

Advocacy and Inclusionary Practices

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The past fifty years have seen tremendous social changes which have led to persons with disabilities being enabled to take their rightful place as participating members of their community. We have gone from people being hidden away and parents being told your child 'is different' and will not survive outside an institution to inclusive schools, community living and employment opportunities. Much of this change can be attributed to the efforts of ordinary people who recognized the injustices in the treatment of people with disabilities and sought to create changes in the service systems and communities to make them more supportive and inclusive of all citizens. Through advocacy people's perceptions of and attitudes towards those with disabilities have changed and with this change has come the concurrent evolution of inclusionary communities (Porter & Richler; 1991; Stienska & Wight-Felske, 2004; Vera Perlin, 1994).

How did this come about and what are today's challenges? How has advocacy impacted normalization in Newfoundland and Labrador and will advocates continue to play a critical role in the inclusion of persons with disabilities in society. Will all people, including those with disabilities, continue to live in community or are we in danger of a return to the old ways?

Advocates are those who seek "to influence government policy but not to govern" (Young & Everitt, 2004, p5) and speak out in order to influence "individual behaviour or opinion, corporate conduct, or public policy and law" (Youth Advocacy Training Manual, p3). Advocacy for persons with disabilities is founded on the belief that all people have the same human rights and must be afforded equal opportunities to participate freely and effectively in communities. The provision of necessary supports and choice are guiding principles of the opportunities sought by advocates of inclusionary communities (Spectrum, 1964; Steer & Browne, 1978; Stienska & Wight-Felske, 2004).

The rights of all people, including those with disabilities, to education, employment and full citizenship are principles outlined by the United Nations Declaration of Human Rights and enshrined in the Canadian Constitution Act 1982. Since 1982 this human rights legislation became ammunition for advocates who had already begun the struggle to achieve

equality for all (Stienska & Wight-Felske, 2004). In Newfoundland and Labrador as elsewhere in the world the advocacy movement for those with disabilities took flight during the Civil Rights movement of the 1950's (Kappel, 1981; Spectrum, 1964; Stienska & Wight-Felske, 2004).

In this province an inspirational leader of the movement was Vera Perlin, a philanthropist and volunteer who worked diligently to support children and youth in an orphanage in St John's, the capital of the province. She observed that a disproportionate number of children in the orphanage were those with disabilities and so became very familiar with their plight. Mrs. Perlin recognized that a contributing factor to the growing trend toward institutionalization of children with disabilities was the fact that few if any supports were available to families of these children. In addition at that time children with disabilities were denied an education in this province. Mrs Perlin felt strongly that children with disabilities could and should learn. Thus she pioneered the way for the creation of educational opportunities. She sought support to establish a special school and went to England to learn about effective strategies for educating children with special needs. In 1954 her dream was realized when the first class opened in a church basement in St John's. Over time Mrs Perlin established similar classes in communities throughout the province (Fagan, 1983; Open school, 1963; Seven schools, 1962; Spectrum, 1964; Stacey, 2004; Vera Perlin, 1994).

Vera Perlin was an inspirational leader and perhaps a key ingredient in effective advocacy movements is the availability of unique individuals with vision who can inspire others to become involved and to act. In 1956 she became the first president of the Newfoundland Association for the Help of Retarded Children that today is known as the Newfoundland and Labrador Association for Community Living (NLACL). The St John's chapter still bears her name (Seven schools, 1962; Vera Perlin, 1994). From this small beginning the advocacy movement grew to challenge societal attitudes, barriers and to seek services for people with disabilities. As people banded together local, provincial and national associations were formed to advocate for persons with disabilities.

The work of the associations and the Vera Perlin Schools, as they came to be known, were largely dependent upon voluntary public subscriptions as there were no government policies for the education of children with disabilities nor for training, vocational or employment services for adults (Kappel, 1981; Spectrum, 1964; Vera Perlin, 1994). However, the advocacy efforts of Vera Perlin and the NLACL were recognized in 1959 with an annual Government grant of \$10,000 to help defray costs. By 1962 there were seven Vera Perlin schools operating across the province (Seven

schools, 1962; Spectrum, 1964; Vera Perlin, 1994). In 1963 the Government built its first school for those with special needs in Gander but responsibility for running the school was given to the community (Open school, 1963). In 1968 the Cerebral Palsy association, formed in 1961, opened a classroom in St John's for children with physical and learning disabilities because of inadequate schooling possibilities for them (Dooley, 2005)

Notwithstanding the annual grant for these classes few if any services were available to those with disabilities except in institutions. However, a Federal-Provincial Task Force had recommended in 1964 that training, education, vocational and employment services for persons with developmental disabilities be a government responsibility (Spectrum, 1964). The province is geographically very large but sparsely populated with many people living in small outport communities far away from the few urban centres that exist and where there might be some services available. Thus there were broad relatively unmet needs for people with disabilities and families. For example if someone was assessed as having a physical or developmental disability there was little that was done outside of the medical model of care in the absence of facilities for education and treatment. In the absence of any specific plans or policies what existed evolved in order to meet the day to day demands within the framework of 'general services' that volunteers provided (Fagan, 1983; Spectrum, 1964). However in 1967 the Warren Royal Commission recommended that special education receive more attention and funding and in 1969 the Department of Education (DOE) authorized a Special Education Division (Fagan, 1983).

In 1970 the Government assumed responsibility for the payment of teachers salaries in schools operated by NLACL. After a brief was presented by NLACL to the Provincial Government in 1971 legislation was enacted which provided for the education of all children in the province. Thus, the government finally assumed total responsibility for the operation of these schools. In 1972 programmes for the hard of hearing and visually impaired also came under the auspices of the provincial government. There was a school for the deaf in St John's and those with visual impairment could attend the school in Nova Scotia. This legislation led to the creation of schools in hospitals as well as the special classes in the regular school system. In the next few years the number of children with disabilities attending school increased dramatically (Annual Report, 1970; 1971; 1972). This change enabled the Vera Perlin Society to move beyond education into other areas of need. In the years following they established pre-school classes, an activity centre for adults and eventually provided vocational and employment opportunities (Stacey, 2004; Vera Perlin, 1994).

Due to the efforts of the NLACL government came to see the need for comprehensive community services and the Department of Social Services (DOSS) established direct home services. This included 'home teachers' to help parents of pre-schoolers with developmental disabilities, up to age six or until ready for school, to teach their children (Annual Report, 1970; 1971; Fagan, 1983; Steer, 1983; Steer & Browne 1978). In 1979 the Schools Act was amended and Newfoundland became the third province to mandate that school boards ensure the education of students with disabilities (Schools Act, 1979). However, there were no extra supports given to schools to help these students and this lack of support became the impetus of yet another surge in the advocacy movement.

Advocates, many the parents of school aged children, began to campaign for student assistants and eventually DOSS not the DOE provided 10 week workers to assist these students. While this met the immediate need, there were several deficiencies in this model of support. Perhaps most significant was that these workers had no training and were only available to work for a limited period of time (10 weeks) and were then replaced by a new worker. These realities were partially addressed in 1989 when the DOE assumed responsibility for the employment of student assistants. This opened the door for more consistency in terms of workers but even today student assistants assert that they are provided little, if any, appropriate training.

In the early days of education in the regular school most students with disabilities were educated in segregated classrooms. Special classes were often found in basements of schools or far from other classrooms and students. Thus, although children were now going to school many were isolated in special units away from their peers or even in another community. Once again advocates were not satisfied with the status quo and advocated that students with disabilities should be educated alongside their peers. The DOE established a task force comprised of advocates, DOSS and DOE to investigate and report on education for students with disabilities. They discovered that many school boards had no written policies and so any education for these students varied from school to school. The intent of the legislation had been to ensure that school boards were responsible for this education and also that it should not be segregated. This was not the case as for the most part they were in special units. Student assistants and adequate training of them as well as teachers themselves were also seen as problems. The fact that DOE was not involved with student aides was seen as a problem because of funding restrictions on school boards. As a result of this report educational policy began to change towards a more inclusive model.

In 1989 DOE took over the responsibility for student assistants as well as their training and many of the policies concerning the education of these students began to change (Just one of the Kids 1987; Special Policy, 1992).

Though government policy was now supportive of inclusion, the reality was somewhat different (Royal Commission, 1992) and important questions were raised about special education. Numerous difficulties were identified and addressed by the Canning Report (1996). Though many students were now included with their peers in the regular class there were inadequate supports for successful inclusion. The cascade of services model was recommended which implied that different needs and abilities require different educational settings, not just inclusive, as well as individualized curriculum and appropriate supports to meet individual need. As part of this model the Individual Support Services Plan (ISSP) would determine student placement and the services needed for student success (Canning, 1996; NLTA, 1998; Philpott, 2002; Ministerial Panel, 2000).

After an interdepartmental review process concerning the delivery of services to families and children the present model of shared responsibility was adopted (Coordination, 1996; Philpott, 2002) with the ISSP central to the model. Now the ISSP process can begin any time between birth and graduation from high school with parental involvement a crucial aspect (Coordination, 1996; Special Policy, 1999; Special Policy, 2002). 'Pathways' is the provincially prescribed educational model that is used to guide the educational component of the ISSP. This model determines educational needs, resources and placement of students. It has five categories of supports for student with disabilities including those who: can be educated in the regular class with supports (2); need a modified curriculum with support due to an identifiable exceptionality (3); require an individualized curriculum because of significant learning difficulties (4); have a severe developmental delay requiring an alternate programme (5). As much as possible all students are to be included in the regular class with their peers (Canning, 1996; NLTA 1998; Pathways, 1998). Today, in general students go to their neighbourhood school and must receive the most appropriate education, wherever possible in inclusive settings (Special Policy, 2002). However, parents and advocates are still having to battle for adequate resources (Doherty, 2003; Crosbie, Luscombe & Vardy, 2001; Jackson, 2001). They also advocate for more training for teachers in the area of inclusion but as of now special education courses for classroom teachers are still not a mandatory part of their programme. This is presently under review.

For many years, concurrent with their fight to change educational policies, the advocacy movement campaigned to close institutions for people with developmental disabilities. Collaborative efforts by the advocacy movement and different levels of government began in the 1970's. Many people lived with their families with minimal if any supports from government agencies. When a family was in crisis, because of lack of community supports, their only option was to send their child to an institution. Some ended up in children's homes such as Exon House and others in the Waterford Psychiatric Hospital. In 1977 an assessment of Exon recommended that there be improvements to the quality of life, including educational opportunities, in the institutions and community supports established with a view of returning people to community (Kappel, 1981).

In 1981 DOSS established a Review Team comprised of advocates and professionals to assess the progress that had been made in these institutions and related community services. The review found that though there had been some improvements in educational policy and community supports there was lack of change in other areas. Children in these institutions for the most part were not receiving an education and essentially this review determined that these 'homes' had not changed and could not change because all, including staff, had become institutionalized. They recommended that government should listen to local voices and not impose its solutions but change policies and direct monies so as to support people with disabilities in the community. As a result government declared that institutions should play no part in the lives of people with disabilities and initiated the closure of these institutions. Admissions to these institutions were frozen and the Children's Home in St John's closed in 1981 but Exon House did not close until 1989. The province became the first to have no children with disabilities living in institutions (Callahan, 1978; Kappel, 1981; Right Futures, 1994). These closures led to the establishment of small group homes run by local associations for those who could not return to families. However, for many advocates group homes were seen only as a stepping stone on the road to independent living.

In the early 1980's advocates again focused attention on the Waterford Psychiatric Hospital where over 100 adults with developmental disabilities lived, some for most of their lives as they had been sent there as children. As with the children's institutions efforts to bring these people 'home' had begun in the 1970's but now there was a concerted effort by both levels of government, the NLACL and the national association to ensure that this would finally happen. The NLACL focused on ensuring that those moving from the institution and their families/advocates would be at

the centre of the planning process. It also focused on community development and linkages as well as supporting individuals and their families through the whole process. Funding, for this project, was provided by both levels of government and individual support teams were developed for each person, somewhat like the ISSP team. This truly was a collaborative effort by all concerned and by 1994 people began to move 'home' (Right Futures, 1994). Although the dream was realized that these individuals would live in their own 'homes' ten years on some of them are now in alternate living arrangements as supports have diminished. As with education adequate resources come and go.

The campaign for services to families and adults in the areas of vocational training and employment also continued throughout this time. In 1977 with the assistance of DOSS and Manpower Canada three Work Oriented Rehabilitation Centres (WORC) came into being, the first of their kind in Canada and were operated by the local associations (NLACL) in St John's, Lewisporte and Corner Brook. The WORC provided training in the centre but about 40-50% of the training was in the workplace with support staff from the centre (Kappel, 1981; LeDrew, 1977; Vera Perlin, 1994). In the 1980's advocates began to seek alternatives to the WORC and sheltered workshops. In 1986 the first Supported Employment Corporation (SEC) opened on the west coast of the province and gradually extended across the province. Basically the SEC seeks work opportunities for people with disabilities and provides support to them on the job. In some cases individuals now own and operate their own businesses with supports where necessary (Group, 1987).

Much has been achieved over the past twenty years and we have seen profound changes in our society. People are no longer locked away in institutions but live in the community and some go to work. In a relatively short period of time we have gone from providing very limited, if any, formal educational opportunities for those with disabilities to special schools for different conditions, special classes in neighbourhood schools to the provision of education for many students in the regular classroom. Many of these changes came about because of ordinary people of vision like Vera Perlin and professionals who were also visionaries but within the service systems of government. As advocates needed them so they needed the advocacy movement but where are we now?

We appear to be in a period of stagnation and even sliding backwards in some areas as services fought for and provided now disappear and it is possible that we are in danger of returning to the medical model. So there is a very real need for advocacy at this time. In the 1990's economic well being

of the nation and provinces became the main agenda item for governments and the level of support of the 1980's dissipated (Stienska & Wight-Felske, 2004). We presently lack visionary leaders and soldiers both within the advocacy movement and the service systems. Perhaps a reason for this lack of advocacy today is that people are too busy with their lives to devote the necessary energy and time required to effect real change. It is possible too that advocates may be seen by the service systems as never being satisfied. Another is that many people, including professionals in the service systems, may be relatively pleased with the present situation as they grew up in an era when children and others with disabilities were segregated and isolated from community. It is enough for them that persons with disabilities are more visible and being supported to participate in the community. Unlike many of us who have been active advocates involved for many years they do not see the deficiencies in the current arrangements but rather they see only positive progress. This applies equally to parents of school children as well as siblings and relatives of adults with disabilities. Have attitudes really changed or do people still stigmatize people with disabilities?

For these reasons it is vitally important that we continue to educate present and future generations about the history of the treatment of people with disabilities so that we might reduce the likelihood of repeating the mistakes of the past. At the same time we must support and encourage the voices of self-advocates since they are the one's living the experience. They know better than any of us the deficiencies that continue to exist. We need to recapture public attention through a mixture of challenge and collaboration with government and reforge the partnerships which enabled the positive changes of the past two decades to occur.

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