family ADVOCACY

PO Box 502
Epping NSW 1710

305/16-18 Cambridge St
Epping NSW 2121

Phone: (02) 9869 0866
Facsimile: (02) 9869 0722

Record 310

File Number 10277

Author: Dickey, Jo

Title: The Meares Oration: Leaving the bridge: The journey into citizenship by persons with disabilities

Original source: Australian Disability Review 1-90

Resource type: Written

Publication Date: 01/01/90

Publisher Info: DACA

Abstract

This report is aimed at raising community awareness on disability issues, with emphasis on new concepts and introducing challenging and progressive ideas. It is based on experiences of service brokerage and individualised funding observed in Canada and stresses the role of citizenship. The impediments to brokerage and individualised funding are found in factors which include "deep attitudinal and structural factors (which) impede persons with disability from participating in the full benefits of citizenship". The author of the report believes that the implementation of brokerage and individualised funding could act as a powerful catalyst for social change. **Keyword: Individualisation**

The Meares Oration: 28th February 1990
Brisbane Australia
by
Jo Dickey*

Leaving the Bridge: The Journey into Citizenship by Persons with Disabilities

The Meares Oration is sponsored by the Disability Advisory Council of Australia (DACA). It is named after the Hon. C.L.D. Meares. CMG, QC, AC, a former judge of the Supreme Court of NSW, formerly Chairman of the National Advisory Council for the Handicapped. and subsequently a DACA member. The aim of the Meares Oration is to raise community awareness on disability issues, with particular emphasis on new concepts. and to introduce challenging and progressive ideas. DACA also conducts a series of seminars and workshops around the Oration's theme.

* The contributions of co-authors Cameron Crawford and Glen McClughon are acknowledged.

Background

Having a constitution less than 10-years-old, and seeking to find its voice within one of the world's most prosperous economies, Canada finds itself redefining its understanding of citizenship. This process is having a critical impact on people with disabilities, on the discourses concerning their rights and concerning the place and structure of social services. In Canada, as in most other countries, the exact meaning of citizenship is open to endless philosophical discussion and difference of opinion.

Despite the various meanings the term may have, citizenship is usually taken to imply the right of the individual to participate in the ordinary benefits and rights enjoyed by other members of society. Citizenship thus means having a sense of rightful belonging within one's community. It means having a recognised and valued place within the state or the nation as a whole, and having the corresponding right and power of choice as a valued citizen to pursue a destiny that is self-determined. It means having one's participation and membership, and one's rights and freedoms as a citizen, clearly recognised and vigorously protected by the state from discrimination and other interferences.

It is perhaps natural within the emerging consensus on citizenship that people are increasingly demanding the right to be able to hold onto and even to celebrate the very factors that make them unique and distinct from one another. This newly recognised dimension of citizenship implies that the State has an important role to play in facilitating and safeguarding people's differences within the context of equality for all. Many definable groups within Canadian society are pressing for greater access to the full benefits of

citizenship. As they put the public on notice that they intend to accept nothing less than their constitutionally guaranteed distinctness and equality, Canadians are coming to accept their demands as a part of the democratic process.

During the public consultations that led up to the publication of 'Obstacles', Canada's House of Commons Report of the Special Committee on the Disabled and the Handicapped of 1981,(1) people with disabilities had critically important opportunities to publicly assert their views of and claims to citizenship.

On the basis of those views, the Committee members explicitly and unanimously drew attention to the principle of participation as worthy of being embraced by all Canadians. In doing so the Committee implicitly endorsed the principle as worthy of being adhered to by all levels of government in matters concerning people with disabilities. The Committee defined participation as having 'the same opportunity to participate fully in all of the educational, employment, consumer, recreational, community and domestic activities which characterise everyday Canadian society. (2)

In 1986-87, Parliament gave more formal recognition to the features of citizenship that people with disabilities had been articulating on the international scene for over a decade. That recognition was clearly spelled out in the Declaration on the Decade of Disabled Persons, a document outlining guiding principles for Canadian initiatives that were to reinforce the United Nations World Program of Action Concerning Disabled Persons. Respect for the 'abilities, integrity, right of choice and dignity of individuals with disabilities . . . in all stages of their lives' was featured among the norms that were to guide Canadian initiatives. The principle of enabling individuals to remain within or close to their families and communities was also to guide the implementation of programs and services.

Along with these standards, social integration and the corresponding de-segregation of persons with disabilities, access to 'fundamental elements of daily life that are generally available in the community', the provision of adequate public resources to facilitate integration, enabling persons with disabilities to participate in public policy-making and social change, and elimination through public education of the 'ignorance, indifference and fear' at the base of discrimination were brought into the conceptual framework. (3) These and similar public policy statements found support in principles entrenched within human rights and other legislation at the provincial and federal levels, and within the Canadian Charter of Rights and Freedoms.

Examples of the strides that have been made to advance the citizenship of people with disabilities in recent years are numerous. They include the recently won right to vote for persons residing in mental health and other specialised institutions, and the precedent-setting-right to integrated education for all children in the province of New Brunswick.

The Eve decision has had a powerful impact in limiting the power of the State and other third parties to perform intrusive medical and other procedures on non-consenting adults who have a disability. These developments, along with federally supported deinstitutionalisation (4), broad and ongoing reviews of guardianship and competency, new employment equity measures, and government implementation of special task forces on disability, are all indicators of progress.

Remaining Problems

Despite these and other steps forward, on many fronts the progress has been limited. The reasons for this are complex and deeply rooted. Perhaps at the head of the list of contributing factors are public attitudes. It is still a fact that people with disabilities tend to be valued as equals only to the degree that they can demonstrate their functional equivalency or sameness with the non-disabled population. Consequently, most are unemployed. Those who are employed usually have part-time, low paying jobs. Most are poor, living substantially below Canada's poverty lines in each of the provinces. (5) A fundamental attitudinal shift towards unconditional valuing, inclusion, and accommodation of people, regardless of their ability or disability, has not yet occurred.

This attitudinal fact of life is still reflected to a large degree in our laws, our social policies, and our social programs.(6) If people with disabilities are generally not regarded as equal citizens in the full sense of the term, they have correspondingly few clear entitlements to social services and other supports. In theory, they may have access to many of the benefits that are guaranteed to non-disabled persons by ordinary civil rights and other laws. Yet they will frequently enjoy access to those benefits only to the degree they are prepared to wrestle for them in the public domain.

These attitudinal and structural facts of life directly shape a variety of concrete responses on the part of society. If individuals have limited value and social entitlements by virtue of their disability, government and non-government organisations have attempted to reverse the situation by implementing a combination of initiatives designed to modify or eliminate the disabilities that produce the corresponding deficiencies in citizenship. The logic behind these efforts has in turn led to an enormous range of discrete programs that attempt to make people less disabled, and therefore less unequal, so they can be more like real citizens.

Many of these initiatives fall into the realms of rehabilitation and therapy, education and primary care. Others fall across several domains(7). They are frequently coloured by the medical model because the medical system has traditionally supplied a ready conceptual framework for thinking about the initiatives, a highly developed administrative framework for organising the initiatives, or a large delivery system for making the initiatives available to persons with disabilities. The medical system has no monopoly in this area, however.

Although these initiatives exhibit the honourable intention of seeking to ameliorate disabling conditions that most citizens would find inconvenient, burdensome, or even painful, they reflect the darker attitudinal and structural facts of life. It is as if the programs have been constructed to serve as a bridge to citizenship, with the disabled person's actual arrival at, and enjoyment of full citizenship, made to depend on his or her participating in the programs and performing according to the standards the programs set. To the degree that individuals are on the bridge, they remain vulnerable.

Positioning on the bridge is often used as a rough measure of the individual's incapacity and consequent vulnerability, and as a rationale for invoking other measures that are designed to ensure adequate insulation and protection during their transition to full citizenship. These measures are frequently custodial in nature, or have a strong custodial dimension. Of course, those who cannot be adequately fixed will remain on the bridge, more or less remotely situated from the mainstream of social life. These people are destined for long term protection and insulation in proportion to the remoteness of their situation from full citizenship.

The way in which public resource allocations are structured amplifies the seriousness of this situation. Responsibility for fixing people with disabilities has fallen usually to specialists and para-professionals who inhabit service delivery structures in the public and private' sectors. Public funding has been fed into these delivery structures to enable staff to fulfil their professional duties, and to allow for the provision of other specialised goods and services. At present, most levels of Canadian government allocate money in this manner to service providers for programs on a per diem basis. People in need of the goods and services delivered through the programs secure access to them through referrals from local ministries on the basis of program vacancies or 'program development'.

Funding for the programs is allocated annually through block or 'global' funding. Along with responsibility for these public resources, a large measure of managerial control has also been passed to service providers. Strong and intelligent managerial control is, after all, considered to be an essential condition for ensuring that public resources are appropriately used. There is, then, an enormous consolidation and exercise of managerial and financial power by those who control the delivery structures that surround people who have disabilities. Acquiescence with this power structure has become a basic requirement that people with disabilities are usually forced to accept in return for the privilege of participating in the de-institutionalisation process that in turn serves as a bridge to citizenship.

In itself, the funding mechanism can seriously militate against citizenship. The problem is compounded by the fact that the structures delivering the benefits of care, therapy, and training are often the same structures through which society delivers a wide range of other goods and services to people with disabilities that are not essentially therapeutic, or care-related, or training-related in nature. Specialised structures thus serve as mechanisms for distributing the fundamental elements of daily living that should be but that are not generally available in the community for persons with disabilities.

Furthermore, those structures are in many cases given power to determine who does and who does not get access to ordinary and specialised goods and services. In this instance, the benefits of citizenship have again been structured so that they must be won by acquiescence with the specialists and para-professionals who dominate the power structures that implement de-procedures.

This situation naturally produces tension and conflict between persons with disabilities and the professional community. Because of the way in which the funding is tied to those delivery structures, it is generally the case that persons with disabilities wishing to leave the structures will not be accompanied out the door by the fundamental elements of daily living to which they would have access if they were to remain.

Their entitlements, and therefore their citizenship, are not portable. The features of these social institutions become more ominous when they are viewed as service industries, machineries, and bureaucracies that operate at arm's length from political institutions that would ordinarily ensure program accountability to the public. The structures are driven, to a large degree, by priorities and agendas that have not been extensively shaped by public or disabled persons' input. That a variety of government departments are often involved in any given program through cross funding, makes it all the more difficult for persons with disabilities to look to any one elected public official who can clearly be held accountable for negative program effects.

The problem of diminished citizenship thus occurs within a context that encourages buck passing between government departments when serious violations of citizenship and other crises do occur. Clearly, wide scale infringement of the ordinary citizenship of persons with disabilities is rendered probable in such conditions. Evidence of widespread infringements can be found in the frequent references by persons with disabilities to the erosion and stripping of their human dignity, their feelings of powerlessness, the unjust fear they are made to feel about raising their voice in complaint, and the feeling of having extremely limited freedom and self-determination. (8)

That global policy documents like the National Health and Welfare's "Health for All" and "Striking a Balance" attempt to deal with these issues again suggests something about the extent of the problems. There are, then, systems and programs that begin with a mandate of serving, restoring, and caring for persons with disabilities, but that inevitably slide into a posture of owning, controlling and overprotecting them. The way in which the programs have been designed to operate almost requires that they slide into that posture.

There is an irony in the present situation. On one hand the public seems to feel little need to assume greater collective responsibility for having demanded that politicians and professionals become more and more adept at assuming control over citizens with disabilities. Not a few citizens are surprised when presented with the resistance of disabled persons and their families to the present system. Many are shocked when exposed to calls for the dismantling of what has become a multi-billion dollar industry. On the other hand, every non-disabled citizen is merely an auto accident away from becoming dependent on the very systems passively condoned for 'others'.

Surely, presently non-disabled citizens would, in the event of such a trauma, desire to retain their right to choose how to live, and to have a strong measure of control over the systems and procedures that should be facilitating this right.

Solutions

The problems that have been outlined are not superficial, and cosmetic solutions will not address the underlying causes. The real issues are not about simple improvement of programs and systems. Neither are they simply about better and more extensive training, for no amount of education will create professionals capable of making and actualising the right decisions for citizens with disabilities or their families.

The basic issues are about the right to citizenship, and about the empowerment of individuals that arises when citizenship is guaranteed. The structural changes that are required can be ,and ought to be, made consistent with constitutional and legal rights that are meant to safeguard the citizenship of all persons, including those with disabilities. This means broadening and securing the basic entitlements that people with disabilities have a right to expect. To some extent this process will involve disengaging entitlement to benefits from variables like functional ability, so that participation in the benefits of citizenship is no longer made to depend on functional ability.

This in turn implies implementation of a model of legal equality quite different from the one that prevails. The Supreme Court in the recent Andrews case extended the concept of equality beyond the formal notion of 'similarly situated should be similarly treated' by recognising that 'every difference in treatment between individuals under the law will not necessarily result in inequality and, as well, that identical treatment may frequently reproduce serious inequality. In fact, the interests of true equality may well require 'differentiation in treatment'. Accordingly, a decisive step in the direction of profound structural change would occur through a more general adoption of the principle that the accommodation of differences by the State and by other agencies, whether the differences are racial, cultural, sexual or functional, is consistent with the notion of equality.

To the extent that people require different goods and services in order to participate fully as citizens, and to the degree that individuals cannot obtain these goods and services because of their disability, employment status, poverty, or some other factor related to disability, the State, directly or through private delivery structures, should ensure the necessary resource distribution. For the State not to do so would be inconsistent with the principle of equality. If these premises are accepted, it follows that the required changes involve diversifying and broadening the distribution of professional and other goods and services, and broadening access and entitlement to these resources, so that those goods and services can more truly become 'fundamental elements' of daily life that are generally available in the community' for persons with disabilities.

Then those goods and services ought to be made available in a manner that is consistent with individual need rather than according to criteria developed for abstract, homogenous groupings of 'the disabled' presumed to have sameness of need. The changes also mean empowering people to make and act on their own choices about how they are going to live and about how they are going to utilise their entitlements. 'Correct' decisions in this area always begin with having the right to make those decisions for oneself.

The changes further require ensuring that people with disabilities have the power and the freedom to take the ordinary risks by which other citizens gauge the measure of their freedom, opportunity and citizenship in a free society.

This emphatically does not mean irresponsibly 'cutting people loose' to face their fate unsupported in a Darwinian universe. It does, however, mean implementing funding and other structures that will 'follow' rather than impede individual decisions, initiative and ordinary risk taking. Until these things occur to a much greater extent, the public discourse about persons with disabilities having equal opportunities for participation and citizenship will remain largely a theoretical discussion.

On a more concrete level, steps need to be taken to shift power from delivery mechanisms back to the people whose citizenship is in jeopardy. This shift implies developing an empowered constituency of consumers whose rights are legally and constitutionally protected. In order that such a consumer driven 'market place' be established, consideration must be given to certain critical principles. One of these that needs to be simply assumed is that a disability does not change a person's human value, nor their presumed right of citizenship, nor their right to health and well being, nor their right to the other benefits of citizenship. Disability simply affects the nature of support a person requires.

It follows that people with disabilities should not be viewed as social units needing to be repaired or restored in order for them to acquire the status of 'real' persons and citizens. They should be viewed as citizens requiring information so they can make informed decisions, assistance with the planning that they author so they can map out their own blueprints for living, and services and supports to which they have a right of access and that they are at liberty to direct in the process of living. If we are serious about embracing people with disabilities as fellow citizens, we must accord them this form of empowerment materially. These considerations imply a need to move beyond traditional notions of extending opportunities for 'involvement' in service planning to people with disabilities. Traditionally, where opportunities for involvement have been extended at all, they have rarely amounted to more than token representation on various boards and planning committees. This has occurred despite everyone's best intentions. Consideration needs therefore to be given to mechanisms that will actuate the right to choose in a realistic, practical manner, and the right to have a strong measure of control over the decision-making process. The mechanism should, however, be something more than a bare, legal guarantee that allows the launching of a legal claim if the right to choose is violated. Making decisions is not simply a legal matter; it is a social and financial matter. The mechanism, then, requires a strong social and financial component.(9)

One component of the mechanism may be some form of individualised funding. This funding model could facilitate individual choices about goods and services. It could also help to ensure people's access to the individually tailored 'packages' of goods and services that they require for equalised opportunities to participate as citizens. Simply defined, individualised funding means funding that is 'attached' to the individual in accordance with his or her needs.

The model is substantially different than conventional models that attach public funding to service delivery structures which in turn redistribute to individuals on a discretionary basis. Although there are obvious advantages to conventional funding models in terms of simplicity for both government and service providers, access to individually tailored goods and services is inherently limited, as are equalised opportunities for participation. In contrast, through individualised funding a service provider's revenue would be comprised, if not entirely, at least substantially, of the sum of his or her 'customers' individual contracts. A further feature of individualised funding is that it can be made portable because there would be no inevitable link between the funding source and service providers. The variable that regulates the link between funding and the service provider is the individual. In the event that the provider cannot satisfy the individual consumer, the consumer retains the option of seeking out and making expenditures for a more preferable service. Establishing a mechanism for portable and individualised funding is in itself, how ever, not a sufficient step towards according functional citizenship to all persons with disabilities. This is because persons actualise their citizenship through the informed choices they make, and funding is not the same as information and counsel.

As the experience behind the Iron Curtain clearly indicates, where opportunities are withheld from people to become more informed as citizens, they feel that their status as citizens is placed at risk. To be a citizen in the full sense of the term in a free democracy, then, implies the existence or creation of opportunities for individuals to become informed. For persons with a disability, access to information and counsel is particularly important with respect to the decision-making that most directly affects them. And because many of those decisions tend to centre around the social services and other supports that are required for participation as full citizens, it follows that people with disabilities, their families, and their friends, ought to have access to a vehicle that can supply the necessary information and advice about those matters. This information and consultative service can be conveniently provided through a conventional social service agency structure.

At the same time. it is important that the information and the consultation be as much attuned to the actual needs of the consumer as possible. This consideration requires that the service be autonomous from the constraints that necessarily inhibit agencies run directly by government. In the latter agencies, government social workers are usually under substantial pressure to bear in mind the various initiatives for which their department is responsible, and to remember the attendant financial constraints that must be factored into decision-making about resource allocations. In turn, that awareness influences how the social worker structures the flow of information and consultation to the client. A similar process is at work where the agency providing information and consultation is also distributing a range of other, usually scarce, goods and services required by persons with disabilities.

Steps can be taken to isolate the agency as much as is realistically possible from these kinds of pressures. The agency can be situated at the regional or community level, and can be made directly accountable to a community board. The agency would have no mandate in the area of direct provision of goods and services such as housing or attendant care staff, and so can avoid the conflicts of interest that prejudice the flow of information and consultation. (10) The constituency represented by the community board can also function as a user group capable of exerting real consumer pressure on the service sector, thus helping to stimulate and regulate the supply of goods and services

Functional citizenship requires not only knowledge about, and funding to purchase, goods and services;It requires actual participation in the benefits of citizenship. Individuals may therefore require some further practical assistance in gaining access to these benefits. To the degree that the benefits can be viewed as goods and services, a linking or mediation function can also be carried out within the agency that will enable the individual to gain access to those elements of daily life that he or she has freely determined through consultation to be necessary. Such an agency has been referred to as a 'fixed point of response'. Employing service 'brokers', the agency can be designed so that it is accessible to all those desiring informational and consultative assistance in planning and/or mediation. Individuals seek access to the agency at their own discretion, not as a precondition of citizenship. Brokers are mandated solely as agents of those choosing to access such assistance. Their role is to facilitate the development of objective, comprehensive planning for acquisition of the critical elements of daily living. The planning can then be used by individuals and their brokers to guide negotiations for these elements with service providers. The outcomes of the negotiations can in turn be translated into legally binding service provision contracts.

It is somewhat surprising that an application of brokerage in the social service sector has not been broadly implemented. Brokers have been enthusiastically utilised in areas as diverse as insurance, commodities, and housing. Legal referral services are not functionally dissimilar, and family physicians play a similar role in helping their patients to become aware of and to gain access to specialised medical goods and services. Nor is the concept of individualised funding foreign to the Canadian experience. Outside the human social service sector universal medical funding allows citizens to change doctors with little inconvenience to either physician or themselves in the pursuit of the treatment that best suits their needs. Some Aboriginal groups have individualised funding mechanisms in place in their movement towards forms of self government. In the social service sector, social assistance programs frequently use an individualised funding approach. Unfortunately, the levels of funding delivered through the latter programs are seldom adequate to address individual needs.

Conclusion

Deep attitudinal and structural factors impede persons with disabilities from participating in the full benefits of citizenship. These are the same factors that act as impediments to a more wide scale distribution of goods and services for persons with disabilities, and that have made it difficult to implement brokerage, individualised funding, and the corresponding changes in program funding and design on a large scale.

If fundamental structural changes are in order, it is also true that correct implementation of individualised funding and service brokerage could have a dramatic impact on the present inertia. In this sense, the implementation of brokerage and individualised funding could act as powerful catalysts for social change. For those who are serious about enabling persons with disabilities to move off the bridge into full citizenship, carrying through on the necessary social changes is an inescapable responsibility.

Footnotes

1 cf. House of Commons. Canada. Report of the Special Committee on the Disabled and the Handicapped, 'Obstacles', Ottawa. Supply and Services Canada. 1981, p. 18.

2 Ibid., p. 4.

3 ' Declaration on the Decade of Disabled Persons, in Canada, House of Commons, Initial Report of the Sub-Committee on the Disabled and the Handicapped of the Standing Committee on Communications and Culture, 'Challenge: Putting our. House in Order', Ottawa, 1987.

4 Address of Minister of Health and Welfare, at the Annual General Convention of the Canadian Association for Community Living, Regina, 1988.

5 cf. The G. Allan Roeher Institute, Income Inse curity: The Disability Income System in Canada, Downsview, The G. Allan Roeher Institute, 1988, pp. 5-7 and table 5. See also Secretary of State, Profile of Disabled Persons in Canada, Ottawa, 1986; Statistics Canada, The Health and Activity Limitation Survey, the Daily, 31 May 1988, p. 10.

6 i.e. government

7 i.e. for profit and non-profit

8 cf. Patrick Worth, 'President's Message', in National Organizer, No. 20. February 1990, Downsview, The National People First Project, p. 4.; The G. Allan Roeher Institute, The Power of Positive Linking: How Families can Empower People Who have a Mental Handicap through Mutual Support Groups, Downsview, The G. Allan Roeher Institute, 1989; the Proceedings of the Disabled Native Persons' Think Tank Cornwall, Ontario. 1988; Carla McKague, (an interview with), 'Out of the Closet', in People Have to Be Listened To, Winnipeg, COPOH, 1989, pp. 3-7.

9 Marcia H. Rious, Deinstitutionalization and Community Living: Towards a New Model of Legal Entitlement, unpublished paper developed for symposia in France and Switzerland, June 1989; pp. 11-14.

10 Brian Salisbury, Jo Dickey and Cameron Crawford, Service Brokerage: Individual Empowerment and Social Service Accountability, Downsview, The G Allan Roeher Institute.