Enabling people with intellectual disabilities to lead fuller lives : comparing national strategies for reform

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Introduction: towards a Framework for Comparative Analysis

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This collection of papers comes from contributions to the 10th World Congress of the International Association for the Scientific Study of Intellectual Disability (IASSID) in Helsinki, July 1996. A key theme of the Congress was "Global Problems - Local Approaches," providing a unique opportunity to compare experiences across national boundaries to better achieve common goals.

In all our countries, improving the lives of people with intellectual disabilities starts with individuals—understanding their situation, wishes, the support they need, and how it can be provided. We're also asking how to ensure a better life is available to everyone with an intellectual disability, not just a few.

Drawing on global experiences, these papers address the question of how to establish and implement national strategies for reform. The five papers offer first-hand accounts of what is currently happening in Canada, Australia, Sweden, the Slovak Republic, and the Americas (primarily less affluent countries).

The selection of these countries was neither systematic nor random. A more comprehensive comparative study of national progress could draw on UN monitoring of the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the UN General Assembly on December 20, 1993. Our approach was more selective and modest. Through the international connections of the King's Fund, I have worked with advocacy groups in Australia, Canada, and Slovakia. Knowing people from these countries attending IASSID, we agreed to present a symposium comparing our national experiences.

At IASSID, we heard many excellent contributions, but two in particular complemented our analysis: Sweden, which has long focused on promoting equity and participation, and the Americas (a coalition of less developed countries in Central and South America and the Caribbean), starting from different social and economic circumstances.

This selection of countries offered a range of perspectives on reform. Among our six contributors, one leads the reform unit in her country's Social Affairs Ministry, two lead national advocacy organizations (initially based on voluntary associations of parents of people with intellectual disabilities), and three are active in local movements for change. They bring different kinds of professional expertise, and three also have family members with severe intellectual disabilities.

Comparing our different experiences, we suggest that there are global problems, meaning that similar challenges exist in different countries. We will identify many common elements in the strategies needed to address these challenges. However, we also argue that these elements must be adapted to each country's unique historical situation, political system, and culture, meaning every country must create its own distinctive approach to maximizing progress.

We acknowledge that methods for comparative analysis at this level of complexity are not well developed. Our hope is that these papers provide insightful stories that reform leaders elsewhere can reflect upon and that they also stimulate further "action learning," extending and deepening this analysis through wider dialogue. With this goal in mind, the King's Fund agreed to publish this collection more widely in this form.

Common Aspirations

In the 30 years since IASSID was founded, most of our countries have made significant progress. However, this sense of advancement, even in the most "developed" countries, partly stems from the very low starting point from which this period of change began. In all our countries, there has been a long history of discrimination and exclusion of people with intellectual disabilities. Until recently, and still in some places, people had only two options: a lifetime of support from parents or care in an institution. In many countries, it is also only recently that the right to a full education through public provision has been recognized—and often this still means some form of segregated education.

Nevertheless, the past two decades have seen increasing convergence in the aspirations we hold for people with intellectual disabilities. Rooted in the simple ethical principle that we should treat others as we would wish to be treated, these aspirations have been expressed in different ways in different places—normalization in Scandinavia, community living in Canada, and an ordinary life in Britain—but with common goals.

However, nowhere have these aspirations been fully realized. In all the countries we are familiar with, large numbers of people are still deprived of opportunities that most of us take for granted. Even under favorable conditions, achieving real change for the majority of people has proven to be both a long and uneven process, with periods of progress followed by setbacks. For many older parents of people with intellectual disabilities, a lifetime of effort has not been enough.

I have summarized this situation simply in Box 2, which illustrates how most people's experiences lag behind what is being achieved in the best areas, and both fall short of the rising expectations of people with intellectual disabilities and their supporters, as modern aspirations for a fuller life are taken seriously.

Box 1 contains the following text:
Title: Common Aspirations.
A full life for people with intellectual disabilities means:
- Growing up in families
- Learning with other children
- Living in ordinary flats and houses in the neighbourhood
- Having opportunities for real work
- Enjoying life with friends
- Making choices for oneself
- Being accepted as citizens
- And receiving the support necessary to achieve all this

Box 2 contains a line graph titled: Recent trends in achieving fuller lives.
The vertical Y axis is titled ‘Performance’.
The horizontal X axis is titled ‘Time’.

There are three lines on the graph:

1. The top line is titled ‘People’s aspirations’ and is a wavy line showing an upwards trend.
2. The middle line is titled ‘Local innovation and best practice’ and is a wavy line showing an upwards trend.
3. The bottom line is titled ‘Most people’s experience’ and is a wavy but mostly straight line that is much lower on the ‘performance’ axis than the other two.

End of description of Box 1.

National strategies for reform

So what is needed to close the gap between our aspirations and most peoples' experience? Well, of course, there are a large number of contributory factors and a broad summary' has many overlapping elements. (See Box 3).

Box 3 is titled "Seven overlapping elements in national strategies for reform" and contains the following bullet points:

1. Advocacy by people with intellectual disabilities, their families, and friends
2. Individualized planning that offers each person the opportunities and support required to meet their needs flexibly
3. Partnerships among local leaders—people, families, professionals—in campaigning for rights and services
4. Professional leadership in service design and organization, using the best of what we are learning internationally about supporting community living and ending segregation
5. Public participation in achieving social integration by opening up opportunities and removing barriers to inclusion
6. Government policies based on modern principles that promote a full life for everyone with disabilities
7. Legal reform that establishes the rights of people to full citizenship in a multicultural society.

End of description of Box 3.

In presenting these elements as a list however, I am oversimplifying what we know from our experience is actually involved in achieving nationwide changes. What we are describing is more like a social movement in which people with different interests and working at different levels combine together in a lengthy struggle to make a real difference in people's lives. Those involved in this struggle need to include people with intellectual disabilities, families and professionals in our field; but they also need to include people in the public authorities, elected politicians and interested citizens. It may also be necessary for allies in these coalitions for reform to take on different roles - for example, some working 'within the system' to make small steps forward; others 'causing trouble' from outside by speaking out about discrimination and abuse. In each country this is necessarily a dynamic and lengthy process in which the trajectories of change show many twists and turns (as I have tried to represent in Box 4).

Box 4 is titled "Strategies to achieve nationwide changes". It consists of a number of circles with arrows between them. Each circle has a caption and an illustration. The circles are loosely arranged from National action at the top to local action, then to individual action at the bottom. The circles are linked with a multitude of arrows to illustrate the twists and turns. The circles from top left to bottom right are:

- People seeking better opportunities
- Public authorities providing opportunities and services providing support to people
- Society welcoming all its members
- Campaigning together
- Influencing national policies
- Establishing rights
- People, families and professionals sharing a vision of a better future
- Building public support
- Individuals speaking for themselves
- Building circles (for support)
- Demonstrating good opportunities and services

The arrows all lead to a final circle containing the words: “Vision: a full life for everyone”. End of description of Box 4.

Moreover while there are necessarily similarities in both the elements and trajectories of large-scale change, these strategies also have to adapt to significant differences between national situations. See Box 5.

Box 5 is titled “Aspects of national differentiation”. It contains the following bullet points:

- Constitutional frameworks, e.g. the relative emphasis on legally defined rights vs. state assessed needs.
- Political ideologies, e.g. the relative emphasis on self-help vs. collective provision.
- Economic development, e.g. the balance between urban and rural communities and relative affluence.
- Professional leadership, e.g. the relative strength of medical, social work or educational dominance.
- Scientific traditions, e.g. the relative emphasis on classification, development or environment in
- research and intervention.
- Culture and history, e.g. the meaning given to disability, the relative extent of voluntary
- association and the nature of recent opportunities for social change.

End of description of Box 5.

Making comparisons; learning from each other

The common aspirations identified in Box 1 and the characteristics of national situations and change strategies identified in Boxes 3, 4, and 5 provide a framework for examining the five stories that follow. Starting from the broad national context, we can see, for example, that the five countries differ in the extent to which a written constitution includes amendments outlawing discrimination and giving explicit rights to disabled people. In Canada, the Charter of Rights and Freedoms, combined with a strong advocacy movement, has been an important lever in strengthening public attitudes toward equality and promoting mainstream reform. In Slovakia, the significance of constitutional change since the Velvet Revolution is still emerging.

These countries clearly differ in both the extent of economic development and the political response to global economic pressures, which may change over time. For instance, the changing political landscape in Australia over the past decade has seen left-leaning governments, with a bias toward a rights agenda and collective provision, replaced by right-leaning governments emphasizing consumerism, self-help, and the superiority of market solutions. Campaigners have had to adapt their arguments and tactics to maintain political support for community living. In the poorer countries of the Americas, which are particularly dependent on transnational public and private agencies for developmental investment, it has been crucial for human rights programs to demonstrate the relevance of disability reform to transnational agendas for economic development.

Against these diverse backgrounds, many elements of national strategies need to be considered. The papers focus on a few that seem especially important in generating social movements for reform, showing how these take shape in different contexts. All emphasize the significance of legal reform to establish the rights of people to full citizenship, whether this is constitutionally expressed, as in Canada; through specific laws, as in Sweden; or by initially seeking widespread political and social commitment to bold aspirations, as in the Declaration of Managua for the Americas.

However, even when successful, legal reform is a weak instrument unless complemented by widespread commitment to a vision of social integration, i.e., how people's lives should be different, expressed in clear national policies and supported by local communities. In Sweden, for instance, new opportunities may only benefit individuals who are strong advocates or who have strong advocates supporting them. In Australia, past gains have proven fragile where people lack effective support networks. In Slovakia, after 40 years when arguably the entire population was excluded from democratic participation, there is anxiety that some of this history may be incorporated into how otherwise promising developments are implemented.

The third common theme is the importance of developing effective advocacy by people with intellectual disabilities, their families, and friends, and mobilizing this advocacy at different levels within national systems of policymaking, management, and service delivery to initiate and sustain the momentum for reform over the lengthy periods required. Each paper illustrates some aspect of this challenge relevant to its specific country.

We offer these five stories from our personal experiences in different parts of the world as a contribution to help us all reflect on the optimal strategies for progress in our own national situations.

Canada: Constitutional Rights and Advocacy for Social Change

By Margaret Brown

Introduction

Leading a full life for a person with an intellectual disability is easier said than done in most countries. In Canada, the extent to which a person can live a full life depends on several factors: the legal structures in place to mandate full participation in community life, the capability of support services to provide the necessary range of supports, the general societal attitude toward people with intellectual disabilities and the willingness to include all members of society equally, and the strength of advocacy organizations such as People First (comprised of people with intellectual disabilities) and the Canadian Association for Community Living (comprised of family members, friends, and interested professionals) to promote and facilitate necessary changes in structures and services. Within a broader framework of human rights and change, this paper examines how each of these components supports people with intellectual disabilities in their quest to live full lives as meaningful participants in Canadian communities.

Legal Structures

As early as 1867, the first Secretary of State of the Dominion of Canada stated in the House of Commons, "We must respect everybody's rights..." When introducing the Canadian Bill of Rights in 1960, the Prime Minister declared, "No Canadian can give sanction to bigotry. That is the essence, one of the major portions of this Bill of Rights." In 1982, that early commitment to rejecting discrimination and guaranteeing human rights was significantly strengthened with the proclamation of a new Constitution Act containing the Charter of Rights and Freedoms.

The Charter is a legal document that clearly outlines the rights and responsibilities of all citizens and envisions a future offering all Canadians pride in themselves, confidence in themselves, and acceptance of one another (Crombie, 1991). The values expressed in the Charter were not new to Canadians but have, over the years, served as the foundation for an open and tolerant society that has evolved peacefully and democratically.

Three sections of the Charter of Rights and Freedoms are particularly relevant to disability-related issues, stated as follows:

Section 2: Everyone has the following fundamental freedoms:
a) freedom of conscience and religion;
b) freedom of thought, belief, opinion, and expression, including freedom of the press and other media of communication;
c) freedom of peaceful assembly; and
d) freedom of association.

Section 7: Everyone has the right to life, liberty, and security of the person, and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

Section 15: Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination, particularly without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.

Each of the three sections cited above has been used in both provincial and federal court cases. Freedom of association (Section 2d) has supported cases like a person wanting to move from an institution to the community but being prevented due to an inability to communicate verbally, and cases where a child was denied access to a local community school because of an intellectual disability. The right to life, liberty, and security of the person (Section 7) has been invoked in cases against actions like murder or so-called mercy killing of a child with a disability, and to support cases against aversive treatments like electric shock. The protection against discrimination based on mental or physical disability (Section 15) has been used in a wide range of cases, such as denial of access to public transportation, inclusive schooling, and community housing.

The Charter not only applies to the government of Canada but also to "the legislature and government of each province in respect of all matters within the authority of the legislature of each province" (Section 32b). The Charter's influence can be seen in changes in provincial legislation, as all provinces now promote inclusion in their education laws and policies. Most provinces are also shifting toward more community-based services in health care and social services. Government documents are increasingly available in alternative formats (e.g., audiotape, braille, large print, simple language) to ensure access for people with disabilities.

Support Service Structures

In 1991, the federal government implemented a National Strategy for the Integration of Persons with Disabilities, which was a commitment to people with disabilities aimed at achieving equality and inclusiveness. However, upon reviewing the National Strategy at the end of 1995, it became evident that the original plan lacked a clear vision or commitment from the highest levels of government. Additionally, important government departments, particularly finance, were not involved at all. Although $159 million was spent on the National Strategy between 1991 and 1996 and several worthwhile projects were implemented, weaknesses in the development, coordination, and communication of the National Strategy led to the conclusion that the overall approach was not sufficiently strategic to produce the desired results.

The December 1995 report of the Standing Committee on Human Rights and Status of Disabled Persons, entitled “The Grand Design: Achieving the ‘Open House' Vision” (Pagtakhan, 1995), proposed a series of recommendations to the federal government.

1. With regard to people with disabilities, the federal government should continue to provide visible leadership in developing policies and programs in areas that fall within its jurisdiction and assist the provinces and territories in areas where jurisdiction is shared. People with disabilities should be involved in setting priorities, advising on policy, and evaluating the success or failure of programs.

2. The federal government should negotiate with the provinces to ensure protection for people with disabilities, particularly regarding funding for disability-related income programs, supports, and services.

3. All employability measures that receive federal funding should make adequate and comprehensive provisions for the requirements of people with disabilities, especially concerning disability-related accommodations and supports and services.

4. The government should review the parts of the income tax system that impact people with disabilities and provide better methods for considering both the actual costs of a disabling condition and the specific expenses incurred by people with disabilities.

5. A national standard for motor coach accessibility should be established to ensure that all new intercity buses are accessible for people with disabilities.

6. A comprehensive review of disability policies and programs in Canada should be undertaken to improve the funding and delivery of disability-related supports and services, enhance the disability income system, and eliminate disincentives to employment.

Some professionals are also adding their voices to these discussions. For example, at the Canadian Society for Studies in Education conference in May 1996, the Canadian Association of Education Psychologists unanimously approved a recommendation to the federal government that the department concerned with the Status of Disabled Persons Secretariat be maintained and that funding for research on inclusive education practices be prioritized. Inclusive education in Canada is at a critical stage of development, with all provinces at some stage of implementing inclusive education practices in their schools. Researchers and scholars in this field need the resources to support the professional development of practicing teachers, and teacher training programs must be able to refocus their curricula to prepare new teachers for inclusive classrooms.

General Societal Attitude

It would be difficult to find any Canadian who is unfamiliar with at least the general principles of equality rights for people with disabilities. For the most part, the general attitude toward equality rights is favorable. It seems that Canadians are very willing to accept the idea of equality but have given insufficient thought to how this idea gets translated into daily practice. In the past 25 years, there have been many examples of situations when someone, or some group, would say, “of course people with intellectual disabilities should live in the community the same as anyone else... but not on my street, or not in my restaurant, or not in my child's classroom, or not on board the school bus, not as my employee,” and so on. Fortunately, the extent of this mixed view has much reduced in recent years, but it has not yet completely disappeared.

However, a new barrier to full inclusion in the community seems to be looming on the horizon. Like many countries around the world, Canada is experiencing financial constraints related to debt management and involvement in an increasingly competitive global economy, resulting in a rise in unemployment and a reduction in financing available for health, education, and social services programs despite increases in taxation. A national study of teacher attitudes towards the inclusion of students with disabilities indicated that both elementary and high school teachers supported the idea of inclusive schooling but had serious concerns about the level of support and training they were or would be receiving to enable them to do the job well. There also appears to be a growing suspicion among the teachers that the government’s relatively new interest in inclusive education is motivated more by an attempt to reduce education costs than by an interest in improving education for all students through the reallocation of existing funds.

Beyond the school years, people with intellectual disabilities face systemic discrimination and entrenched attitudes throughout the range of programs, support services, and lending authorities. Finding employment continues to be fraught with difficulties. For example, a person must be on social financial assistance to receive disability-related supports. To acquire income and other types of supports, an individual often must declare themselves unemployable. Yet to enter some training programs, that same person has to prove that they are “independently employable.” This is obviously an impossible situation. To complicate matters further, the current Canadian economic difficulties with high unemployment rates in the overall population cause greater reluctance on the part of employers to even consider hiring a person with a disability. While most would still agree that people with disabilities should have work in the community, the response becomes, “but not until the unemployment rates improve.” It seems we still lack a certain willingness to include all members of society equally.

Strength of Advocacy Organisations

The Canadian Association for Community Living is the national association that advocates for and on behalf of people with intellectual disabilities. It is a federation of 10 provincial and 2 territorial associations made up of 400 local associations. Its 40,000 members include individuals labelled as having an intellectual disability, parents, families, professionals, and advocates. Through its membership at local, provincial, and national levels, the association has had, and continues to have, significant influence on social policy.

Largely through provincial advocacy, all provinces now have legislation supporting inclusive schooling. Local advocates work hard to see that the legislation is put into action in local schools. At the national level, the association is promoting social security reform for adults who have an intellectual disability. With the present global pressure to embrace a free-market philosophy to foster economic growth, there is a risk of losing equity and seeing a further marginalization of disadvantaged people in society. The cost of inequity, in the form of increased welfare dependency, inactive labour force, instability, and disenfranchised populations, acts to stall economic growth. Estimates indicate that it costs the Canadian economy $4.6 billion a year to continue excluding people with disabilities from participating in the economic and social life of their communities. The association's position is that real economic gains for people with intellectual disabilities will only come from comprehensive reform of the social security system.

The association takes every available opportunity to educate, inform, and influence legislators and policymakers and to remind them of our constitutional obligation of non-discrimination based on intellectual disability.

People First of Canada is a national advocacy organization of individuals labelled as having an intellectual disability who promote equal rights for people with disabilities. Started 10 years ago with the help of the Canadian Association for Community Living, People First is now its own organization engaging in public awareness and education campaigns, preparing and presenting briefs to government regarding policy issues, serving as witnesses in legal cases involving equality rights, and participating on the self-advocate advisory committee to the association. As Paul Young, President of People First of Canada, said in his address to the closing plenary of the 1995 CACL National Conference,

“The community must understand that we are part of the community, that we want to be part of the community, that we have a right to be part of the community. We have lots to contribute to society. We are of value and we will not sit down and be quiet. We are not preaching anymore. We’re negotiating, we’re talking, we’re exchanging ideas, and that’s the key. The challenge for all of us is to keep that going so we will belong in the community in an equal setting.”

Formal advocacy is beginning to take shape in Canada as well. With the growing concern that many people are considered vulnerable due to a significant disability or illness, and have difficulty finding out about their rights, exercising them, or simply expressing and acting on their own wishes, groups such as People First of Canada and the Ontario Advocacy Coalition have persuaded one provincial government (Ontario) to enact the Consent to Treatment Act and the Substitute Decisions Act. The new law provides for a province-wide system of non-legal advocacy overseen by the province’s Advocacy Commission. Advocates do not have a mandate to make decisions for the people they are supporting unless the person is unable to provide instructions to the advocate and the person's health or safety is at risk of serious harm. Advocates are to assist individuals in arriving at their own decisions by providing information and support, and to work collaboratively with the family and friends of the vulnerable individual to promote that person's well-being, if, that is, the individual does not object. While not perfect, this law seems to be a step in the right direction.

Summary

Most worthwhile and lasting changes come about because of an identified need, careful planning, clear strategies, building on existing strengths, and patient and persistent nurturing of the growth process. Canada is fortunate to already have in place many of the elements necessary to facilitate change. The general attitude of acceptance of difference and equality has long historical roots - we are after all a very diverse population comprised largely of immigrants from other countries. Apart from a now rather small aboriginal population, we and our families have all come from many different backgrounds.

The Charter of Rights and Freedoms provides definition and strength to the meaning of equality rights. The manner in which equality rights are translated into support service structures has grown up over many years with little vision, planning or co-ordination of activities. Much work needs to be done to improve this cumbersome and inefficient system so that all people with intellectual disabilities can expect, and receive, a full life in the community, with public schooling, community recreation, stable incomes, meaningful employment, community housing, and so on, similar to the expectations of any citizen.

The pressing economic hardship faced by many countries, including Canada, places a strain on the positive attitudes generally found in most sectors of the community. However, the strength of the advocacy associations in this country is impressive as seen by the many important improvements in legislation, policy and practice that have been achieved in the last 20 years. But there is no time to rest on our laurels. The growing power of self-advocates is a welcome addition to the community, and along with CACL, must focus attention on protecting what we have already achieved, finding opportunities to share and learn from people in other countries around the world, continuing to press forward to the ultimate goal of a full life in a welcoming community for every citizen. It surely is worth the struggle.

References

1. Berthiaume, P. (1995). Letter to the Prime Minister of Canada. North York, ON: Canadian Association for Community Living.
2. Bunch, G., Brown, M., & Lupart, J. (1996, June). Resistance and acceptance: Educator attitudes toward students with disabilities in inclusive classrooms. Paper presented at the Canadian Society for the Study of Education Conference. Brock University, St. Catherine's, ON.
3. Canadian Association for Community Living. (1996). Everybody's business: Self-employment issues and opportunities for people with a disability. North York, ON: Author.
4. Canadian Association for Community Living. (March, 1996). A new federal role in employment: What will it mean for people who have a disability? Submission to the Parliamentary Committee on Human Resources Development. North York, ON: Author.
5. Canadian Association for Community Living. (November, 1995). Submission to the Financial Committee Pre-Budget Consultations: Preliminary proposal for a framework and terms of reference for a social audit of the Canada Health and Social Transfer. North York, ON: Author.
6. Canadian Association for Community Living. (May, 1995). A submission to the Finance Committee Re: Bill C-76. North York, ON: Author.
7. Canadian Association for Community Living. (November, 1994). The costs of inequity: Submission to the Finance Committee. North York, ON: Author.

8. Crawford, C. (1995). Advocacy in Ontario: Supporting people's rights to control their own lives. Abilities, 22, 50-51.
9. Crombie, D. (1991). Preface. The Charter of Rights and Freedoms: A Guide for Canadians (p. I.). Government of Canada, Communications Branch. Multiculturalism & Citizenship Canada, Ottawa, K1A 0M5.
10. Government of Canada. (1995). Ministerial Council on Social Policy and Reform and Renewal: Report to Premiers. Ottawa, ON: Author.
11. Pagtakhan, R. (Chair.) (1995). The grand design: Achieving the “Open House” vision. Report on the Standing Committee on Human Rights and the Status of Disabled Persons. Ottawa, ON: Canada Communications Group - Publishing, Public Works and Government Services Canada.

Young, P. (1996). We will not sit down and be quiet. Entourage, 9(2), 13.

Australia: Advocacy, Deinstitutionalisation and Changing Ideologies

By Kelley Johnson

Introduction

Over the past fifteen years in Australia there has been an increasing commitment at a Commonwealth (Federal) and State level to strategies which assist people with intellectual disabilities to lead fuller lives. However this commitment has proved problematic in practice. The two stories told in this paper focus on developments in Victoria, one of these States, although similar developments have occurred elsewhere in Australia. They explore the difficulties of translating a theoretical commitment into policy and practice and discuss some reasons for these difficulties. The paper presents the argument that in Victoria two different discourses have been operating in the development of strategies designed to assist people with intellectual disabilities to lead fuller lives.

The first of these is a rights discourse. The second is a customer discourse. Both of these discourses are informed and driven by wider social and economic forces in the community. By discourse. I mean fundamental ways of thinking and acting which relate to wider political ideologies (or expressed more technically ''ways of constituting knowledge together with social practices, forms of subjectivity which inhere in such knowledges and the power relations between them" Weedon, 1987, p. 108)

Story 1. The Rights Discourse

Throughout the 1980s a number of trends combined to lead to a profound change in the way people with intellectual disabilities were regarded in Victoria.
These included:

- information and ideas coming from overseas which emphasised the importance of people with intellectual disabilities as citizens with rights and criticised the quality of sendees available to them,
- a strong parent advocacy movement which demanded a voice in shaping services for people with intellectual disabilities and lobbied Government to effect change.
- an increasing emphasis on the rights of minority groups in Australia. For example the Aboriginal land rights movement and the multicultural nature of the society led to increasing awareness of the needs and political rights of minority groups.
- a Labour Government which had obtained office with a commitment to social justice issues (Victorian Government, 1987).
- a series of reports in the early 1980s which had documented the need for changes in services for people with intellectual disabilities (Cocks, 1982; Cocks, 1985).

In Australian terms it was time for people with intellectual disabilities to have a ‘fair go'. From being seen as primarily sick or as in need of care and protection they were seen increasingly as citizens with rights. The thrust of Government policies was to ensure that people with intellectual disabilities had such rights and that these were to be safeguarded by a range of advocacy and accountability mechanisms. The consequences of this emphasis on rights can be seen in specific legislation, new processes of policy development, new emphases given to advocacy and an increasing commitment to deinstitutionalisation.

Legislation

In 1986 the Intellectually Disabled Persons Services Act (Intellectually Disabled Persons Services Act, 1986) was passed in Victoria. The Act clearly identified people with intellectual disabilities as citizens with rights. The first of its set of fourteen principles stated that:

“Intellectually disabled persons have the same right as other members of the community to services which support a reasonable quality of life.” (Intellectually Disabled Persons Services Act, 1986, Section 5).

It stressed the importance of maximising physical and social integration, utilising generic rather than specialist services, ensuring that one organisation did not have total control over an individual’s life and encouraging consumer participation (Intellectually Disabled Persons Services Act, 1986).

Following this Act came other national legislation: the Disability Services Act (1986) and the Disability Discrimination Act (1992) designed to protect the rights of people with disabilities and to prevent discrimination against them.

Policy and Service Development

Following the enactment of the Intellectually Disabled Persons Services Act (1986) a Ten Year Plan was developed by consultants employed by the State Government (Naufal, 1988; Neilson Associates, 1988(a); Neilson Associates, 1988(b); Neilson Associates, 1987(a); Neilson Associates, 1987(b)). Over a two year period an intensive review of services for people with intellectual disabilities was documented and a State wide consultation was held with advocacy groups, parents and government and nongovernment agencies.

The result of this was a Ten Year Plan which was highly critical of institutional living for people with intellectual disabilities and which argued strongly for a transition from institutional life into community based services. The Ten Year Plan was translated by the State Government into a Three Year Plan which came into effect in 1989 (Community Services Victoria, 1989). This Plan set objectives for services over the following three years. It involved an increased commitment by Government to Disability Services of $26.5 million to increase community services such as employment, day programs and residential services. Target numbers were established for new services and there was a focus on people with intellectual disabilities living with older parents and on people residing in institutions.

Both the Neilson Report and the State Plan used the language of rights to establish a rationale for their objectives. There was an air of optimism in both steps which was reflected in the promised injections of Government funding into the intellectual disability area and in the development of new services.

Further during the 1980s a strong network of community' managed residential and support services developed across the State. While sometimes criticised as inefficient these services were often innovative in their approach and worked to include people with intellectual disabilities in their management (O’Brien and Johnson, 1987; O’Brien and Johnson, 1988; O’Brien and Johnson, 1993).

Advocacy

Since the early 1970s there had been a strong parent advocacy voice in Victoria. During the 1980s this became more powerful and people with intellectual disabilities began to be heard directly through their self advocacy organisations. These voices were given added strength by a Government recognition of the importance of advocacy in all its forms. Five advocacy organisations including two self advocacy groups, were funded by the Government. These carried out research, publicised issues affecting their constituents and had a place on Government policy making bodies.

As part of the Government emphasis on rights an independent office (the Public Advocate) and Guardianship and Administration Board were established by law to advocate for people with disabilities, to safeguard their rights and to provide assistance in the form of guardians and administrators for those people who found it difficult to make life decisions (Guardianship and Administration Board Act, 1987).

The Office of the Public Advocate was a strong voice in arguing for systemic change in disability services and policies. It produced annual reports which were tabled in Parliament and attracted the attention of the Press. These reports were highly critical of institutional life for people with intellectual disabilities and were an important ingredient in the movement towards deinstitutionalisation (see for example: Community' Visitors, 1990; Office of the Public Advocate, 1990). The Public Advocate's Office stressed the importance of Government accountability for the services it provided, documented incidents of abuse and poor quality' services. It also helped to educate the public about issues affecting people with intellectual disabilities.

Deinstitutionalisation

During the 1980s there was an increasing emphasis on the need for people with intellectual disabilities to live in the community. The Government made commitments to closing institutions and gradually some of the worst and largest institutions were closed. There appeared to be general agreement among Government representatives and the State bureaucracy that large institutions were not fit places for people to live and a number of reports from the Office of the Public Advocate and other Government appointed investigators (see for example Wallace, 1991) supported this stance. The closure process was slow and difficult. But by 1992 four large institutions had closed their doors.

Accompanying the closure of large institutions were policies which severely restricted the admission of people with intellectual disabilities to large scale congregate care and focussed on the development of community based services, which, however remained inadequate to meet the demand from individuals and their families.

Story 2. Care and Protection and the Customer Discourse

The 1990s heralded the emergence of a new discourse in relation to people with intellectual disabilities. Some of the factors underlying this change appear to be:

- A change to a more conservative Government in the State.
- A continuing economic recession which impacted on Government spending on welfare related issues.
- Recognition by Government of the costs involved in deinstitutionalisation and in its focus on rights.
- An increasing trend away from a commitment to social justice issues by the public.
- The Commonwealth State Disability' Agreement which made States and Territories responsible for accommodation and related services and the Commonwealth responsible for employment services. Under the Agreement advocacy and research were joint responsibilities. The Commonwealth no longer had direct input into residential or support services (Yeatman, 1996).

The resulting change has been demonstrated in the language and emphasis of policies and the ways in which services have been developed. A new Government policy paper prepared in 1992 (Health and Community Services, 1992) established the new focus clearly by its very title: Community Services To Care and Protect. This could have been a theme for the 1960s and 1970s but it was at odds with the strong rights emphasis of the 1980s. Along with this new emphasis came one which strongly emphasised individualism and the customer ethic.

So the new policy stated:
“Funds will be directed to providing services for individuals rather than maintaining a complex and dominating bureaucratic system. The aim will be to empower individuals and their families and provide them with greater control over their lives.”

(Health and Community Services, 1992. p.3)

At first inspection these words are consistent with the aims of the 1980s which sought to empower people with disabilities. However an examination of legislation, policy and service provision, advocacy and deinstitutionalisation in the 1990s demonstrates how the language of rights has been reinterpreted through the new customer discourse.

Legislation.

In 1994 the State Government reviewed the Intellectually Disabled Persons Services Act and changed some of its provisions. While much of the Act remained the same there were interesting and significant changes. New language was being used: terms such as ‘contracted service provider' appeared in the definitions in the Act. New sections were also added to define and clarify issues relating to the contracting out of services. These changes reflected an increasing trend by the Government to relinquish direct State services and to move such services to the non Government sector.

While the principles underlying the Act remained much the same a significant additional one was added emphasising the role of families as key care givers. The families of intellectually disabled persons have an important role to play in supporting and encouraging the development of a family member with an intellectual disability. (Amendments to the Intellectually Disabled Persons Services Act, 1995).

While this was rationalised as a recognition of the importance of family life for people with intellectual disabilities - something with which few people advocating deinstitutionalisation or committed to rights would disagree - it has been accompanied by moves suggesting that families should take on more economic and caring responsibilities for adult members (Star et al. 1995(a)).

Policy and Service Development

The development of a customer discourse is also reflected in the process and content of policy and service development during the 1990s. For example a draft State Plan recently prepared by the State Government received no community discussion and minimal consultation with advocacy groups. So there is now much more a top-down approach to such developments.

There has been a movement towards a “customer" or “user pays” philosophy. So a Ministerial Task Force which reviewed intellectual disability services in 1995 recommended that:
“The Government encourage strategies which allow clients, their families and the community to make some voluntary contribution towards services, should they wish to do so. (Intellectual Disability Services Task Force, 1995 p. 101).

In practice the voluntary nature of this recommendation has in some instances been translated into families paying for additional services for their relatives, for example the costs of using the gymnasium or other leisure activities for people living at one institution in Melbourne are now borne by families. Further, recent research carried out by one advocacy organisation has suggested that there is:
“an alarming trend by Health and Community Services towards a more aggressive application of the policies of families maintaining their relatives at home indefinitely.” (Star. 1995 (b). p.4)

The Ten Year Plan has not been an explicit ingredient in Government policy since 1989. And since 1992 there has been no State Plan to set goals on a three year basis at all.

In 1994 the State Government established an Intellectual Disabilities Task Force to report on the situation of intellectual disabilities. The Report was critical of the current level of services and stated:
“The Task Force believes that a range of decisions are required of the State Government in order to restore confidence in the system of intellectual disability services.” (Intellectual Disability Services Task Force, 1995, p.I).

The Report expressed concern at the level of unmet need in the community, at the lack of day services and at the long waiting lists for residential and day programs. It documented the ‘savings’ (sic) made in disability services as $47.35 million since 1991/2.

Advocacy

The Government now takes the view that advocacy is a luxury with little in the way of measurable outcomes. This has been reflected in Government cuts to advocacy groups across the State. All self-advocacy groups have been defunded. Only one organisation which represents all adult people with intellectual disabilities has received government funding. This has had a number of effects. It has robbed the Government and people with intellectual disabilities of a diversity of voices with which to argue different points of view. It has split the advocacy movement into funded and defunded groups. The Office of the Public Advocate received cuts to its services, reducing its capacity to undertake systemic advocacy.

Deinstitutionalisation.

The Government commitment to deinstitutionalisation has undergone a profound shift. While it states that it remains committed to life in the community for the majority of people with intellectual disabilities its policies and their implementation indicate that the theme of ‘care and protection' is being used as a rationalisation for the refurbishment of large institutions (Disability Services, 1995).

A recent policy paper recommended that: “Institutional living continue to be supported for a small group of people choosing to remain in institutions or for whom there are not the level of resources available to support them in the community.” (Disability Services, 1995 p5).

Nor are these views restricted to policy documents. The current closure of one large institution with approximately five hundred residents has led. for the first time in 20 years to the building of a new institution for one hundred and four residents on the site of the old institution.

Described as a ‘state of the art' residential service the Government has stated that it is to serve those people from the institution who ‘choose' to live in an institutional setting, or whose needs cannot be met in the community. So this decision is couched in part, in the language of rights: in particular the ‘right of individuals to make decisions about their own lives.’

At the same time the argument is problematic in terms of rights. Choice remains a difficult issue for people with intellectual disabilities, particularly those in institutions, and past experience of deinstitutionalisation in the State suggests that assessments of who can live in the community and who cannot are frequently only peripherally related to the characteristics of the individuals concerned (Johnson, 1995). The language of rights is being used to justify decisions which run counter to the thrust of the 1980s rights discourse.

Discussion

These two stories are not comprehensive accounts of changes to services for people with intellectual disabilities in even one State of Australia. But they reveal the way in which two different discourses are being played out in policy and practice. The 1980s focus on rights remains, enshrined in legislation and language. But at least in Victoria it has been subsumed and its language co-opted by a discourse which is about ‘care and protection’ and people with intellectual disabilities as customers.

This shift has happened without open debate about the merits of either discourse and appears to have been driven by political and economic forces outside the disability field. The stories hold a number of morals for those who work with people with intellectual disabilities or who have intellectual disabilities:

- The stories reveal that words such as advocacy, choice and deinstitutionalisation which were used in specific ways by those developing a rights view of people with intellectual disability’ can also be given emphasis and meaning which lead to policies and practices very different from those which were originally envisaged. When this occurs it is difficult for rights advocates to argue against such policies for their language is used against them. There is then a need to carefully consider the way in which language about intellectual disability is used and to engage in open debate about its meanings.
- The discourses around intellectual disability both reflect and are shaped by the economic and political forces operating in the society. The movement towards increased individualism and the increasing emphasis on consumerism have been noted by writers both in Australia and overseas. (See for example Cox, 1996; Lasch, 1995; Marquand, 1988). Failure to consider the significance of these wider issues for the field of intellectual disability may lead to changes in attitudes and service systems which are not grounded in the needs of people with intellectual disabilities but reflect unrelated ideological positions. Careful evaluations of strategies which do seem to assist people with intellectual disabilities to lead fuller lives, analyses of proposed changes in policy emphasis and the use of research to persuade Government of needed changes would seem to be some steps required to ensure that the needs of people with intellectual disabilities are not totally subsumed by wider economic and political ideologies.
- Strategies designed to assist people with intellectual disabilities to lead fuller lives are more fragile than their exponents would perhaps like to believe. Advocacy which had been a strong focus of work in intellectual disability' in the 1980s was perceived by the State Government as an expensive luxury' in the 1990s. There is a need to embed positive practices firmly in the community so that they are less likely to be eliminated or reduced with changes in Government ideology. So if a diversity of advocacy voices are valued by people with intellectual disabilities, workers and families then it is important that strong and independent advocacy organisations be established which can be sustained over time.
- Perhaps most importantly these stories indicate that without the real inclusion of people with intellectual disabilities in their communities they will continue to be subject to changes in ideologies, economic and social forces which have little direct relevance to their aspirations. It is only when they are recognised and supported as fellow citizens within their communities that strategies to assist them to lead fuller lives will be sustained.

Conclusion

Over the past fifteen years people with intellectual disabilities in Australia have achieved a new status as citizens with rights. This status and these rights are protected by laws and have been accompanied by significant changes in policies and practices affecting the lives of this group of people. However the two stories in this paper reveal that the issue of how people with intellectual disabilities may lead fuller lives remains a problematic one and is subject to changes of ideology and to wider economic and social forces in the community. To ensure that the needs of people with intellectual disabilities continue to be recognised in the development of services for them requires an analysis of the impact of these wider ideologies and forces. Without this analysis strategies designed to assist this group of citizens to lead fuller lives will remain fragile and subject to elimination.

References

1. Cocks, E. (1982). Report of the Minister’s Committee on Rights and Protective Legislation for Intellectually Handicapped Persons. Melbourne: Victorian Government Printer.
2. Cocks, E. (1985). Roadblocks to appropriate services for persons with an intellectual disability in Australia. Australia and New Zealand Journal of Developmental Disabilities, 11(2), 75-82.
3. Commonwealth Government (1986). Disability Services Act. Canberra: Australian Government Printing Service.
4. Commonwealth Government (1992). Disability Discrimination Act. Canberra: Australian Government Printing Service.
5. Community Services Victoria (1989). State Plan for Intellectual Disability Services. Melbourne: Community Services Victoria.
6. Community Visitors (1990). Annual Report of the Community Visitors 1990. Melbourne: Office of the Public Advocate.
7. Cox, E. (1996). A Truly Civil Society: The 1995 Boyer Lectures. Melbourne: ABC Books.
8. Disability Services (1995). Redevelopment of Residential Institutions and Congregate Care Facilities. Draft. Melbourne: Health and Community Services.
9. Health and Community Services (1992). Health and Community Services: To Care and Protect. Melbourne: Health and Community Services.
10. Intellectual Disability Services Task Force (1995). Report to the Hon. Michael John, MP Minister for Community Services. Melbourne: Health and Community Services.
11. Johnson, K. (1995). The Women on the Hill: An Ethnographic Study of Deinstitutionalisation. Unpublished Ph.D. Thesis, School of Social Work, University of Melbourne.
12. Lasch, C. (1995). The Revolt of the Elites and the Betrayal of Democracy. New York: W.W. Norton and Co.
13. Marquand, D. (1988). The Unprincipled Society: New Demands and Old Politics. London: Fontana Press.
14. Naufal, R. (1989). The ten year plan for the redevelopment of intellectual disability services. Policy Issues Forum, April, 21-27.
15. Neilson Associates (1987a). Ten Year Plan for the Redevelopment of Intellectual Disability Services: Interim Report. Part I. The Form of the Task. Melbourne: Community Services Victoria.
16. Neilson Associates (1987b). Ten Year Plan for the Redevelopment of Intellectual Disability Services: Interim Report. Part Two. Quantification of the Task. Melbourne: Community Services Victoria.
17. Neilson Associates (1988a). The Ten Year State Plan for the Redevelopment of Intellectual Disability Services: The Final Report. Data Book. Melbourne: Community Services Victoria.
18. Neilson Associates (1988b). Ten Year Plan for the Redevelopment of Intellectual Disability Services: Final Report. Melbourne: Community Services Victoria.
19. O'Brien, S., & Johnson, K. (1987). Having a Real Say: Strategies for Developing Consumer Participation in Services for People with an Intellectual Disability. Melbourne: AMIDA.
20. O'Brien, S., & Johnson, K. (1988). Improving consumer participation. Community Quarterly, 13, 4-14.
21. O'Brien, S., & Johnson, K. (1993). Improving consumer participation. In J. Ward (Ed.), Australian Community Development: Ideas, Skills and Values for the Nineties. Melbourne: Community Quarterly.
22. Office of the Public Advocate (1990). Annual Report. Melbourne: Office of the Public Advocate.

23. Star Vic Inc., Villamanta Legal Services, AMIDA, Westernport Speaking Out, Reinforce, and Options for Community Living Inc. (1995a). The Community Case for Rejecting the Client Account Management System. Melbourne: Star Vic, Inc.
24. Star Vic Inc. (1995b). No home of our own. Paper Presented at the 1995 Association for the Scientific Study of Intellectual Disability Conference. Melbourne: September.
25. Victorian Government (1986). Intellectually Disabled Persons Services Act. Melbourne: Victorian Government Printing Service.
26. Victorian Government (1986). Guardianship and Administration Board Act. Melbourne: Victorian Government Printing Service.
27. Victorian Government (1987). People and Opportunities: Victoria’s Social Justice Strategy. Melbourne: Victorian Government Printing Service.
28. Victorian Government (1995). Amendments to Intellectually Disabled Services Persons Act. Melbourne: The Law Printer.
29. Wallace, J. (1991). Pleasant Creek Training Centre: Report to the Director General Community Services Victoria. Melbourne: Victorian Government Printing Service.
30. Weedon, C. (1987). Feminist Practice and Post-Structuralist Theory. Oxford: Basil Blackwell.
31. Yeatman, A. (1996). Getting Real: The Final Report of the Review of the Commonwealth/State Disability Agreement. Canberra: Australian Government Printing Service.

Sweden: legal rights, support services and individual empowerment

By Elaine Johansson

Six years ago at the ILSMH's (now called Inclusion International) Congress in Paris during the seminar on ’’Profound Mental Handicap”, I declared that I had a dream for my profoundly mentally handicapped daughter. My dream was:

- that she herself, that is to say with the support of my husband and myself, should be free to choose her future home.
- that she should be free to choose the companions she would be living with.
- that she should be able to choose the staff who would be providing her with support and service.

My dream has actually come true, partly thanks to new legislation which came into force on the 1st of January, 1994. and partly because I have started a parent-run residential association together with three other sets of parents.

Recent Swedish Legislation

In May 1993 ”the Act Concerning Support and Service for Persons with Certain Functional Impairments and The Assistance Benefit Act” were passed by the Swedish Parliament. One of the fundamental principles of the new act related to the way we look upon a person with a disability. A disability is not a characteristic of the individual, but a relationship between the individual and his environment. It is the environment that must be adapted to suit the individual.

Who has the right to get support and service from this new act?

The answer you will find in the first section of the act. The new act contains provisions relating to measures for special support and special service for those:

1. who are mentally retarded, are autistic or have a condition resembling autism.
2. who have a considerable and permanent intellectual functional impairment after brain damage when an adult, the impairment being caused by external force or a physical illness, or
3. who have some other lasting physical or mental functional impairments which are manifestly not due to normal aging, if these impairments are major ones and cause considerable difficulties in daily life and consequently, an extensive need for support and service.

People in the first two of these categories are shown to be quite easy to identify, while those in the third can be more difficult.

Who decides who has the right to the support and services according to this act?

The answer is up to the person with disabilities to know his rights and possibilities, to get support and go to the person responsible in the municipality. If there is a disagreement between the person with disabilities and the representative from the municipality the person with disabilities can go to court, which decides if the person has the right to services according to the act.

Specified services

In section 9 of the Act you will find a list of the different services. The measures for special support and special service are:

Advice and other personal support

This means advice and other personal support that requires special knowledge about problems and conditions governing the life of a person with major and permanent functional impairments. This support should be based on medical, psychological, social and pedagogical aspects. It can be the question of physiotherapy, occupational therapy, support from a social worker or a psychologist etc. The new law contains a series of improvements for persons suffering from considerable functional impairments, though there is one particular right which has been decisive in enabling me to realize my dream for my daughter's future home, namely ”The right to the help of a personal assistant or financial support for reasonable costs for such help to the extent that the needs for financial support is not covered by assistance benefit pursuant to the Assistance Benefit Act. ”

Personal assistance

What is a personal assistant? A personal assistant is:

- a personal support which will make possible to persons with functional impairments a life of increased independence.
- a person whose interests are geared to the individual and not to a certain sphere of activity.
- a personal assistant who shall be available for varying needs around the clock.

A personal assistant can be found:

- at a day nursery
- in a classroom at school
- at a recreation centre
- in the work place
- in a day activity centre
- in a respite care home
- at home
- on vacation, etc.

It should be noted that the personal assistant shall not replace the teacher at school or other staff members. The personal assistant shall support only the disabled person. There are two different acts regarding personal assistants, one about the right to a personal assistant and the other about financial assistance. The right to a personal assistant falls under the Act Concerning Support and Service for Persons with Certain Functional Impairments. Questions concerning the right to a personal assistant are handled by the local authorities. The right to financial assistance falls under the act concerning reasonable costs for such help to the extent that the need for financial support is not covered by assistance benefit pursuant to the Assistance Benefit Act. Questions concerning assistance benefit are dealt with by the National Social Insurance Board and the social insurance offices.

Responsibility is shared between the local authority and the social insurance office where:

- The functionally-impaired individual belongs to the group entitled to those services.
- The functionally-impaired individual has the right to personal assistance between the ages of 0 and 65.
- The person must suffer from severe functional impairment.
- The functionally-impaired individual must be in need of assistance for personal hygiene, eating, other personal services and communicating with others.

The responsibility of the local authority is as follows:

- The local authority shall always bear the basic responsibility.
- The local authority shall provide personal assistances up to 20 hours a week.
- The local authority shall provide personal assistance of an occasional nature, i.e. during journeys.
- The local authority shall provide the necessary personal assistance in a group home.

The responsibility of the national social insurance office is as follows:

- The functionally-impaired individual must be living either in a service house or in his own home or together with his family.
- The functionally-impaired individual must require a personal assistant for more than 20 hours per week.
- The national social insurance office shall bear the cost from the first hour of assistance.
- The right of decision lies with the National Social Insurance Board.

Who can be a personal assistant? The functionally-impaired individual may himself decide how, when and who shall be his personal assistant. The functionally-impaired individual may:

- himself be the employer and recruit the personal assistant(s).
- request assistance from the local authority
- together with other persons with certain functional impairments establish an organization or an association to act as employer for several assistants.
- employ the services of other bodies, companies or organizations
- act partly as employer and partly receive assistance from the local authority or other body.
- the parents of persons with certain functional impairments may also be personal assistants.

Escort services

Escort services can be used by the person with disabilities to go to the movies, concerts or some sporting arrangements etc.

Personal contact

Escort services consists of several different persons, but a personal contact is ONE person. The person with disabilities can choose his personal contact. The municipality pays for activity costs and for a small fee.

Relief service in the home

When families with children with disabilities need relief service in the home, they call the social sendees office in the municipality and a person is sent to their homes.

Short stay away from the home

For families who have children with disabilities the municipality provides different kinds of respite care - for instance camps, another family or a special short stay home.

Short periods of supervision for schoolchildren

Short periods of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays is also a right in the new act.

Family home or residential arrangements

There is provision for living in a family home or in residential arrangements with special services for children and young people who need to live away from their parental home.

Residential arrangements for adults

There is provision for housing with special services for adults or some other specially adapted residential arrangements. Recreational and cultural activities are also included in the measures ‘residential arrangements with special services for children and young people’ and also in ‘housing with special services for adults’.

Daily activities

Daily activities are provided for people of a working age who have no gainful employment nor are undertaking training.

It is forbidden to put any person with disabilities in any kind of institution. All institutions should be closed as soon as possible. Unfortunately there is no final date for closing the institutions.

Service quality

Well, you have seen the list of services but what about the quality of these services? To answer that question you have to look into section 5 and 6 of the Act. Please observe that I have underlined the key words. In these sections, you will find the objectives and general orientation of the activities. The overall objective of the separate measures under this new legislation is to achieve the greatest possible equality between people with disabilities and other people.

Section 5

The activities pursuant to this Act shall promote equality in living conditions and full participation in the life of the community for those referred to in Section 1. The objective shall be for it to be possible for the private individual concerned to live as others do.

Section 6

The activities pursuant to this Act shall be conducted in co-operation with other public bodies and authorities. The activities concerned shall be based on respect for an individual's right to self-determination and privacy. As far as possible, it shall be ensured that the private individual concerned shall be allowed to influence the measures provided and to participate himself in what is decided.

For the activities pursuant to this Act, there shall be the personnel needed to enable good support and good service and care to be given. This means that my daughter and all her friends with disabilities have the right to good living conditions.

30 years ago I chose my husband. We have together chosen our house. We choose our friends and we choose when we want to go to the movies. The municipality has not chosen my husband for me. The municipality has not chosen our house for us. The municipality does not choose our friends and so on. I cannot understand, why on earth the municipality has to choose for my daughter.

You could say that this legislation is a change of power. The power is now in the hands of the person with disabilities or his legal guardian. But to be able to take power over your own life, you must know about your rights otherwise the act is only a piece of paper.

What about reality, how is the actual situation for persons with disabilities in Sweden after two and a half year with this new act?

As many other western countries we have had an economic recession with increasing unemployment. The economic resources for persons with disabilities have decreased. This means that some persons with disabilities have a worse situation today and some persons have got better living conditions. When you as a person with disabilities know your rights or if you have a legal guardian who knows these rights, the living conditions have improved.

Why have we in Sweden worked for special legislation for persons with severe disabilities? We also have a general social legislation for everybody in need of social services. If this legislation had been successful, we would never have got this special act. You could even say that it is a failure of the Swedish general social system that this act was passed through the Swedish parliament.

To guarantee a good life for people with severe disabilities there must be solidarity between people. Solidarity has decreased over the last 10 years in Sweden. Full solidarity we will only find in heaven and we are not yet there. That is why the whole handicap movement in Sweden have been struggling for this special legislation.

My daughter and all persons with disabilities should not be dependent on solidarity of people to get the right to:

- a good home
- daily activities
- an active leisure time
- to good living conditions.

These are her human rights.

Slovak Republic: Opportunities and Barriers to Inclusion in a Period of National Reconstruction

By Maria Nadazdyova

Introduction

Recently some of my colleagues visited one of our biggest residential institutions for people with intellectual disabilities. This currently serves 170 men with different needs, some with mental health problems, and employs 60 staff. Our agency is the only one attached to government with a specialised role in monitoring the quality of social care provision and promoting improvements. On this occasion, as now happens regularly, we were invited by the relevant Ministry and the District Authority Social Services Department to examine the quality of life at this institution following expressions of serious concern.

Taking account of what they found there about the lack of human dignity even in the most basic aspects of life and the high capital costs of improving the situation, my colleagues have proposed the most radical solution: that is, to close this institution. This true and very concrete story is a useful starting point for this paper on the situation in the Slovak Republic. It would be interesting to know how the Social Services Authority responds to this proposal, but in any case we can use this example to explore the factors relevant to taking this very first step on a long and far-reaching process of real deinstitutionalisation in our conditions.

As this hypothetical approach to considering our national strategy for reform should make clear, particularly in contrast to the stories from other countries in this publication, we are only at the very beginning of the nationwide changes required and indeed, at the birth of the social movement required to promote such changes.

The Current Situation

You should know that in the Slovak Republic:

- There are still a large number of segregated institutions with the whole variety of problems they always represent and bring about.
- These institutions are the major form of services for our citizens with intellectual disabilities provided by the government.
- The model, generally used in all services for people with intellectual disabilities, has been medical and custodial, laying the emphasis on care, protection, and control, often with poor standards of professional practice.
- These institutions are already perceived as a constant source of problems for the state agencies which are responsible.
- Administrators at both the local and Ministry levels do not have a clear view either about acceptable quality in these services or how to tackle the problems.
- My own agency is however one source of expertise and advice, able both to visit local services and propose an agenda for action.

In addressing these specific issues however, it is also important to understand the wider social context in Slovakia as this shapes the opportunities and barriers to developing community-based services and ensuring real inclusion.

In my country there has been a long history of general exclusion of all our people from wider international trends. The life experience of the whole population was confined by the artificial boundaries of state communist ideology. Arguably people with intellectual disabilities were therefore doubly segregated.

Although we would like to forget this recent history, this 40 years of experience is still part of us. It is not only in attitudes to people with intellectual disabilities that we have not yet learnt that democracy and exclusion from human and civil rights are incompatible.

Moreover, most people continue to perceive government regulations as the key element determining the relationship between public authorities and citizens.

Hidden Messages

Against this background, the most important turning point in the life of my country after the Velvet Revolution has been the new Constitution of the Slovak Republic, which provides the legal basis for radical change in our conception of citizenship. It is noteworthy that despite the general anti-discriminatory statement that all basic human rights and freedoms are guaranteed to all people in our territory', regardless of gender, race, colour, language, nationality etc., there is not a single word about disability.

Of course, the intention of the legislature has not been discriminatory. But what is the hidden message in such an omission. Could it be perhaps that disabled people do not exist; or that they are less worthy; or that they do not need their rights protected by the constitution? Is it that the lack of common understanding of disabled people's lives, combined with subconscious anxiety, has led us to a limited conception of their rights and has created the legal grounds for continuing exclusion?

Concrete examples of this kind of consequences can be found in many areas. For example the Constitution declares a general right to education for everybody and indeed makes school attendance compulsory. By contrast the current School Act gives Educational Authorities the power to exclude some children from education on the grounds of their mental health, which, in the words of the Act, “does not allow them to be educated”. So legally, mental health problems, including here some kinds of intellectual disabilities, can be an obstacle to the exercise of basic human rights. That the School Act was established 12 years ago can be no excuse.

Meanwhile, pressure from advocates has led recently to establishing special educational provision for institutionalised children and those with special educational needs – but provided by the care staff in these institutions. Thus we are reinforcing exclusion and second class citizenship for people with intellectual disabilities and communicating this inferior status to the wider public.

Among the good intentions of our representatives in the legislature was the desire to avoid differentiating citizens in laws by reference to their disability. But this was to mistake the means for the ends. What should be the question here is the impact of legislation on people’s quality of life.

Reform: the struggle for better opportunities.

Turning now from legislation to the government’s more specific plans for social reform, we need to recall the monopolistic position of the state in our previous society. The state mandated, organised, financed and provided all services. So on one side, social security throughout the life-cycle was guaranteed to all. On the other side, this produced uniformity, only basic provision and a widespread feeling of passive dependence. The whole system was costly but ineffective. Hence the need for major reform.

The current reform process based on government proposals in December last year is far-reaching in its focus on welfare policy. Its goals are "to promote the sovereignty, social and economic independence and citizenship of all". Again however there is not explicit reference to disability. There is no statement in a 90-page document on the principles against which to judge their quality of life. There is no indication of the government's commitment to achieving these goals for disabled people or even what priority issues should be addressed by the Social Services Authorities. As a consequence we lack a coherent guide to change in this field when much else is in a complex process of transition - remembering that in my country we are experiencing major historical, social and economic transformations.

Without an unambiguous commitment to change based on the philosophy of normalisation and community living, more detailed initiatives like the recent draft Social Assistance Act become an ad hoc mixture of progressive and conservative ideas, depending much on the personal vision and experience of the leaders of different working groups and the way these are articulated within the government bureaucracy. On the positive side this draft does refer to institutions as a last resort in a more varied array of service options and includes for the first time in our history reference to the ideas of integration and least restrictive environments in services to people with intellectual disabilities. Less encouraging is that almost ever}' progressive service principle is accompanied by some qualifying phrase about only 'when it is possible'! Although this Act is not yet implemented, my own agency already has three years' experience of providing training for service managers and their staff emphasising client-centred services and inclusion which is beginning to show results. We are still struggling however to establish the networks of providers and others required to build a wider movement for change.

Attitudes and the role of advocacy

I believe one of the most promising and powerful contributions to this movement will come from the so far undiscovered abilities of our co-citizens with disabilities. When they are given the chance to lead an ordinary life among family, friends and neighbours with appropriate support, they will themselves contribute a lot to the success of major reform.

Self-advocates working with other citizen advocates is almost unknown in Slovakia. Yet a recent survey suggested that 66% of respondents would be interested in contributing to the work of NGOs helping people with disabilities. Another survey suggested that a lot of advocacy will need to focus on main stream services: for example, 61% of ordinary school teachers believe school integration could endanger their and other children's health.

Development of advocacy and training in advocacy skills for all those interested will be of great importance and so investment in this needs to be regarded as a strategic element in the process of reform.

Conclusion: a piece of living history

Let us return to the concrete story which began this paper. When I started writing I did not know how the Social Services Authority would respond to my agency's proposal for the first institutional closure. To tell the truth, I was pessimistic, given what we know about the general situation and previous local plans. Even so, I thought this 'hypothetical' example would be a useful focus for our attention. I know' in time there will be progress.

In the event, it is good to share here the outcome: our proposal has been accepted. This story is becoming an important part of our current history. Is this victory? Not yet. Rather it is just an opportunity for development. Just a step along the long road of learning how to live together.

The Americas: The Declaration of Managua as a Framework for International Human Rights Co-operation

By Diane Richler

Introduction

Human rights and disability cut across barriers of language, nationality, culture and economic class. As a result of promoting the human rights of persons with a disability we can identify opportunities for broad social reform which might not otherwise be achievable. By providing linkages between the themes of promoting human rights and democratisation, strengthening of civil society and economic development, a focus on respecting and promoting the human rights of persons with a disability can provide governments and transnational institutions with the mechanisms and tools which they need to promote sustainable economic and social reform. The Declaration of Managua has provided a focus and an opportunity- to link human rights and disability- issues across the Americas and to identify opportunities for making an impact on broad social and economic policies.

For example, in August of this year, representatives of the more than forty political parties in Nicaragua will come together for a seminar in preparation for the upcoming national elections. The seminar is being funded by a Scandinavian government aid program and the theme is disability and human rights as embodied in The Declaration of Managua. In June, the Organisation of American States passed a resolution citing The Declaration of Managua and proposing a process to create a convention to eliminate discrimination based on disability in the American hemisphere. In May, the Presidents of the Congresses of Central America endorsed The Declaration of Managua, a step which will influence the mandate of human rights commissions in the region. In October 1995, the Parliament of Central America endorsed The Declaration of Managua and is applying it as a framework for its unit on women, the family and children.

What is The Declaration of Managua? Where did it come from? And what does it mean?

The Declaration of Managua

The Declaration of Managua was developed and signed in December, 1993 by over 100 individuals representing 36 countries in the Americas. The delegates who included persons with a disability, their families and organisations, professionals and government officials had come together under the auspices of a project entitled Partnerships in Community Living. The project, funded by the government of Canada as part of its commitment to promote the United Nations Convention on the Rights of the Child was carried out by a partnership between the Canadian Association for Community Living (CACL); the Inter-American Confederation of Inclusion International (CILPEDIM); and the Inter-American Children's Institute, a technical agency of the Organisation of American States.

The project goal was to promote the inclusion in their communities of children and youth who have a disability. Carried out over three years, the project was launched with the seminar in Nicaragua. The participants engaged in a process of articulating a common vision, analysing the barriers to that vision and developing strategies to overcome them. The Declaration emerged from the work of each stage in the process, and the final wording was agreed to and signed by all of the participants in the presence of the (then) President of Nicaragua, Violetta de Chamorro.

The Declaration states :
“The participants have committed ourselves to work together towards the development of social policies to benefit children and youth with disabilities and their families, based on a

common vision of social well-being and concrete goals to facilitate the realisation of this vision.

- To ensure social well-being for all people, societies have to be based on justice, equality, equity, inclusion and interdependence, and recognise and accept diversity. Societies must also consider their members, above all, as persons, and assure their dignity, rights, self-determination, full access to social resources and the opportunity to contribute to community life.
- Societies and governments have the duty to foster the participation of people with disabilities and their families in the formulation of co-ordinated policies and legislation to achieve the vision.
- We commit ourselves to put in practice policies that support social integration adapted to the specific community that a child lives in; policies that will enable secure employment and adequate financial support for families; social programs oriented to families; policies that do not restrict immigration and emigration; and information to families that fosters the achievement of the vision.
- The participants will pursue our vision by addressing government policy, legislation and advocacy; building partnerships and co-operation; raising public consciousness; developing information and research; and ensuring supports and services."

With The Declaration of Managua as a framework the project then carried out a series of activities: community development (including a series of four regional seminars); research (including a gathering of legislation related to disability in the hemisphere and a preliminary analysis of the legislation to determine its consistency with The Declaration); and information (including the creation of a network of nine information centres). The Roeher Institute was the technical consultant for those activities. As important as those activities themselves was the attempt to develop a new methodology for carrying out the research, community development and information gathering and dissemination. The methodology was designed to promote co-operation in social change from a human rights perspective by providing a working example of the exercise of democratisation and respect for difference in the process.

The importance of international co-operation

The process of developing The Declaration of Managua, testing its applicability throughout the four regions of the hemisphere and across the various project activities produced three key findings. The first was that the human rights framework as embodied in The Declaration was a unifying factor across the variables of language, nationality, culture, stakeholder perspective (ie. person with a disability or family member, professional or government representative) or socio-economic class. It was also transferable from the hemispheric level at which it was developed to the regional and national level. It became a tool which enabled various stakeholders at the different levels to come together with a common vision and purpose and to develop joint strategies, several of which have now been implemented.

The second finding which was the result of attempts to operationalise The Declaration was that many of the systemic barriers to the participation of persons with disabilities as full members of their communities emanated from beyond national borders and were the products of international inter-government, private or financial institutions.

The most recent issue of the journal Foreign Affairs (July/August 1996) includes a review of the book Bringing Transnational Relations Back In: Non-State Actors, Domestic Structures and International Institutions. The book makes the point that "transnational actors, from multinational corporations to international non-governmental organisations have grown in importance since the 1970's, when they first surfaced as a trendy subject." The results of the project Partnerships in Community Living reinforces this finding in the case of policies affecting children who have a disability. In countries which receive much of their funding for social programs from international financial institutions, foreign aid organisations or international non-government organisations, decisions affecting the potential for persons to participate in their communities are often made far away, and with a very different objective in mind. For example, a decision by an international financial institution to place a priority on the impact of land mines can lead to the end of programs for children with an intellectual disability.

Examples such as this which came forward in the regional seminars of the Partnerships project helped to focus the attention of the partners on identifying those transnational actors whose policies were having an indirect but important impact on the lives of persons with a disability within the Americas. Some of the transnational organisations identified included the Inter-American Development Bank, UNICEF and other United Nations organisations, the World Bank, international aid organisations, and the Organisation of American States. Significantly, strategies to address these barriers at the international level have reinforced the validity and value of The Declaration of Managua.

This produced the third key finding: organisations would address disability issues if they saw an opportunity to achieve their own agendas. The Declaration has appealed to a wide group of interests because of its broad perspective and identification of a range of policy options required to tackle the root causes of exclusion. By focusing on The Declaration of Managua and its themes of equality, equity, inclusion, justice, diversity and interdependence and at the same time examining some of the priorities of these transnationals, it has been possible to find many converging themes, primarily related to efforts to promote equality, democratisation, the strengthening of civil society and ultimately economic development. Organisations which previously had not seen disability as a priority have recognised that by applying The Declaration of Managua they could promote their own agendas.

Disability organisations have much to offer to transnationals. Because disability respects neither class nor race, nor religion, nor political affiliation, disability groups often bring together coalitions of individuals who would not ordinarily be working together. By working with them, transnationals can begin to build bridges with groups which previously have lacked a common ground for co-operation.

Failure of previous policy frameworks is forcing transnationals to re-examine their assumptions regarding the strategies to best address the problems faced by the most marginalised citizens. Increasingly, there is a recognition that it is ineffective to think that economic development issues can be addressed in isolation. Rather it is being recognised that equity is a prerequisite to economic development. Excluding marginalised groups from the benefits of economic development at best leads to creating classes of dependent people. At worst, it leads to societal unrest, and exactly the conditions which make economic development efforts a failure.

Conclusion

In this changing economic and political environment, The Declaration of Managua offers a way to introduce disability on to international agendas. For while solutions to the challenges facing persons with a disability have traditionally been perceived by funders as an economic drain, the options resulting from The Declaration of Managua offer solutions to governments not only to problems affecting persons with a disability1, but for broader social problems as well. Furthermore, The Declaration has an economic rationale since it is less expensive to create systems which include persons with a disability than to create the need for parallel ones. [In Canada, for example, the Canadian Association for Community Living has estimated that the savings to Canadian society' to include persons with an intellectual disability would be almost $5 billion per year.]

In the three years since its proclamation, The Declaration of Managua has opened the door to discussions about disability with heads of state of at least ten countries, presidents of international financial institutions, countless ministers, ambassadors, executives of transnationals and others whose decisions can impact on the lives of persons who have a disability. It has also challenged traditional disability associations to modify their objectives and to create new mechanisms and processes for international collaboration. For me. the symbol of The Declaration is a photo of a little 9-year old girl living in La Paz, Bolivia who could not go to school because she had Downs Syndrome, and who spent her days locked alone at home while her single mother went out to work. The Declaration of Managua will not help her mother to put food on the table or assist the school system to include her. However, it does have the potential to give us the tools to make those things happen.

Contributors

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