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Flynn, Robert J., Lemay, Raymond

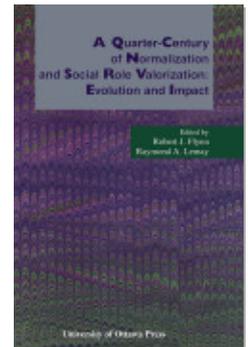
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The impact of Normalization and Social Role Valorization in Canada

ANDRÉ BLANCHET

This country is vast with 10 provinces and 3 territories having jurisdiction over the organization of social and health services. Over the last 20 years, I have had occasion to visit each of these provinces and to meet many people who have handicaps, their families and advocates, and professionals and administrators. All have influenced the various levels of support that exist in each of these regions. It has a lot more than symbolic significance that the 1994 conference that reviewed Normalization and SRV was held in Canada—and moreover in Ottawa, which is, in a sense, the very boundary between the French and English cultures—where the Scandinavian idea of Normalization has had the greatest impact.

When, at the beginning of the 1970s, Wolfensberger came to teach and lead a team at the National Institute for Mental Retardation and a few months later Nirje came to work for the Ontario government, we had the privilege to live through an exhilarating period of new and exciting ideas and favorable sociopolitical conditions that nourished the hopes and actions of families and young professional dissidents.

Let me list the elements that I think were the most important.

1. A vision and a practice of consumer participation, which was at the heart of the work of G. Allan Roeher, the then director of the Canadian Association for Mental Retardation (CAMR). Allan, like many of the reformers of that era, came from the province of Saskatchewan, where governments, with the participation of agricultural cooperatives, were the first in Canada to establish in 1944 a hospitalization

insurance program and then in 1960 a health insurance regime. It was also in Saskatchewan, in 1964, that we witnessed the first closing of an institution—Weyburn—in good measure because of the leadership of its medical superintendent, Hugh Lefave. Also, again before all other provinces, Saskatchewan was the first to decentralize its social services. It was not surprising, therefore, that the CAMR wanted to establish a network of integrated community services, COMSERV, where families, in collaboration with local administrations, would establish the required services and supports to allow persons with handicaps to live their lives in the community. I can still see Wolfensberger explaining to us, with many overheads, the necessity of a central point of responsibility and the interdependent relationships or “chaining” between different levels of responsibility.

2. A relatively sophisticated parent association movement was beginning to understand that the role of parents was not so much in the delivery of services, but more in the area of advocacy for better living conditions for their sons and daughters. In Quebec, for example, between the short period of 1970 and 1976, local parent associations withdrew from the administration of services, which then became managed by public corporations under a new law on social services. There were many associations in the country that had already attained the third stage, as described by Wolfensberger (1973), that of advocacy and political representation.

3. A number of young professional dissidents, many of whom were present at the 1994 Ottawa

Conference, who were drawn and in certain cases fascinated by the possibilities of change that were doable with the application of Normalization. They came in great numbers from all parts of the country, to seminars and workshops of the National Institute on Mental Retardation (the former name of the G. Allan Roehrer Institute) to learn all those important things that the university had not taught them. Many returned to their corners of the country, convinced that one had to work with families to change the system that was then in place. They became members, oftentimes informally, in the "brotherhood" of change agents.

On a more global scale, there was this Canadian sociopolitical reality and historical tradition based more heavily on social justice than in the United States that usually defines Canada as between the social democracies of Europe, particularly Scandinavia, and the American culture. This social justice tradition permitted then and still today to define an identity typically Canadian quite different from that of the United States despite the powerful attraction of American culture. Though social policies for persons with handicaps were almost nonexistent at that time, this context was sympathetic to the development of policies aimed at integration, like those described by Jacques Pelletier (chapter 25 in this volume), or the inclusion of the rights of persons with handicaps within the Canadian Charter of Rights and Freedoms and this without having recourse to the courts, as was the case in the United States.

The question that we must ask, a quarter-century later, is the following: Have all these hopes borne fruit and, more analytically, what developments in Canada today are, to repeat Michael Kendrick's expression, consonant with Normalization or Social Role Valorization?

Let us review as precisely as possible, taking into consideration the variations between provinces, the situation of persons with intellectual handicaps in Canada.

1. Institutionalization and congregate life milieux. Despite the closing here and there of institutions—one in Newfoundland, another for children in New Brunswick, one in Saskatchewan, another in British Columbia—we can estimate that there are still close to 10,000 people who reside in such institutions. Moreover, and this to me is what is most alarming, few

people will have the possibility to live where they or their families will have chosen. Many live in group homes, which, in certain provinces, exceed in size that which is the recognized and acceptable cultural norm for residences in industrialized countries. The number of children in pediatric hospitals and especially in chronic care hospitals (pediatric extended care) remains high. For example, in British Columbia, which has looked at this problem very closely, we estimate that there are still 60 children and young adults who are in these extended care centers. The transfer of mentally handicapped adults from institutions to nursing homes has been broadly practiced, particularly in Ontario.

2. School integration. Despite many efforts and some successes in each of the provinces where, by and large, school policy has been coherent with school integration, a great deal remains to be done. We estimate in British Columbia that 40 of the 75 school boards of the province have managed to integrate children, though this reality is quite fragile and risks changing according to priorities and available funding in the school boards. Other provinces, such as Quebec, despite individual successes, continue to maintain a sector of special schools and classes that continue to grow.

3. Employment and significant work. Despite the fact that sheltered workshops are slowly disappearing and that employment support initiatives are to be found everywhere in the country, we estimate that over 80% of persons who are intellectually handicapped are without employment or without significant day activity.

4. Poverty. More than 90% of adults with intellectual handicaps live from income support programs. The available allocation represents a monthly amount that is 70% under the poverty line according to standards established by the Canadian Council on Poverty.

5. Law. Despite the Charter of Rights voted in Quebec and in Canada in 1977 and 1982, respectively, few decisions of the superior courts of this country have had a national impact. We will come back to this point.

6. Solitude and social isolation. Here, again, despite some famous initiatives (like the Joshua Committee), many persons live in great isolation with

few ties to their family, friends, or advocates, and this is especially true for those who have left institutions and group homes and who almost tragically form a kind of sacrificed generation.

Despite this dark tableau, which testifies to inherent tendencies of discrimination that are more or less conscious in our societies, it is quite important to nonetheless highlight those initiatives related to Normalization and SRV that continue to show promise.

1. The development of advocacy is, to me, the strong point.

(a) Inspired by Judith Snow and Marsha Forest in Ontario, support networks exist around the country. The Maps process, developed by Snow and Forest, is used in school areas, communities, and families, particularly when such groups need to refocus their strength when faced with difficult situations. Of course, these groups exhaust themselves. They have to start their operations all over again because of conflicts of interest, and this has sometimes resulted in disillusionment and even personal tragedies. However, they have also assisted in breaking the isolation of many persons, offered the necessary supports, and in general been much more consistent than citizen advocacy groups because they have been more sustained.

(b) Very individualized services have emerged, for instance, the microboards organization inspired by the work of David Wetherow in Manitoba. Again, there are enormous risks of converting family and friendly relations into administrative relations. However, the experience in British Columbia—where over the last 2 years, more than 30 of these microboards have been established, sustaining in community persons whose needs are very complex—is worthy of more research and analysis and should create much interest.

2. The emergence of welcoming committees, as influenced by the work of John McKnight (1995). From Newfoundland to British Columbia, and passing by the Italian community of Montreal, in small villages and in the neighborhoods of great cities, there exists in an embryonic form the intention of welcoming home persons who are returning after a long life in institutions.

3. The emergence of associations and of groups of young families created most often around the fight for school integration. Particularly in Ontario, but now in

all provinces, these groups work apart from traditional parent associations and have the advantage of not being burdened by the responsibility of delivering services. They are also very clear in what they want for their children: no segregation, no group homes, no special classes, and life in the community like for other families. The Family Focus Conference in British Columbia, which is the annual event where these young families meet, now brings together more than twice the number of participants than the traditional annual conference of the provincial association for community integration.

4. The continued rapid growth of People First and the creation, in 1991, of a national People First movement giving them their own voice, nationally and provincially. Their message is clear: to leave behind the oppression of which they have been and continue to be the victims. People First of Canada also wants to play a role on the international scene. One of the great moments of my life was participating in 1993 at the International People First Congress held in Toronto, where 1,300 delegates from 32 countries worked and exchanged for a week. There exists within this movement a potential for change that is difficult to evaluate for the moment.

5. In the field of legislation, despite the existence of very few national laws, I wish to underline the Supreme Court's judgment concerning Eve, which has made illegal the nontherapeutic sterilization without consent of persons in Canada. There was also the Stephen Dawson ruling in British Columbia, which, despite a very difficult application, has made illegal the withholding of medical treatment because of physical and mental handicap. Also, because of the action of the National Parent Association, every person in this country, especially those living in institutions, has the right to vote and the right to receive the information necessary to exercise this right.

Whether these developments are directly or indirectly related to Normalization or to SRV is a question that is to me quite academic. What I find important is to underline that Normalization and SRV and all of the intense activity that was generated around these theories, particularly in the 1970s in Canada, created a favorable terrain for the emergence of these initiatives. One has only to consider the supports available for persons with mental handicaps and compare them to the services in mental health and

services to elderly persons to realize that despite all of the lacunae, they compare very favorably. These other fields also benefited from the same sociopolitical environment and yet have not done as well, possibly because they remained aloof of such ideas.

In closing, I would like to speak very briefly about a question that on its own should be the object of a conference: The ethical dimension of Normalization and SRV. Fundamentally, these ideas have proclaimed the right to equality and the respect of the choices of individuals of a same community by the valuing of the social roles of those members who are at risk. And

more than that, it allows the establishment between the members of one and the same community conditions that promote relationships between people. In this sense Normalization and SRV are very close to the thought of that Canadian who has greatly influenced the lives of tens of thousands of persons in this country. Jean Vanier said: "Life in the community is a great adventure. My hope is that many persons will be able to live this adventure which is in the end one of interior liberation—the liberty of loving and of being loved." There is much of this in what was discussed at the Ottawa conference.

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