern of ASSID, which will be reiterated throughout this position paper, is that the *Victorian State Disability Plan 2002-2012* and the *Review of Disability Legislation in Victoria Discussion Paper* risk rendering invisible the realities of life for those with intellectual disability.

The move to the use of an undifferentiated generic category, ***disability***, to aggregate people with physical, sensory and intellectual disabilities runs the risk of masking the particularities, and resource and support needs, of each disability group. Data consistently demonstrate that people with intellectual disability constitute over 60% of disability service users in Australia (Australian Institute of Health and Welfare, 2000; 2003). Such data suggest that people with physical and sensory disability are well supported in the community, while service development is still needed to ensure an adequate response to the needs of people with cognitive impairments.

Consequently, the legislative review needs to move beyond the use of categories that are aggregated at too high a level, in order to reflect the complex realities of, and the differences within, the disability population, which includes a majority of people with intellectual disability. Throughout this position paper an imperative will be expressed that

any new legislative framework must sufficiently differentiate between different disability types so that real and existing conditions are addressed.

It is acknowledged that it was appropriate for the State Disability Plan (DHS, 2002) to take a whole of Government approach to disability service provision and it is therefore broad in aims and directions. However, legislation results in more specific consequences to service provision. It is necessary for the legislative framework to provide specific reference to people with intellectual disability, if their position, experience and needs are to be addressed.

Principles

The place of explicit principles

ASSID strongly supports the incorporation of explicit principles into the new legislative framework. The Intellectually Disabled Persons' Services Act 1986 demonstrated well the important role that explicit principles have had in this field in shaping and controlling service provision and establishing and maintaining service quality. Principles provide an enabling context and make clear the broad philosophical underpinnings of the legislation. To be most effective principles need to be placed in an enabling and integrated set, have the force of minimum standards, be applicable to both government and non-government sectors and future legislation needs to establish accountability for the implementation of the principles.

While ASSID acknowledges the philosophical and practical usefulness of the principles enunciated in the 1986 legislation, it is less convinced about the principles set out in the State Disability Plan (DHS, 2002). The exclusive focus on a community development approach is not sufficient for people with intellectual disability, whose needs include development of individual personal capacity. The nature of intellectual disability (i.e. cognitive limitations and limitations in adaptive behaviour compounded by deficits in society's responses to their needs) is more likely to be served by a balance between the principles and strategies of personal capacity development on the one hand and community development on the other.

Principles in the State Disability Plan (DHS, 2002) make more sense when viewed within a larger framework and with *supporting legislation*. Although it is recognised that it was appropriate for the State Disability Plan to be broad in aims and directions, the Guiding Principles were not clearly aligned with the rest of the document. In the view of ASSID, the Guiding Principles in the State Disability Plan (p.7), ought to be more explicit in how they are linked to Goals (p.9) and Strategies (p.11). Any principles in legislation need to align clearly with the principles of other strategic documents (such as the State Disability Plan) to demonstrate a clear and coordinated approach.

While keenly supporting the need for explicit principles in legislation, ASSID also recognises that a single principle in isolation can lead to unintended consequences. For example, s.5 (n) of the Intellectually Disabled Persons' Services Act 1986 provides for use of restrictive practices where “the means chosen should be the least restrictive of the available alternatives having regard to all the circumstances”. Considered as a free standing principle, the least restrictive alternative was often misinterpreted and became synonymous with inadequate practice that was condoned because available alternatives were viewed as less adequate.

Particular principles

The right of a person with an intellectual disability to opportunities for the development of personal capacity

ASSID proposes that a principle be specifically enshrined in future legislation to ensure the right of a person with an intellectual disability to opportunities for the development of personal capacity. Associated with this is a need for the inclusion of a principle to access whole of life planning that anticipates planning for transitional stages and times of increased service need. Although such a principle should have the effect of ensuring service continuity and coordination in a proactive manner, the choice to receive such planning must remain with the service user and his/her family.

The right to have a service plan developed, costed, implemented and reviewed

ASSID is of the view that a principle should be included in future legislation that establishes a persons right to have a service plan developed, costed, implemented and reviewed, and that this be driven by client need.

Government departments take the initiative in relation to policies and practice for employment of people with disabilities

Another principle which ASSID would welcome in future legislation would require that all Government departments take the initiative in relation to policies and practice for employment of people with disabilities, including intellectual disabilities. Such a principle would include departments and service providers to demonstrate that they actively seek

to provide employment for people with disabilities. The principle would mirror the affirmative action legislation for women, meaning that successful tenders to government that have a workforce above a certain number, or who are obtaining a tender above a certain figure, have similar policies in place.

People with an intellectual disability will not be restricted in their rights or opportunities

ASSID proposes that a principle be included in future legislation that reflects the position that people with an intellectual disability will not be restricted in their rights or opportunities. Allowance could be made, in sections other than the underpinning principles, for the use of any type of restriction to be proven through a structured process. Currently the Intellectually Disabled Persons Services Act 1986 assumes the position, expressed as a principle, that people will need to be restricted, and as mentioned above, principles in isolation can be misrepresented.

Reorienting Disability Supports

Eligibility

In general, ASSID considers the current eligibility criteria as appropriate for identifying most, but not all of those who require disability services. It is acknowledged that there is debate surrounding the role and use of diagnostic criteria, adaptive functioning assessment and classification of support levels, in relation to eligibility for people with an intellectual disability (AAMR, 2002 pp. 19-37). The use of assessments of adaptive functioning to determine eligibility should continue, and more specifically, ASSID proposes that two areas – communication and socialisation – be considered priority areas, which are given the highest weighting in scores of adaptive functioning for eligibility. This proposal is directed to all people with a disability, is aligned with concepts of the support paradigm (AAMR, 2002 pp.10, 82, 145-148) and is aimed to ensure that those most likely to have problems with mainstream support due to communication and social problems are prioritised first, regardless of diagnosis.

ASSID would welcome, in future legislation, the enabling of a streamlined and straightforward eligibility process that would include scope to argue for individuals to gain eligibility for services based on their particular circumstances. A certain degree of flexibility would protect against situations where those who most need support are unable to receive services because of stringent criteria. For example, a person with Autism Spectrum Disorder may record a high IQ and satisfactory scores on all measures of adaptive behaviour, yet engage in challenging behaviour or require support for an upcoming transition period that could result in crisis without Government services. Such legislative support needs to achieve a balance between flexibility and predicability in the application of eligibility criteria.

Service planning

It is a concern of ASSID that there are two types of planning that do not occur effectively at present, (a) planning across services and, (b) planning of services for individuals (Nankervis, 2001). The Intellectually Disabled Persons' Services Act 1986 established a framework for individual service plans to be developed within a specified

time frame (i.e., General Service Plan and Individual Program Plan). These plans aimed to coordinate the provision of services and individual program planning to maximise service benefits for the user. What often occurred, however, was the development of many service plans that were meaningless to the individual, that were not implemented and, although re-written within the specified time frame, were without meaningful review.

In the view of ASSID, future legislation needs to extend beyond the requirement for development of individual service plans in specified time frames, to include a mandate for implementation and subsequent review of such plans.

To encourage effectiveness, efficiency and competitiveness, ASSID proposes that future legislation require individual service plans to include a costing. Costing would make planning and provision of services transparent and more accountable to the service user. Service plans should identify the individual's priorities for support with available funds directed towards their highest priorities.

On the basis of such individual service planning, where user's aspirations and priorities direct the service system, ASSID recommends that costed plans be recorded at a regional level for service planning purposes. The Government could annually publish aggregate data, with no identifiers, of the number and content of such plans to provide valuable data to monitor service trends and in particular, indicate areas in need of strategic development.

Legislation that required the development, implementation, review and costing of user centred service plans, and that also provided data for Government reporting, would promote confidence in the field of disability because of transparent and accountable mechanisms concerning service provision.

Funding

In relation to funding decisions the Discussion Paper (DHS, 2003) raised a question about the location of funding decisions, particularly whether they ought to be taken locally or regionally. The principle that ASSID proposes is that funding decisions should be taken as close to the individual service user as practical.

The issue of funding processes is one where distinctions between disability types may need to be made. ASSID recognises that plans to give control over a funding allocation to individuals may work well for people without cognitive limitations. Such an approach assumes the capacity of the individual to make decisions. If that capacity is not present, then account needs to be taken of the existence of families and their capacity to manage finances on behalf of people with intellectual disabilities.

ASSID supports the view that some individuals with disabilities and some families of people with disabilities have a need for, and legitimate claim on, support of how best to have the funds allocated, in addition to support (e.g. service brokerage models) on how best to spend allocated funds.

Linking new legislation to a wider framework

It is recognised that future legislation needs to be consistent with any other relevant legislation for people with intellectual disabilities (e.g.: Guardianship Board Act 1986) as well as align with the wider framework outlined in the State Disability Plan (DHS, 2002). On a more practical note it would be useful if, accompanying new legislation, notes were provided giving direction to other statutes that should be read and considered in conjunction with any new Act or amended Act.

Developing Strong Foundations for Disability Supports

Accountability and monitoring

It is a strong view of ASSID that future legislation include clarity about access to service provision with a legislative requirement for monitoring. This would mean that the responsibility of Government to ensure services are implemented would be enshrined in legislation. In the view of ASSID the Government needs to be accountable for the provision of services and not just their management. ASSID would look toward a clause binding the Crown in this regard. Such a responsibility for the Crown would apply particularly to ensuring the effective application of a minimum set of standards of care.

ASSID understands the place of the Commonwealth Disability Standards, but maintains that there is a need for standards to be constantly reviewed and monitored. It is especially important that standards of care established by any future legislation apply equally to all sectors of the field, i.e. the government sector and the non government sector.

ASSID would expect that bodies outside of Government would conduct any monitoring of government services against a minimum standard of care, and that the monitoring of standards of service provision across all sectors would involve independent peer review, and not self-assessment alone. In making these points, ASSID is proposing the adoption of standard of care strategies in the disability sector, in a way that is similar to, or the same as, those used to monitor and deliver Aged Care. In making this proposal, it is recognised that Aged Care standards have specified standards for services and for staff, and compliance is linked to standards to service funding.

On the basis of legislative requirements for accountability in relation to standards of care, the Government could publish aggregate data, without identifiers, on an annual basis on the performance of the sector in the light of the standards.

Promoting and Protecting People's Rights

Community Visitors and an independent body

In relation to promoting and protecting people's rights, ASSID makes two major points.

The first point is that any future legislation should maintain the function of Community Visitors to deal with individual complaints and to make periodic inspections of services. Periodic inspections would continue to adhere to the right of individuals with a disability to restrict or deny a Community Visitor access to records held about themselves, or any part of the service.

The second point is that there is a need for a complaints body independent of Government. The body, with responsibilities in relation to accreditation of service provision and service standards (as previously suggested, modelled on systems already in place in Aged Care) could be based on the roles and responsibilities adopted by the Health Services Commissioner or an Ombuds. This independent body could have the function to deal with individual complaints, the monitoring of practices such as restraint and seclusion, and the use of some classes of drugs. Such an independent body could have a screening process (like the Health Service Commissioner) where complaints that are rightly in the jurisdiction of other legislation (e.g. Disability Discrimination Act 1992; Equal Opportunity Act, 1995; Information Privacy Act, 2000) would be referred to the appropriate agency, before the independent body handled the complaints under the new disability legislation.

The establishment of one independent body would provide an ongoing avenue in which professional expertise in intellectual disability could be fostered and developed. The functions of the Intellectual Disability Review Panel established by the Intellectually Disabled Persons' Service Act 1986, could be transferred to the proposed independent body, which could have a responsibility to publish aggregate data annually on its activities and performance.

Disability Advisory Council

In the view of ASSID there is currently no apparent reason to formally establish the Disability Advisory Council in legislation, given that its role remains advisory. Any monitoring that the current Disability Advisory Council performs or intends to perform, could be transferred to the independent body recommended above.

Other issues for legislation

In relation to the promotion of protection of people's rights, there are other issues to be considered for inclusion in future legislation. These include: (a) mandatory reporting of abuse, sexual abuse and neglect of people with intellectual disabilities; (b) Forensic Services; and (c) medication and psychiatric diagnosis.

ASSID recognises that people with intellectual disabilities are extremely vulnerable to exploitation from others because of their inability to speak out, an inability to defend themselves or recognise abusive situations. While avoiding the historical misperception of people with intellectual disabilities as being 'eternal children', ASSID supports the application of a reporting model similar to that used to safeguard children from abuse.

The Discussion Paper (DHS, 2003) raised for consideration the role of Forensic Services and the ability to keep someone in a service against their will. ASSID regards the complexity and specificity of this issue as requiring careful consideration and review (eg: Victorian Law Reform Commission, 2002) and suggests that it may well be better positioned somewhere other than in general intellectual disability legislation.

Another issue that requires consideration and review, but might be better located in legislation other than general intellectual disability legislation, is the matter of drugs of restraint and the current need for a psychiatric diagnosis. This feature of the Intellectually Disabled Persons' Services Act 1986 originated in a time when there was a great need to stop inappropriate medication of people with intellectual disability. Given advances in understanding and practices in this area, ASSID recommends that an expert clinical panel review the issue. One way to move forward would be to consult with the appropriate medical college to have a set of clinical guidelines developed.

Conclusion

The Intellectually Disabled Persons' Service Act 1986 is recognised for its effective shaping of service provision for over 15 years, offering facilitation, direction and a predictable framework for service planning

To achieve the vision of a community characterized by participation and integration (*Victorian State Disability Plan 2002-2012*) ASSID recommends that legislation continue to support the particular needs of people with intellectual disabilities. The whole of Government approach and focus on community development outcomes, outlined in the State Disability Plan provide a broad framework and direction for achieving this vision. Revised legislation could operationalise the broad aims of the State Disability Plan and more specifically, provide a framework whereby people with intellectual disabilities have their right to develop personal capacity upheld.

This Position Paper recognises that services for people with an intellectual disability need to be provided within a framework that effectively and efficiently provides quality support to all people with disabilities, in addition to building community capacity to foster partnerships between all citizens.

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Appendix A

Australasian Society for the Study of Intellectual Disability

Constitutional Objectives

1. Promote the study and understanding of intellectual disability
2. Provide a forum for people who have a personal or occupational association with intellectual disability.
3. Bring together those working in the field of intellectual disability
4. Facilitate communication between members via conferences, national networks, symposia, workshops and lecture tours.
5. Publish journals, magazines, newsletters and brochures of interest to members and the wider intellectual disability community.
6. Foster high principles and standards of work practice.
7. Promote and safeguard the rights of people with an intellectual disability.
8. Advocate on behalf of people with an intellectual disability.
9. Frame policy with regard to services to people with an intellectual disability.
10. Influence legislative developments in the area of intellectual disability.