Five challenges for the future: A personal perspective*

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As a society, I think we face five major challenges in terms of our life with our fellow citizens and friends with mental handicaps. The challenges are:

1. To determine what kind of society we want—one based on the survival of the fittest or one based on supporting people to reach their potential.
2. To address the discrepancy between what we know to be decent and possible, and what we know to be the present situation with which our friends and fellow citizens live.
3. To put into place systems which at least meet the criteria established in *Mandate for Quality* (McWhorter & Kappel, 1984) for the successful redesign of mental retardation systems.
4. To respect the rights of people with mental handicaps and empower them to meet their responsibilities as Canadians.
5. To release people from dependence on services and to support their integration and interdependence.

Challenge 1: The kind of society

As a society, not just as a collection of people concerned about people with mental handicaps, we desperately need to decide what kind of society we want, and then to vigorously build that society. Very simply, there are two choices. The first is to continue as a society based on survival of the fittest. Such a society is characterized by charity, custodial care, waiting lists, letting families go unsupported, responding only to crises, ensuring there is nothing meaningful between the family and the institution (and maintaining that the family is the bulwark of society), basing policy decisions (and the lives and futures of people affected by them) only on cost-benefit considerations, debating which lives are worth saving, and so on.

The second choice is for a society that supports individuals to their fullest potential. Such a society is characterized by rights; encouraging growth and development; non-discriminatory practices; supporting individuals and families; building the capacity of communities; preventing crises; promoting the efforts of natural support systems (such as families, neighbourhoods, classmates, friends, fellow workers) rather than supplanting them with services; recognizing and appreciating the abilities of all citizens; and so on.

Challenge 2: Eliminating the discrepancy between the present and the possible

The Canadian Association for Community Living (formerly CAMR), has recently submitted a Statement of Principles to the Government of Canada (CAMR, 1985). Most of that document addresses the growing discrepancy between the present situation and what we know to be possible and practical—discrepancies which continue to debilitate individuals, families and communities. As one of the drafters of the Statement, I will quote and paraphrase from it.

- We know that individuals with mental handicaps and their families can be supported to maintain an environment where members of the family grow, develop and care for one another together. We know that adults can live and be supported to live with friends of their own choosing in households of their own creation. These things are possible.

  Yet in the present situation, tens of thousands of Canadians live in institutions, special care homes and other facilities that group them together and keep them separate from community and family.
- We know that children with and without handicaps learn best and prepare for adult life best when they learn and prepare together in the same schools and classrooms. We know that education is most effective when it starts early, involves the family, and is directed toward acquiring skills, information and experiences that are essential to social and economic participation.

  Yet the present situation is that the vast majority of children are isolated from one another in segregated schools and classrooms, and are not being given the opportunity to learn those things and with those people that will foster the levels of independence, interdependence and participation of which they are capable.
- We know that it is possible for adults with mental handicaps to engage in meaningful work for which non-handicapped people are paid, and to

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• Over the last year I have been asked by numerous and diverse organizations to deliver speeches and papers on topics such as policy, rights, trends and deinstitutionalization. Much of what is said in this paper is based on the responses of these groups to my "words of wisdom" but also the fine counsel of colleagues such as Joe Cawthorpe, Malcolm Jeffreys, Jo Dickey, Bernard Graney, Lyle Wray, Colleen Wieck, and Alan McWhorter.

do so in real community settings. We know that some will require short- and long-term support to do such work and with other people. We know that the vast majority of citizens with mental handicaps are able to work, to contribute and to produce. They are capable of earning incomes and paying taxes. We could be capable of supporting them.

Yet the present situation is that the vast majority of adults are deemed "unemployable"; are unemployed because they are never given the opportunity to build a career or to work; and are only given the opportunity to contribute in token ways.

- We know that people with mental handicaps need friends and chances to participate in the social life of the community. We know that they and their fellow citizens are capable of forming friendships and participating together.

  Yet the present situation is marked by the fundamental separation of many citizens with mental handicaps from the community because of the places in which they live, learn and work. They are prevented from forming friendships and engaging in social relationships because they are not given access to normal places in the community in which friendships and relationships develop.
- We know that people with mental handicaps are citizens, that they have rights, that they and others are willing to stand up for those rights. We know that they are fully capable, often with support, of meeting their obligations as citizens.

  Yet in society, generally, and in human services, specifically, these rights are denied. People are not allowed to associate freely and speak on their own behalf. All too often, fundamental rights of life and protection from harm are denied.
- We know that people with mental handicaps grow and develop, learn and participate, and take advantage of opportunities best when the services that support them are designed to meet their individual strengths and needs. We know that all people, including people with handicaps, need families, friends, decent places to live, opportunities to learn and work to their fullest potential, and chances to belong. We know it is possible to provide these things.

  Yet the current situation is characterized by services not meeting these fundamental needs. Most often, services require the individual to fit into the service or go without support. In many communities, services do not even exist

Challenge 3: Build successful systems

In the Summer 1984 issue of the *Canadian Journal on Mental Retardation,* Alan McWhorter and I summarized the 13 elements apparently associated with successful attempts to redesign mental retardation service systems. The findings and recommendations of the Pennhurst Longitudinal Study (Conroy & Bradley, 1985) among other recent publications (see also Novak & Berkeley, 1985; Leismer, undated; Wray & Wieck, in press) confirm these elements, as well as suggesting more detailed considerations especially in terms of quality assurance, case management, outcome-related funding, and service design.

Without repeating here the details of the *Mandate for Quality* criteria, they include:

- A mandate to use government authority to redesign the system;
- Case management or individual service co-ordination;
- Individual service plans;
- Regional planning and administration;
- Available support to service providers through regional authorities, including crisis assistance, behaviour management, and professional consultation;
- An ongoing, comprehensive staff development program;
- An orientation to preventing long-term service dependency;
- Freeze on institutional admissions and implementation of the scheduled evacuation of institutional facilities;
- Quality control and external monitoring systems;
- Division of powers and a system of checks and balances;
- A coherent humanistic service ideology;
- Adequate funding, including contracts for services based on individual needs and having funds follow people not just going to programs;
- A wide range of services developed in response to identified individual service plans.

My experiences and involvements with deinstitutionalization efforts across Canada indicate that we in Canada have a long way to go in terms of meeting these criteria particularly in terms of:

- designing, developing, delivering, monitoring and adapting services and supports in response to the strengths and needs of the individual;
- training and developing manpower resources equipped to support individuals to live with dignity and respect in the community;
- preventing long-term dependency on inappropriate services, especially in terms of our apparent systematic disregard and non-support of families;
- quality control and external monitoring;
- adequate funding related to quality and individuals;
- individual service coordination or case management.

The challenge is to "do the right thing" and to "do things right" (Wieck & Wray, 1985). These systems criteria are required.

Challenge 4: Respect rights/empower responsibilities

Canada's Charter of Rights and Freedoms holds the promise that people with mental handicaps, among others, will be afforded the rights of citizenship. Rights also imply responsibilities and obligations to one's community. Because their rights have been denied, our fellow citizens have often been denied the opportunity to fulfill many basic responsibilities of citizenship, including those to participate in the social and economic life of the community.

As a society, we have been quite systematic in denying the rights of people with mental handicaps. The challenge is to change all of that and focus our attention on ensuring their rights and empowering them to meet their responsibilities, often with our support. The following represents some of the rights formally and informally recognized as belonging to citizens, and a listing of the many ways we deny those rights in residential services. The list is far from complete, but begins to outline at least part of an agenda for the future.

Rights: Their denial where people live

- Protection from harm, from cruel and unusual punishment
    - isolation
    - physical and chemical restraint
    - emotional injury (deprivation of affection and stimulation/ inappropriate criticisms, threats, humiliation, accusations or expectations)
    - limited access to medical treatment
    - physical and sexual abuse
- The right to habilitation
    - lack of role models
    - absence of programs
    - absence of community contact
    - ineffective training
    - medications in the absence of programs
- Freedom of movement, freedom of association
    - isolated locations
    - absence of companions
    - limited access to transportation
    - house rules
    - lack of privacy
- Choosing with whom one lives
    - no choice
- Having a sense of home
    - living in a house someone else pays for
    - having to move when your needs change
    - limitations on privacy and possessions
    - regimentation
    - being moved out with no choice or say
- Being a neighbour and a member of a family
    - no neighbours
    - intimidated neighbours
    - separation from families
    - disincentives to families
- Individual identity
    - being defined only by one's impairment, disability and handicap.

Interestingly enough, the State of New York has recently adopted a "Bill of Rights for Mentally Retarded and Developmentally Disabled Persons Living in Community Residences." Among the provisions to be covered in regulations is the right to:

- request either a new residence or a new roommate;
- be involved in decisions concerning a new room or residence;
- have privacy and sufficient space for personal belongings;
- have visits in privacy with family and friends;
- receive and send communications;
- carry out meaningful and productive activities within his or her capability;
- use personal money and property;
- participate in the establishment of house rules; and
- express concerns, suggestions and grievances without fear of reprisal (NASMRPD, 1985).

This is far from a comprehensive list based on what I think most of us would choose as our rights in the most intimate place we spend time—our homes—but it does indicate the extent to which some of the more subtle rights we all hold dear are being recognized.

Perhaps the most challenging area in terms of responsibilities is contributing to the economic life of the community. As mentioned earlier, we are learning more and more about not only the capabilities of our fellow citizens, but our own capabilities in supporting them, in terms of employment and meaningful work. There is growing evidence that we are in fact capable of developing alternatives to sheltered, congregated, and useless activities and places of activity (see references). As noted in the final report of the Pennhurst Longitudinal Study:

> The data show that Pennsylvania's community residential model [community living arrangements with three or fewer individuals per home] has overwhelming advantages, but the data also lead to the inference that day programs [for the former residents of Pennhurst] are not very different from decades-old workshop and adult day care models. ... We suggest that, at least in Pennsylvania, the issue of residential settings has been resolved in favor of the community, but that day services should be the next target for capacity building through technical assistance and innovative demonstration programs (Conroy & Bradley, 1985).

Challenge 5: Release from dependence on services and support integration and interdependence

It appears to me that many service agencies see the final outcomes which are important for people in terms of service continuity and permanence. These are both very important On the other hand, services should only be seen as means for achieving ends, and as means which are only used when natural support systems need support.

Another way of defining final outcomes is in terms of what is important for people. Most people with mental handicaps I know do not strive to be dependent. They strive to be as independent as possible, and interdependent with others. When a group of NIMR volunteers and staff got together recently, we identified the following three outcomes as a way of summarizing what is important

1. Membership: being seen and treated as a respected member of a family, a community, a workplace, a school, a group of friends, a neighbourhood, etc. In other words, to be seen as one of us, not one of them. To feel a part of the human community, not set apart from it
2. Citizenship: having one's rights respected and receiving whatever support or assistance required to meet one's responsibilities as a citizen, especially to contribute to the social and economic life of the community.
3. Determination: being able to control one's life, body and circumstances.

The challenge, in this context is to foster independence and interdependence, not dependence. The challenge for a Canadian Association for Community Living, then, is to ensure that our friends, neighbours, family members, co-workers, classmates and fellow citizens with mental handicaps achieve membership, citizenship and self-determination.

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