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Abstract

This paper addresses the emergence of Australian government policy relating to intellectual disability and the resulting impact upon those who live with its consequence. Governments at all levels are recognising the need to legislate re: the needs and right of people with disabilities but people in the field have problems with interpreting legislation and then putting it into practice. The Disability Services Act, the Disability Reform Package, employment and various policy issues are discussed. **Keyword: Government**

DISABILITY AND LEGISLATION: THE RELATIONSHIP BETWEEN CHANGING POLICY AND CHANGING PRACTICES¹

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Governments at all levels are recognising the necessity to legislate for the rights and needs of persons with a disability as a result of the failure to have those needs met in wider legislative provisions. Australian laws and regulations such as the Disability Services Act, the Disability Discrimination Act, and other potential legislation reflect the importance placed on ensuring that persons with a disability receive appropriate services. The problems of translating legislated services and rights into adequate practices can, however, be a source of frustration for all players in the field - persons with a disability, carers, advocates, service providers and governments. The role of lobby and pressure groups is an important one both in a reactive and proactive sense in ensuring that the best services are provided to their constituents. The paper addresses the emergence of Australian government policy relating to intellectual disability and the resulting impact upon those who live with its consequence.

Australians have grown accustomed, even tired, of the ever-increasing number of national and local special days, weeks, months, and years we hold to highlight issues perceived by specific groups to be important. In some cases, such as Red Nose Day to raise money for research in Sudden Infant Death Syndrome, people are prepared to pay money to wear red noses or place large red noses on their cars. Our national airline QANTAS each year paints the nose of one of its plane red to lend support. Other organizations that have attempted to imitate the concept of red nose day have achieved much less success. In the same way international years have become commonplace and many are ignored both by citizens and governments.

It is fortunate that the International Year of Disabled Persons, or IYDP as it *is* still commonly referred to, occurred in 1981 at a time when the concept was new and fresh. It is important to remember that it wasn't government that made the first moves in attempting to address the issues raised by IYDP, it was the people with disabilities, their families and some service providers who gained a platform to argue for change. As the former Australian Minister for Community Services, Dr Don Grimes said in this year's Meares Oration,

at that time there was a general feeling in the community that we didn't need to do much. There were people providing services who were seen as public-spirited citizens relieving the rest of society of a burden. The recipients weren't complaining because there was no one to complain to. So why change anything? (Grimes, 1992).

Governments did decide to respond and implement change. Perhaps in hindsight they may have rethought the whole concept of asking people to contribute ideas and point out the weaknesses of the existing system. Had they realised the profound changes that were to occur in the economy and the pressures they would be subjected to by the mushrooming number experts, lobby groups, public service bureaucrats and persons seeking services for themselves or their families, no government would have embarked on more than cosmetic change. It could be argued cynically that governments have done little more than that anyway. Some organisations, I fear may have been happier to have continued operating with monies obtained through fund-raising drives that actively used public sympathy towards disability. At least they knew where the money came from and could decide how to spend it.

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Government, particularly at the Commonwealth level, put disability on the political agenda, particularly following the election of the current government in 1983. The Handicapped Programs Review and the release of New Directions began the process of rapid and perhaps chaotic change and reform that has characterised the past 10 years. How much longer disability can remain on the political agenda is a matter of speculation. The state of the economy in a time of prolonged recession and the realities of the need to fund priority areas such as unemployment may reduce the resolve of the government to fund high cost services. In a time of extreme political pressure for state and Commonwealth governments, the term for hard-liners is economic rationalism; social justice is for the weak and those who can't make the tough decisions.

Development of Government Policies and Programs

One of the difficulties facing a country based historically on a federation of states is that government operates on a multitude of levels. The Commonwealth, the eight states and territories and the multitude of local government areas all seek to have either a stakehold in the development of policy, or to deny any responsibility for policy, depending on the power they may acquire or lose as a result. In addition, the tyranny of distance in a country the size of the United States but with a population of 18 million means that services have to be duplicated many times over for a small number of people and that the bureaucracy has to be devolved further to regional administrators for both Commonwealth and state programs.

The Commonwealth Government remains the key player through a series of major policy initiatives such as the Disability Services Act and the Disability Reform Package, although states have produced a number of important legislative reforms such as Guardianship and anti-discrimination legislation. In partnership, the Commonwealth and State and Territory Governments are currently working on a rationalisation of policy and practices in the field of disability.

An examination of some key legislation provides an understanding of the tension that can exist between policy formulation and the reality of service provision.

Disability Services Act

The Disability Services Act (1986), or DSA as it is widely known, arose from the discussions and options canvasses in the earlier Handicapped Programs Review and New Directions. It provided a policy statement on the rights of people with disabilities and a set of principles and objectives to apply to service provision. The principles addressed concepts such as "People with disabilities should be afforded the same basic human rights as all other Australian citizens" or in the terminology of the consumers' kit "Every person with a disability should be treated as a human being."

The DSA had two key foci that were to challenge many existing services for people with intellectual disabilities and, even more dramatically, the way in which those services were operated. The Act sought to develop new and innovative services that would meet individual needs and secondly provide a transition program to assist "older-style" services that existed prior to the Act move towards "quality services". Traditional sheltered workshops were to change their operations to reflect one of two employment models: competitive employment or supported employment. Both models focused on the importance of moving toward labour market practices, hence reducing the social and employment marginalisation of people with disabilities.

The Act was applauded at the time, yet support for the rhetoric has not been translated into practice. In 1991, the current Minister, Mr Howe, noted that 58% of services were still unable or unwilling to meet the minimum outcomes and others had failed to respond to the Government's program audit (Howe, 1992). The response of the Government has been to threaten sanctions on those unwilling to comply with the request to

move forward in employment programs. In addition it has stepped up funding for the National Technical Assistance Unit to help service move forward.

Considerable funds have been invested in some organizations to try to move practices away from a philosophy that the people attending sheltered workshops are not employees but clients receiving day programs. The reality is that some transition monies may have perhaps been wasted by investing large sums in some services to force the pace of change. Other services were prepared to make changes without the need to be coaxed by funds. Clearly the quantity of money spent doesn't equal quantity of change.

Current amendments to the Act (Health, Housing and Community Services Legislative Amendment Bill, 1992) have addressed the funding problem by softening the terminology used, by changing the objectives in the Act from "enable" to "assist" and from "achieve" to "assist in achieving". It is to be hoped that such changes do not provide loopholes for government and service providers to accept a retreat in program standards. A positive feature of the amendments is the opportunity for groups of people with a disability to establish a business or company. A Company operated by people with a disability in the open market, employing those without disabilities, would be an excellent example of the DSA's philosophy in practice.

Disability Reform Package

The failure of the DSA to come to grips with the transition of programs away from traditional models led in part to the enactment of the Disability Reform Package (DRP) (1991). In contrast to the social justice focus of the DSA, the DRP had a strong economic rationalist philosophy. It was designed to provide employment, training and education options to reduce the numbers of persons with a disability requiring income support. Under the DRP, all school leavers with an intellectual disability come under the legislation, and access to employment placement services for all persons with a disability occurs via a Disability Review Panel. This panel provides an assessment of the person's ability to be employed and hence the right to have access to the Commonwealth Employment Service (CES). The Panel therefore acts as a sieve or screening process. The major problem of such a process is its effect on persons not accessed as eligible for employment and who no longer have the option of entering existing services. As the Panel consists of staff from economic rationalist government departments, the pragmatic view could be that those assessed as capable of employment pass through, while those who are not become the leftovers for the social justice focused Health Housing and Community Service Department to deal with. In a time of chronic unemployment, the effectiveness of Disability Jobseeker Advisers in achieving their role of seeking placement for persons with disabilities is yet to be demonstrated.

A major restructuring of government policy and practice is currently taking place with rationalisation of responsibilities for funding between the Commonwealth and state governments. Under the Commonwealth States Disability Agreement (CSDA), responsibility for accommodation, respite care and recreation are to be administered by the states, while employment and TAFE training are to be administered by the Commonwealth. While all players have agreed in principle, problems implementing the agreement are appearing. The difficulty for the Commonwealth government lies in the failure of some states to pass the necessary complementary legislation in order for the transfer to occur. The challenge for consumers, service providers and government is to follow the changes in the various pieces of legislation and pinpoint where to target requests for funding and assistance.

One piece of Commonwealth legislation that is important for persons with a disability is the proposed Disability Discrimination Legislation (Attorney-General's Department, 1992), which seeks to eliminate discrimination in existing laws, in employment, accommodation, education, provision of goods, facilities and services, and in the activities of clubs. Such legislation complements discrimination legislation in some states and is well worthy of bipartisan support in this next session of parliament

While specific legislation has been passed relating to disability, some issues concerning disability are incorporated in broader pieces of legislation in which disability is linked to other areas of social disadvantage such as English as a second language and the provision of remote services. The Broadbased National Equity Program for Schools is a Commonwealth program designed to allow flexibility in funding rather than having specific funding allocated to each aspect of disadvantage, such as special education grants. Such an approach is commendable, provided that services to students with disabilities are not lost in the funding. There is tendency in global funding for a disproportionate share to go to the group with the loudest advocates.

Competency Based Training

In an increasing number of cases, disability is being included in generic legislation. One generic area that will have a most significant impact on all persons in the field of intellectual disability together with all workers in Australia is the impact of Competency Based Training. The Mayer Committee (1992) on behalf of the Commonwealth Government is currently examining the issue of training standards for all Australians in order to develop a national standards framework for six key employment related competencies.

The committee is seeking to establish a series of competency levels for each key competency strand. To date, three levels have been identified together with examples of the nature of work expected at that level:

Level 1 Routine predictable repetitive tasks

Level 2 More complex tasks under supervision

Level 3 Self-directed application

At a later time the levels will be increased to seven to include competencies for all possible skill levels. The six key competency strands and the levels within each competency are designed to achieve national standards that are consistent, transportable and able to be articulated. For persons with an intellectual disability seeking to enter the workforce, they highlight the need for greater training support and the need to provide training that is functionally related. In some strands, they recognise competencies already stressed in special education such as working with others. For staff they should provide a framework in which to obtain training that will better meet the needs of clients. After obtaining those competencies and qualifications, personnel should be able to move between states and services and have those qualifications recognised. Importantly for staff, it should provide a framework in which articulation of qualifications can occur, leading to enhanced career prospects.

For persons with an intellectual disability however, there are some serious weaknesses that need to be addressed in order that they are not further disadvantaged. Although the report does acknowledge that disability exists, this is not demonstrated at the minimum competency level. The level 1 competency standard in working with others and in teams has, as one of the examples, "being able to serve behind a counter in a fast food outlet". If a person with an intellectual disability cannot meet the minimum standards at Level 1, technically they would be excluded from employment. There is also a heavy emphasis on literacy and numeracy without acknowledging that alternate methods are available to compensate for these. If lower or pre-competency levels were introduced and alternative compensatory strategies were permitted, failure to be able to read the time on analogue or digital clocks could be overcome by listening to the radio or watching when workmates are preparing to go to a break. To achieve this, however, will require substantial rethinking by the National Standards Committee.

Many employment programs for persons with an intellectual disability focus on training employment and social skills whilst placed in employment. The Competency Based Training approach requires that employees have these skills at the time of employment. There is a need to consider the relationship between Competency Based Training policies and the employment options currently operating under the CSDA and

the DRP to ensure that persons with an intellectual disability are not disadvantaged in seeking training in employment related skills and in undertaking meaningful employment.

The focus of Competency Based Training relates only to employment in the open labour market. For persons with more severe disabilities and who are ineligible for traditional employment support because they do not pass the Disability Review Panel, the question of how competencies will be determined for supported employment or in the 58% of programs that haven't yet moved to that level, remains unsolved.

One very positive potential outcome of including lower or pre-competency levels would be that once the person with a disability had demonstrated those competencies they couldn't be excluded from employment under anti-discrimination legislation.

The issue for staff in programs and services is also confused. As discussed earlier, the changes in the field of intellectual disability that have seen a reduction in the number of larger residential institutions, and the development of smaller, local, needs-based programs have raised the need for staff with new skills or redefined skill. One of the challenges for both the Commonwealth and states is to develop competencies both for new staff employment areas and changing areas. The skills of nursing in a large ward-based residential institution are different to the skills required to support persons with an intellectual disability in their group home.

If such competencies are developed, as they must be, there needs to be an agreement across states on those areas of disability services that are state responsibilities under the CSDA, otherwise the concept of transportability of skills is lost. The Heads of State Services in intellectual disability are to be commended for their current efforts to seek funding for a project to examine CBT standards at the direct care staff level. The background work of the two main organisations in intellectual disability, ASSID and NCID in working jointly to push for such a review demonstrates the importance of lobby groups and government working together with the common goal of improving standards.

At a higher level, the ability to obtain common standards for workers in the disability field at University level, including diplomas and degrees will be more difficult. Universities are strongly opposed to the concept of competency based training, arguing that their role is academic excellence and that they are concerned with the whole person not a series of discrete competencies. Given that within the competency strand of solving problems, performance level 1 requires that a worker be able to repair a photocopier, many of my colleagues, in other disciplines, would fail to meet even the base competency level.

On a more serious note, the standard of training for staff at higher levels is inadequate. Parmenter (1992) has suggested that psychologists working in the field of intellectual disability do not possess the competencies required to adequately assess and make decisions about clients. Questions have also been raised about the ability of generic government department staff to cater for client needs. If it is appropriate to expect persons with an intellectual disability and direct care staff to have specific employment competencies, it is certainly appropriate that those who supervise or place clients and staff should also possess minimum or preferably enhanced competency levels.

Where persons with an intellectual disability are included in generic legislation, their needs can be inadvertently overlooked. Currently legislation is being proposed for the provision of employer contributed superannuation for all workers to ensure that on retirement workers have an adequate income. Such a move is important given the ageing nature of Australian society and the aged pension entitlements that currently exist. The minimum monthly wage an employee may receive before the employer has to pay the superannuation levy is \$450. As many people with an intellectual disability earn below this level, on retirement they will be doubly disadvantaged.

Devolution of Policy

The development of major government specific and generic policy in the field of disability reflects an underlying current of disagreement on the role of government in the funding of services, and in the degree to which government should control activities it funds. The battle between the economic rationalists and the social justice advocates occurs both within and between political parties. Both Commonwealth and State public services have undertaken major restructuring in recent years. Department are in some cases duplicating services both within and between themselves. As a result, staff can become disenfranchised and as a consequence there can be a lack of continuity of programs and decision making. It is a tribute to staff in disability programs that in general, services and programs do continue to operate.

One feature of restructuring is the tendency to move disability services into generic services. The attraction is economies of scale and a reduction in the need for specialist staff and divisions within departments. Such a move completes a cycle in some states where disability services were created because generic services were unable to meet the needs of persons with intellectual disability, to a point now where the need for such a service is no longer politically possible. Only one state continues to have a Minister for Disability Services, few states have a separate Disability Service Department and an increasing number are moving towards a generic welfare administration. The tendency to place intellectual disability with aged care and child abuse has not been matched by the pooling of funds to administer the broader role. The concept of general management skills has become the ultimate measure of corporate efficiency with the belief that successful management of public utilities or inanimate objects means that persons will be equally skilful in managing human services.

The movement towards generic service provision requires that a broader range of staff is able to meet specific needs and conversely that specific skill staff is able to provide a broader range of services. Staff previously trained to perform a specific role, such as mental retardation nurses, is required to undertake very different roles when acting as direct care staff within group homes. Assuming that appropriate retraining is provided to these staff, their new role precludes them from being considered as nurses by nursing unions and hence they become disenfranchised. Such changes of role emphasise the need to ensure that staff as well as consumers and parents are considered in any restructuring of services. A related outcome of the move to local service provision is that staff are often not available, and rather than have the most qualified staff working with people with high support needs, the lowest trained staff are frequently the only staff available

Policy and the Participants

Policy formulation in the past 10 years, both in specific legislation and in generic legislation, has changed substantially the way in which governments interact with persons with a disability both directly and through service funding. Under existing legislation and even under the Disability Services Act, the Commonwealth government kept a very tight rein on the provision of funding and the management of services. In the future, the CSDA will see a change in the carving up of that control, yet the management of monies and expenditure will remain with government. The increase in the number of non-government service providers, as the government seeks to have services respond to local needs, provides a dilemma for government. There is a need to balance freedom to provide appropriate service whilst at the same time monitoring quality and funding levels.

Robin Wilkinson in an ASSID conference in Tasmania earlier this year (Wilkinson, 1992) spoke of the importance of power in disability services and whether power should be in the hands of government, service providers, workers or consumers. The answer was that power remains with government and service providers so long as they control the money. The ultimate concept of power would be for the person with a disability to be able to purchase services at a local level, perhaps through a service brokerage or by direct negotiation. Then that person has both power and choice which is the combination we, as part of the general

community, strive for. New Directions in the early 1980s spoke of the dignity of risk-taking for persons with disabilities. Perhaps we should see the devotion of funding and management to states and service providers as part of that risk taking. Perhaps the next step, Wilkinson argues, is to take the risk of providing funds to persons with disabilities.

Changes in government relations with participants have had an even more significant impact on the way in which participants interact with the government. Prior to the DSA, service providers operated from a charity model with minimal government intervention. The consultations that took place before the DSA gave those services and parents a platform for demanding change and lobby groups became more vocal and numerous. Through negotiation, some service providers were able to develop innovative programs in earnest. Discrepancies between the best and worst programs began to emerge. Existing lobby groups began to split and realign, based on perceptions of what was the best for their constituents. New lobby groups emerged to of staff and consumers in new programs. In one state there has been a very clear move away from one service provider as the prime lobby group towards a number of groups established to meet the perceived deficiencies.

On a broader scale, one of the most important groups to emerge were the Self Advocacy groups which developed out of a need for persons with an intellectual disability to have a voice. The establishment of service brokerage where potential consumers could receive advice and negotiate for services was another important development. Unfortunately, with the implementation of the Disability Review Package, such a service will become even more important as those ineligible for employment support seek appropriate services.

As the impact of policy continues to focus on those with minimum or medium support needs, families of persons with high support needs are becoming far more vocal as a lobby group. The government is reluctant to fund persons with high support needs on an individual costing basis because of the budget blowout that would result. In response a National Carers Council has emerged because of the concern that parents at home are receiving no services and that the time to speak out had come. The aims of establishing a national network and a united voice have been heard by government and funding has been promised. One can be forgiven for a feeling of *deja vu* in the lobby process of seeking change.

The provision of funds raises an important feature of the relationship between government and lobby groups. Once an organisation receives government funding, the government is able to tie down that organisation by seeking response to documentation or in asking them to provide consultancies to government. In this way the lobby group subtly moves from being proactive to reactive. Funding brings responsibility and power remains in the hand of the funder.

Lobby groups in the field of intellectual disability face a number of key problems. The diversity of groups and the changing focus of groups can have serious consequences for future services, particularly where those ideas represent only a small group of players in the total field. Where lobby groups start to serve themselves or won't change as the field changes, government sees the diversity and responds either by drawing back or by overcompensating. Governments and oppositions need to hear a broad-based constituency before making changes. The lack of co-ordination between lobby groups can be overcome where a strong, representative co-ordinating organisation can exist. The concept of an umbrella structure as proposed by the Commonwealth government is feasible only when the organisations under it can receive protection or assistance from its shelter. The Field of intellectual disability is not well served by the umbrella groups that currently exist and any restructuring must be cognisant of that. We need to go back to being proactive as lobby groups to ensure that the gains that have been made in areas such as self-advocacy are not left to be forgotten as we respond to other's initiatives.

The key issues that have emerged in the last decade focus on three main areas: employment, housing and access to services. Governments have attempted to address these issues both through specific and generic legislation. While some legislation has clearly sought to advantage persons with an intellectual disability, other legislation has highlighted how far we need to go in ensuring that all citizens are not disadvantaged by the practices that will result.

Yet as the NSW Office of Disability (1992) has stated “we have seen people with disabilities do not always have their rights observed and maintained.” Do we therefore need a Bill of Rights to protect the rights and freedoms of persons with a disability or does doing so imply that society does not see that they have rights and freedoms? If these rights and freedoms don't exist in practice, then legislating them to happen changes nothing. We have begun to change community attitudes and perhaps it is better to do this by action not decree as has occurred in some of our state racial vilification laws.

What then has been achieved in the past decade? Francis (1992) argued that we have a different pattern of service delivery which, significantly, is in favour of keeping people with intellectual disability in the community. What hasn't been delivered is integration in the sense of having relationships with people who don't have disabilities or having carers who are not parents or paid.

The contradiction for all of us is that as we strive to ensure those persons with an intellectual disability become an integrated part of the society, we continue to seek positive discrimination for them in ensuring they have the support to remain there.

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