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#### Contents

#### Focus on History of Disabilities / L'historique des handicaps du développment

Editorial	i
Ivan Brown	
From Charity and Exclusion to Emerging Independence:	
An Introduction to the History of Disabilities	1
Gary Woodill and Dominique Velche	
Architecture's Quest for Sanity	12
Barry Edginton	
Linking Mental Defect to Physical Deformity:	
The Case of Crippled Children in Ontario: 1890-1940	23
Roy Hanes	
Broca's "Discovery" of Brain Localization in Aphasia	40
Gary Woodill and Marie-Therèse Le Normand	
The Eugenic Legacy	
John P. Radford and Deborah C. Park	
Bureaucracy and Ideology: A Case Study of the Development	
of Community Living Policy in Ontario in the 1970s	75
Tim Stainton	
Mailbag	90
Film Reviews	97
Rook Reviews	00

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#### **Editorial**

#### Reflecting On The History Of Developmental Disabilities

This issue of the *Journal on Developmental Disabilities* marks the end of my 4-year term as editor. Serving as editor has been both an interesting and educational experience for me, and I have grown considerably from it. As the "founding" editor, a great deal of groundwork had to be done, but it has been an honour to have had the opportunity to be able to do such work.

The idea of having a journal that was very accessible to service providers, educators, health professionals, as well as academics, had arisen periodically in Ontario for several years. Getting it off the ground, however, took the enthusiasm of the Board of Directors of the then-new Ontario Association on Developmental Disabilities and, more particularly, of a group of people who comprised the Publications Committee of that organization. Individual members of the Publications Committee deserve recognition here for the considerable time, effort, and expertise they have contributed in carrying out the great many organizational and support tasks. Among these, Rebecca Ward and Adrienne Perry perhaps merit special recognition.

The new editor of the journal is **Maurice Feldman**, Department of Psychology, Queen's University, and Chief Psychologist, Ongwanada, both in Kingston, Ontario. Maurice brings to the position a broad background and considerable expertise in the field of developmental disabilities. He is one of Ontario's most respected professionals, from both the academic and clinical points of view. I am fully confident that Maurice is highly suited to make a solid contribution to the continued development of the *Journal on Developmental Disabilities* during his term as editor.

The theme on which I chose to focus for this issue is *history of disabilities*. Reflecting on our past is never untimely, but to do so in an issue that signals a change in editorship is perhaps particularly timely. Many changes have occurred in the field of developmental disabilities over the past several years, and many more are likely to occur over the next few years. Increasing community involvement, providing efficient and supportive services, educating in an exemplary way, and improving quality within the lives of people with disabilities—all in a context of shrinking funding from governments—are challenges that will necessitate further change and creative innovation. In times of change and innovation, it is usually helpful to reflect on where we "fit" in the larger, historical scheme of things.

Numerous important issues emerge from the articles that follow. Three of these seem particularly relevant for me, and thus worthy of highlight here. First, our thinking has changed quite radically, presumably for the better, in the past 30 years. No longer are the parents of children with developmental delays encouraged by health professionals to institutionalize their children. We have developed a great many new methods of integrating people with developmental disabilities into everyday life experiences in communities everywhere. There has been a considerable change toward accepting people with all disabilities as worthy citizens who have equal rights and their own dignity. These and other changes are clear when we read, in the history of our field, of how things used to be so different—right up to the 1960s and 1970s. Even deinstitutionalization was an idea, but not a reality, until the 1980s, as Stainton points out. It is important for us, when we are compelled to make further changes and innovations, to remember that we have already come a long way in recent years.

Second, it is very tempting, but erroneous, to judge that what we are doing at the present time is a great deal better than what was practised in the past. It does appear to be true that, over the past few centuries, people with developmental disabilities have been institutionalized, ostracized, sterilized, and devalued in any number of other ways. At the same time, there have been many worthy attempts to provide

EDITORIAL

education, training, whole-community environments (institutions), and other services that tried to improve the lives of people with developmental disabilities. It is easy for us to judge these attempts as primitive, misguided, or just plain faulty, and to overlook their benefits within the context of their times. It is also easy for us to focus on the advances we have made, and to overlook the very real possibility that our current attempts may not be without their own flaws. Analysis of the historical practices within developmental disabilities is of little benefit unless we can apply that same type of analysis to our current ways of thinking.

Third, and perhaps most important, historical accounts raise the question of the degree of value we place on developmental disabilities. The many attempts to curb the incidence of developmental disability in some historical periods suggest that it has generally not been valued. Within the last 100 years, for example, the eugenics movement, mentioned in several articles but explored in depth by Radford and Park, showed its lack of value for developmental disabilities by attempting to better the general "stock" of nations in a scientific way by preventing those who were "feebleminded" from propagating. These attempts were primarily aimed at using segregation within institutions, and sometimes sterilization, to prevent additional "feebleminded" children from coming into the world. In its extreme manifestation, the eugenics movement under the Nazi regime in Germany actually sought to eradicate inferior "stock" who were living.

But eugenics principles are still being practised. Prenatal genetic screening identifies many likely forms of disability, and the very fact that potential parents can request this, receive counselling after the procedure, and are freely given choices not to proceed with the pregnancy, all suggest that a disabled baby will be much less valued than a nondisabled one. Many adults with developmental disabilities who live in our service residences and with families are not allowed, and do not have an opportunity, to engage in sexual activity with others. Many others do have such

opportunity but only on condition that measures have been taken to prevent pregnancy. These and other practices raise troubling questions about whether we actually value developmental disability itself, or whether we simply value assisting people with disabilities if we were not able to prevent them coming into the world.

If we do value developmental disability itself, how do we show this? There have been many personal accounts of how lives have been enriched through social involvement with a person with developmental disabilities. But these accounts have hardly begun to explore the complexities of such experiences, and have not even speculated about the complex ways such experiences impact groups of people and societies. At the broader level, our value of disability has not gone beyond protecting some general rights and providing basic care. If we do value developmental disability itself, we need to explore and describe clear ways that the value of developmental disability itself could be shown at the personal, group, and societal levels.

What this suggests is that we—as a field—need to come to terms with our own views, attitudes, and values toward developmental disabilities. In reality, we get so caught up in the demands of everyday service provision, education, and health care that we neglect to stop to examine these fundamental questions. Sometimes it takes a reading of historical accounts to make us stop and think, "My goodness, what made them think that way?"

It is my hope that asking ourselves such a question will also lead us to ask ourselves, "We don't still think that way...do we?" and "What makes us think the way we do today?"

Ivan Brown Editor

#### From Charity and Exclusion to Emerging Independence: An Introduction To The History Of Disabilities

#### **Gary Woodill and Dominique Velche**

Persons who are intellectually or physically different have traditionally been treated with ambivalence in Western societies. On the one hand, there is the "humanitarian" tradition, the impulse to help those perceived to be in need. On the other hand, there is the "social control" tradition, the tendency to want to hide or rid ourselves of those among us who don't fit in.

These dual positions of assistance and repression towards persons with disabilities have a long history in our society, starting with the attitudes of the ancient Greeks, Romans, and Hebrews, and continuing through the history of Christianity. More recently, a third attitude—promoting independence—has gradually been building over the past thirty years. In this brief overview of the history of disabilities, we try to show how the balance between assistance and repression has shifted over time, and how it is now being replaced by a new attitude of supporting maximum independence for persons with disabilities.

#### From Antiquity To The Enlightenment

In ancient Greece, being born with a physical difference was seen as a sign of anger of the gods. The Greeks exposed such "marked" infants to die in order to appease the gods. At the same time, they provided pensions for soldiers who had become disabled as a result of wounds in battle (Stiker, 1982). The Romans abused persons with disabilities in circuses and other forms of entertainment while, at the same time, they developed medical procedures designed to cure or prevent certain disabilities (Scheerenberger, 1982). The Hebrews, as recorded in the Old Testament, held that a person

with a disability is blemished and therefore unable to "offer the bread of his God" (Holy Bible), but also believed that persons in need were to be cared for by the community. Christianity has projected this dualism by associating disability with sin, while promoting healing and forgiveness of those who have sinned (Le Disert, 1987).

In the Middle Ages in Europe, those who were intellectually or physically different were often found living in the community, but at the same time, were usually living as poor beggars. Being a *disabled* beggar at that time was an advantage, in that it was easier to receive alms from the rich if disability were present. Organized guilds of disabled beggars existed, sometimes sharing their "take" and helping each other.

The Enlightenment brought new "scientific" ideas on how to diagnose, classify, and treat the "unwanted" of society. The 1500s in Europe was the period of the development of state welfare, the establishment of locked institutions for those seen as undesirable, and the beginning of medical involvement in the determination of who was really "disabled" (and therefore deserving of welfare), and who was not.

With the rise of science, human beings became both objects for study and for "treatment" by experts steeped in scientific culture. Thus, Francis Bacon's ideas on the domination of nature through the new scientific method were a precursor to Itard's experiments with the Wild Boy of Aveyron. Locke's sensationalist theory of the primacy of experience in learning, promoted in France by the Abbé Condillac, provided the philosophical foundations of the new methods of teaching blind, deaf, and intellectually impaired children. Rousseau's call for a return to nature led directly to the methods of "object teaching" found in the pedagogies developed by Pestalozzi, Froebel, Seguin, and Montessori. The French *philosophes*, such as Diderot, Voltaire, Rousseau, Condillac, and La Mettrie, questioned the legal, moral and religious foundations of the French state while, at the same time, believing in the idea of progress through science and reason. The ideas of progress, perfectability of humans, individual freedom, the

efficacy of empiricism, the importance of direct experience and concrete activity to learning, and many aspects of modern Western culture were Enlightenment ideas on which the new methods of educating and treating disabled children were founded (Winzer, 1986).

#### The Rise of Special Education

Special education with children who were labelled at the time as "idiots" and "imbeciles," began at the end of the 18th century in Zeitz, Germany, in an "industrial school" which offered additional tutoring for children who were "slow." The school was open all days of the weeks except Sundays. Students learned to do work with flax, sew, and draw. Children who had insufficient knowledge for their age received one to two hours of additional help. The idea was that children were to be useful to industry, as well as to develop skills.

Early efforts at educating children with disabilities often were the initiative of private tutors. For example, in 1819, in Germany, Johann Vollharth was involved with "blind, deaf, and blind idiot" children whom he taught in his private school in Weimar. In 1820, another German, Johann Traugott Weise, a teacher at the school for the poor in Zeitz, wrote a book entitled Observations about mentally weak children in regards to their diversity, basic sources of problems, characteristics, and the methods by which, in a gentle manner, through education, we can help them: With special reference to the Pestalozzian methods of calculation. Weise also introduced the traditions of the industrial school into the school for the poor to help the students who were behind. His colleagues complained because he forced them to help the children who were behind, even at mealtime, without pay. He was one of the first educators to develop a systematic plan for special education, and he believed that teachers had to be trained to work with these children. When he died, however, there was no immediate follow-up to his efforts, and the extra tutoring of intellectually impaired children stopped.

Elsewhere in Germany, by 1834 there were also special tutoring classes within the school in Halle, but these ended after a few years. In 1835 a

special school in Chemnitz for those who were "deranged" and "those in need of help" was instituted. A second special class was started in Chemnitz in 1856. By 1860 this special class in Chemnitz became a tutoring class where children in need received separate instruction for 13 hours, later 17 hours, per week. The view of special education at that time was that the special help could be ended after a period of time, and that the children in the special class would be returned to their regular classrooms.

In 1859, another special education class was started in Halle with 17 boys and girls who were "not mentally complete," deaf, blind, physically weak, or "so badly neglected that they could hardly speak." The Halle class became a separate institution in 1862 with a curriculum which consisted of Bible study, reading, writing, arithmetic, singing, and, for girls, hand work such as knitting and sewing. These various pioneering efforts in Germany were reviewed in a 1864 study by Heinrich Ernst Stötzner entitled "Schools for children who are not very capable."

During the same period, Jean Itard in France began to work with "Victor," the "wild boy of Aveyron." Itard, who worked at the Deaf and Dumb Institute in Paris, first saw Victor in 1799. He and Madame Guerin tried to teach Victor to speak and to read. They were only partly successful, but their methods, along with those evolved by Itard's successor, Edouard Seguin, started a tradition which drew attention to the importance of sense-training and stimulation in the development of children's cognitive abilities. At the Salpetrière Hospital, Seguin used Itard's methods to teach intellectually impaired children to read, write and draw, and invented various teaching devices to aid his students. (These were later adapted by Maria Montessori). In the United States, the teaching of "idiot children" began as early as 1818 at the American Asylum for the Deaf and Dumb in Hartford, Connecticut:

It is not to be understood, however, that idiots had not been instructed, in this country, previous to the Autumn of 1848, the period when the experimental school, at South Boston, was

organized. Indeed, there is reason to believe that their instruction had been attempted, with success here, prior to the first efforts in Europe. As early as 1818, an idiot girl was admitted into the American Asylum for the Deaf and Dumb, at Hartford, Conn., and remained under instruction till 1824. Others were received during nearly every subsequent year, and some of them made very considerable progress. In all, thirty-four idiots have been pupils at that institution, and the success which has followed the efforts for the instruction of several of the cases, of which we have a detailed narrative, would do no discredit to any Asylum for Idiots, either in Europe or this country. (Brockett, 1856)

In 1830 in France, Dr. Voisin published a report entitled "Application of the physiology of the brain to the study of children needing special education," one of the first uses of the term "special education." The next year J.-L. Falret created a school at the Salpetrière for 24 "idiots, imbeciles and chronic slow learners." In 1845, Seguin, tired of problems with the administration of the hospital, founded his own private school for such children on rue Pigalle in Paris.

Seguin's fame had spread throughout Europe and North America. Influenced by his methods, the first school for "idiots" in England opened in 1846, followed by the first such school in the United States in 1848. In 1848, Seguin emigrated to the United States where he helped set up educational programs for "mentally deficient" children in the newly formed "training schools."

At the same time as Seguin was developing his "physiological method" for educating children with developmental disabilities in France, Guggenbühl in German Switzerland, and Saegert in Berlin developed their own approaches to teaching children and adults in terms of sensory-motor training and socio-vocational goals. Guggenbühl opened one of the first specially built institutions for intellectually impaired persons near Berne, and this institution was visited by

leaders in the field of "mental deficiency" from many countries, including Dr. Samuel Gridley Howe, founder of the first residential schools for blind children and "mentally defective" children in North America.

The migration of Seguin to the United States spurred on the development of educational institutions for persons with intellectual impairments, so that by 1876 there were twelve training schools in eight states. "All of these schools, frequently in the face of public opposition, were conceived primarily as training schools for education and release rather than as custodial asylums" (Doll, 1962). Seguin credited H. B. Wilbur with adapting his method to classroom instruction:

Wilbur laid great stress on motivation—in arousing the will and the senses from lethargy by utilizing in progressive sequence the muscular feelings, the appetites, the desire for movement, the gratification of the senses, curiosity, affection, and finally intellectual and moral discrimination. Habit was used to govern self-determination. He also emphasized the involvement of the child in active learning with concrete objects and a close relationship between observation, inference, and practical use. He especially interested himself in the developmental aspects of communication (Doll, 1967).

#### **The Eugenics Movement**

The optimism of the 1840s and 1850s gradually turned to pessimism in the late 19th century. The work of Itard, Seguin and Montessori was eclipsed by hereditarian Darwinism and the belief in the immutability of intelligence which characterized American psychology of the early twentieth century. Consequently, Seguin's enlightened educational approach was replaced by the eugenics movement of the early twentieth century, which resulted in the institutionalization and forced sterilization of many persons with intellectual impairments in North America.

By the 1880s, intellectually impaired persons were no longer viewed as "unfortunates" or "innocents" who, with proper training, could fill a positive role in the home and/or community. As a group, they had once again become undesirable, frequently viewed as a great evil of humanity, and placed in the same category as the vagabonds, criminals, prostitutes, and paupers. Anyone remotely connected with the possibility of transmitting "mental deficiency" was viciously attacked. In 1891, the 51st Congress of the United States amended the Immigration Act to exclude "all idiots, insane persons, paupers or persons likely to become a public charge, persons suffering from a loathsome or a dangerous contagious disease, persons who have been convicted of a felony or other infamous crime or misdemeanour involving moral turpitude, polygamists..."

The eugenics movement in the United States received much support from several studies of the family backgrounds of selected intellectually impaired people. In an 1877 study, Richard Dugdale traced the lineage of the "Jukes" family through six generations (Dugdale, 1877), locating 709 out of 1200 descendants. Those related directly by blood to the Jukes had a preponderance of problems, while those related by marriage or cohabitation did not. Although Dugdale attributed the results to environmental factors, his study was interpreted by many as proof of the influence of heredity.

Goddard's 1912 study of the lineage of the "Kallikak" family was also very influential for the hereditarians and those who advocated "negative eugenics" through sterilization or segregation. In Goddard's book the photographs of presumably feebleminded rural kin of "Deborah Kallikak" were retouched with heavy lines which accentuate the facial features.

Like much of the Western world, Great Britain was to experience a "eugenics scare" at the beginning of the 20th century which would greatly influence the treatment of people with intellectual impairments (Barker, 1983; Macnicol, 1983; Ray, 1983; Woodhouse, 1982). For Henry Maudsley, a eugenics advocate, it was a question of national survival. The *Report of the Interdepartmental Committee on Physical Deterioration* (1904) tried to demonstrate that the British, who had just

lost the Boer War, were in a poor physical state, thus contributing to the theory that the nation was in danger of immediate "degeneracy." Degeneracy theory was first developed by Morel in France in the 1850s and essentially held that:

- 1. hereditary trait is polymorphous, that is, the degenerative tendency expresses itself in different ways and with different forms of deviance;
- 2. acquired traits are transmitted to the offspring, and thus parental experiences have an effect on offspring; and
- 3. the condition would become progressively worse from generation to generation if not checked. (Abbott & Sapsford, 1987)

The response to the eugenics movement in Great Britain was a call for segregation because sterilization of persons who were intellectually impaired was deemed to be to controversial.

Alfred Binet in France, who developed the first intelligence test, was an exception to the pessimism of the eugenics movement. He believed that intellectual levels could be improved over time through "mental orthopaedics," a series of exercises designed to improve the intelligence level of "slow" children. But Binet and Simon's work reached the United States in 1908 through Henry Goddard, an outspoken hereditarian who had been appointed director of research at the Training School for the Feebleminded in Vineland, New Jersey. Goddard, who advocated a unitary view of intelligence determined by heredity, was also an enthusiastic supporter of eugenics. By not allowing the "mentally defective" to procreate, he believed, the human stock would be improved. Although he privately supported compulsory sterilization, he felt that the public was more likely to accept his other proposal—collecting and segregating persons with intellectual impairments into closed institutions like Vineland.

However, misgivings about the wisdom of establishing segregated classes

and schools existed from the beginning. The city authorities of Berlin in 1898 wrote, regarding the establishment of special schools, that "the definitive assignment of children to such a school would place upon them the stamp of inferiority for all time, and often prematurely" (Sarason & Doris, 1979). Instead, they preferred the use of auxiliary classes, "but always with the purpose of replacing the special instruction as soon as possible by the regular." An editorial in a leading newspaper in Canada in 1880 railed against special classes for "problem children," arguing, "The boys would be 'branded'! They would be shamed for life! And—most impossible of all—how could such characters be disciplined? The only hope would be the slender one of finding a man of exceptional skill and power in the management of bad-boy nature." Thus, resistance to exclusion also has a history, but one which is not well documented.

#### From Assistance and Repression to Independent Living

There is a third tradition in the history of disabilities which has received little attention. This is the tradition of "self-help" by and among persons with disabilities. In the Middle Ages, before the organization of human service professions, persons with disabilities formed guilds or other forms of association for mutual self-help. For example, in the 14th century in Spain, there were associations of blind persons at Barcelona and Valencia (Le Disert, 1987). Its bylaws, written in 1329, provided for the mutual loan of guides, visits to each other in case of sickness, and a fair division of alms received.

The modern "self-help" movement in the field of disability has its roots in the 1960s with the anti-psychiatry movement, the "living-in-community" model developed by Jean Vanier in the L'Arche communities in France and elsewhere, and the civil rights movement in the United States. These beginnings developed into various self-help movements for persons with disabilities, such as the Independent Living movement and People First. Because of the newness of these movements, detailed histories of them still need to be written.

The history of disabilities is, for the most part, a mix of examples of charity and exclusion. Only now are we seeing examples of resistance to these dominant attitudes in the form of arguments for inclusion and movements for independence.

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#### **Architecture's Quest For Sanity**

#### **Barry Edginton**

Lunatic asylums were not built on purpose, up to the end of the 18th century. Rather, they were established in, and made use of, existing buildings. The bridewells, houses of correction, gaols, prisons, and workhouses that covered England from the 17th century on are well-documented as institutions for the confinement/ treatment of madness in all its variations. Throughout their history, asylums housed a number of different types of individuals with varied disabilities under the general term "madness."

The reason for this is difficult to discern, since there is no evidence, save secondary accounts, to allow for an exact analysis of the types of disabilities treated under the general category of madness. However, since madness was associated with the loss of normal functioning and thought to be easily identifiable, those refusing or unable to participate in the normal functioning of society were labelled mad. Usually the only criteria for their confinement was that they could neither support themselves nor find someone to support them. Those crowding the already filled wards and halls of these asylums may have had a physical, perceptual, or developmental disability that prevented "normal" functioning in society.

In the 19th century, the etiology of madness tended to be social rather than medical (Jacyna, 1982). Cause was linked to behaviour and many types of disabilities may have been seen as irrational behaviour. Even by the end of the 19th century, it was argued that madness was so obvious a malady that anyone could not fail to recognize it (Maudsley, 1897). Thus, the scope of the definition was as vague or specific as those who did the defining wished it to be.

Throughout this paper, in an attempt to remain true to historical practice, I will use the terms mad/insane to refer to those treated as mad/insane. The use of these terms does not mean that this was a homogeneous group, but rather it relates to an

aggregation of diverse individuals, since, in practice, asylum authorities regard every homeless, hungry person as dangerous to be at large. For many societal casualties, the asylum came to be known as a good provider of food and shelter.

Records show the continuous use of asylums to house part of the overwhelming population of mad throughout the 19th century (Anstie, 1865). This type of treatment (confinement) was changing and new institutions, reflecting current ideas of insanity, were built. These new buildings, used as a mode of treatment, became architectural artifacts in a search to understand how the formalization of specific ideas about the treatment of insanity became manifest in the asylum. In general, the function of the building was important not only to architects but also to physicians.

Ideas about particular maladies and their treatments were realized in the construction of particular institutions. "These discourses enable buildings to become transparent; that is, instead of erecting an opaque and reflective surface behind them, which fixes the interaction between observer and object, it allows them [asylums] to speak of a larger world of ideas, society, values and relationships" (Markus, 1982, p. 5).

Since there were few known medical treatments for insanity during the early 19th century, asylum superintendents had to look to the order, routine, and discipline of asylum life for treatment. Treatment, it could be argued, would be applicable to any type of disability. The principle of treatment was to order the everyday life of the patient. Routine, discipline and classification (order) became the central aspects of building and landscape. Both the building and its landscape were designed to facilitate order and routine and, by association, rationality of action. In other words, order and routine were used to create sanity. The day-to-day living conditions of the patients took priority over medical treatments by asylum superintendents since medical knowledge offered little. For example, at the first Yorkshire Asylum at Wakefield, "treatment...made relatively little progress, although much was done to improve the general lot of the patients. Attention was given to diet, hygiene, accommodation, pastimes and amusements..." (Ashworth, 1975, p. 33).

The assumption of treatment was that by providing a calm, natural environment the asylum would soothe insanity within the person. Through design, an environment close to the idealized harmony of domesticated nature and bourgeois family life would be created. The diversions of daily life were to create an environment that had the ability to reattach the individual's disability to a material reality built specifically to promote order in individuals assisting in the return of their sanity. Although the asylum has been cast as an oppressive institution of order, discipline and routine (Scull, 1979), there is no evidence that these institutions were, by design, unhealthy or oppressive. Also, the horrors of asylum life can be linked more to overcrowding and human interaction than to architectural design (Philo, 1987). It can be argued further that, no matter how oppressive these institutions seemed, they were better than the living conditions of the disabled outside the asylum. "Confinement and discipline came with food and shelter providing a refuge to all those in need" (Nye, 1988, p. 136).

It is obvious that the intention of the builder was to create a salubrious environment, yet it is also obvious that asylums were to provide a space where the observation of behaviour was possible (Micale, 1985). By permitting direct observation of grouped maladies, the varieties of madness allowed for the separation of particular disabilities. The asylum would, in theory, create a population that could be subdivided according to the similarities of particular disabilities, allowing for the growth of particular institutions: for example, idiot asylums.

In *The Birth of the Clinic*, Michel Foucault (1973) illustrated the process by which this nosography of pathology takes places. The chapter, "Seeing and Knowing," places the necessary condition for observation (gaze) in the clinical space of the institution. This space was needed to discern the types of madness, while, at the same time, providing a base from which the results of these observations would become the text for the next generation of medical practitioners. Foucault's analysis holds for asylum construction space, for "clinical observation involves two necessarily united domains: the hospital domain and the teaching domain" (p. 109). The creation of a place to construct the nosology of insanity requires a domain

"...in which comparison is possible and open to any form of pathological event" (p. 109).

By creating a place in which to *capture* insanity the architect made knowing the insane a possibility. Deleuze and Guattari use the term *capture* to describe the "...incorporation of bodies, their powers and capacities...[that] only exist in its concrete manifestations" (Patton 1991, p. 47). Capturing includes all mechanisms engaged in the extraction of information about a particular object: "We know nothing about the body until we know what it can do, in other words, what its affects are..." (Patton, p. 46). Therefore, institutional aggregation was a necessary step to developing new clinical categories. This was followed by the separate institutionalization of specific disabilities.

My point in this paper is: how do you create a space for insanity without knowing its particularity, its essence? Therefore, I am interested in the stage prior to clinical surveillance: how the design of these purpose-built institutions was determined. I am not, for this paper, concerned with the continuous construction of "lived, real space" referred to by Foucault as "hetrotopias," but with the construction of "utopias" (Soja, 1989, p. 17).

Utopias are sites with no real place. They are sites that have a general relation of direct or inverted analogy with the real space of Society. They present society itself in a perfected form... (Foucault, 1986, p. 24)

The asylum, as the site of insanity is not a place of the insane but a space of perfected sanity. The ideas of the architects are not tempered by the lived experiences of the mad, but are tempered by the current ideas about madness. The space of the asylum was constructed prior to knowledge about its functioning as a community (asylums were designed as self-sufficient, autonomous institutions). The site of insanity does not exist in the relation between elements within the discourse of insanity, but does exist within the context of a 19th-century utopian formulation of sanity (Foucault, 1986).

How did the architect determine the particular needs of these individuals? If the asylum was not designed as a place of insanity but as a refuge, as a space to regain one's sanity, what were the particular qualities of a sane environment in which one would "place" the insane?

For the architect, the disabled body lives within a particular environment. Its nosology exists in the context of a system of lived differences. In practice, the architect who built an asylum initiated a discourse on insanity based upon the premise of lived opposites: insanity/sanity. Insanity can be understood as a signification that an already sane or able body assumes, but even then that signification exists only in relation to another, opposing signification.

The model of sanity or ability is already constructed as part of the social world: "the abnormal, as ab-normal, comes after the definition of the normal, it is its logical negation" (Canguilhem, 1991, p. 243). Thus, in-sanity (and/or dis-ability) is defined by what comes after the in- or dis-; it is not defined by what people have or are but by what they lack.

If the purpose of the asylum was to create sane individuals through a reflection of sanity, then, which body is the text for its construction? Those architects/builders, in designing an appropriate asylum, did not "use" the body of the disabled/insane to constitute their maladies in construction, but rather they "used" and reflected ability/sanity in their asylums. The sanity and abilities of social life situated normalcy in the domesticated environment of 19th-century England (Showalter, 1985). The asylum represented sanity—a sanity drawn from the salubrity and ordering of nature.

The asylum reflected both natural order (the landscape) and social order (the bourgeois community). But since nature and society are imitated, what is produced are their reflections, not their reality (Lefebvre, 1991). This was also true of individuals. What represented sanity was the representation of sanity in the individual's behaviour. The reproduction of a sane environment within which to house the insane assumed that the body/mind would follow the form of nature and reflect its tranquility.

The perception that the environment is normal and natural and that placement of the abnormal within this environment would make them normal or healthy, assumes that sensation is normal for both the sane/abled and insane/disabled. If sensation is the means to acquire sanity, and if sanity is the placement within a sane environment, then sensation cannot be abnormal (see Canguilhem's discussion of Tarde, 1991). Therefore, the insane had the ability to become sane, and what had to be provided was the environment (this may not be true for certain disabilities, such as blindness). The growing attention to architecture and design during the 19th century created a specificity of institutional types that were developed to fit the particular behaviour of those to be incarcerated. Design was not dictated by the nature of each particular disability but by the social construction of that disability (Gilman, 1988).

The exterior of the 'new Building' now completed and partially occupied, is not pre-possessing, but the lightness, cheerfulness and agreeable temperature found within, the sense of adequate space, and the appearance of comfort, added to an extensive view of the surrounding country, commanding a distant view of the town of Wakefield, with its beautiful church and spire, and finely undulating distant back ground of the Yorkshire and Lancashire hills - are objects unquestionably of greater importance than a building of a more agreeable aspect (Report of the Director of the West Riding Lunatic Asylum, May 1847).

Much care was given by asylum architects to everyday design since design was treatment. A note from the Visitor's Book of The York Retreat illustrates the motive behind specific elements of design: "We were interested to notice the excellent fixed pictures in the part occupied by the more refractory patients, and were informed that the brilliant colours were used so as to produce brain waves" (27 October, 1900). Another example is the design of the patient's room door: it opened out to prevent attempts to block entrance. This attention to detail can be seen in many asylum designs (Edginton, 1994).

The architect was to construct a facility that ensured the detailed ordering of

placement, movement, and perception for all those within its space. The building assessed the limits and types of bodily activities that would define a person as able or disabled, and as sane or mad. Asylum architecture, in its quest to create sanity, became a space for clinical evaluation and a place of sanity. The director of the West Riding Asylum stresses the importance of the asylum as a method of treatment, a place of sanity.

Classification of the type of insanity, social class and behaviour became part of the asylum's discourse and design. Appropriate classification was a problem in the design of small, private asylums as well as 18th century Bethlehem and St. Luke's whose designs being either too small or too large inhibited clinical observation. Size and population—density—became very important to the architect since patients' behaviours viewed after incarceration were seen as a reaction to the space provided and allowed for the administration and/or separation of those who responded one way or another to the constructed environment. The developing profession of psychiatry needed a "space for its intervention" (Castel, 1975), and the architect provided that space.

Those who are violent, require to be separated from the more tranquil, and to be prevented, by some means, from offensive conduct, towards their fellow suffers. Hence, the patients are arranged according to classes, as much as may be, according to the degree in which they approach to rational or orderly conduct. (Tuke, 1964, p. 141)

The focus of asylum treatment was not internal to the building as it is in the modern hospital, but outward to the healing calm of nature. This is evident when looking at the details of asylum design: great window space, verandas, large day rooms, gardens, sports facilities (bowls, tennis and cricket), and farm. Even the perspective from the buildings was part of the design. English asylums have a southerly aspect that allows for a flowing view of the grounds and countryside around. The design ensures that there is little interference from other buildings. Asylum appearance was not to be perceived as opulent, however. The architect's use of a particular design, more akin to a spa than a prison (Havins, 1976), demonstrates the architect's

desire to connect nature with the body through design. Since asylum construction and support came from local taxes (rates), the design was to be plain and the administration frugal. In principle, each asylum was to be self-sufficient, forcing the architect to design a small community, not just a building.

Nineteenth century ideas about the treatment of insanity embodied humanitarian values (moral treatment) in an attempt to transform the unreasonable to reasonability. Implicit in this method of treatment is the notion of a moral or psychological cause of insanity that could be remedied through kindness and proper atmosphere.

This "moral" management further supported a particular architecture—a sober, orderly environment that did not excite, but placed the patient in touch with social as well as natural supports. Design was to assist in patient self-control, discipline in proper habits, removal from excitement, and proper classification to afford treatment. If, as Esquirol said, the asylum is a therapeutic instrument (Donnelly, 1983), then design is management/treatment.

Architects came to control the field of asylum construction since it was thought that they had the ability to design this sane environment. Architecture became a profession in 1834 and attempted to control the design and construction of public buildings (Kaye, 1960). The Commission in Lunacy (CIL) as well as the Royal Institute of British Architecture (RIBA) attempted to ensure that asylums would be designed by accredited architects. In the 19th century, the design of asylums was viewed as a specialized task, and architects who designed and built asylums did not build prisons or workhouses (Harper, 1983).

These design principles held such influence over 19th-century asylum construction that they can be found in a speech given by the premier asylum architect, George Hine, to a meeting of the RIBA in 1901:

Asylums are built for people who cannot take care of themselves, and who have to be watched, nursed, and provided with employment and recreation under conditions inapplicable to sane people; and to provide for all these, while the subjects are under enforced detention, a very special knowledge is required to make their lives bearable, and, as far as possible, comfortable. (p. 161)

To the architect and the physician the organic wholeness of the body signified sanity; a body, in theory a mind, was to be exposed to a wholeness outside itself (Sennett, 1990). The asylum's unity of space, with its occupants, exposed the patient to a constructed wholeness of mind, body, place and nature (Lefebvre, 1991). This was an asylum that signified sanity: the end of an architectural quest and the beginning of clinical psychiatry.

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#### Linking Mental Defect to Physical Deformity: The Case of Crippled Children in Ontario: 1890-1940

#### **Roy Hanes**

Note—Throughout this article the author uses the term "crippled" in reference to people with orthopaedic disabilities. The article is concerned with exploring the social construction of orthopaedic disability as a medical phenomenon and during the era addressed in this article the term crippled was applied to children with orthopaedic disabilities. In essence, children with orthopaedic disabilities did not exist, but crippled children did, and in the author's attempt to be as accurate as possible, the jargon of the era is used. Similarly, the author uses terms such as mental defect in reference to people with intellectual impairments, as this was the term used during the late 19th and early 20th centuries.

The stigma and medicalization of disability has often led to the subjective assignment of nonrelated traits for the individual who was disabled. For example, many children with physical disabilities were treated as though they were intellectually impaired, morally corrupt, and psychologically disturbed. This "spread phenomenon" dominated medical, professional, and lay ideology towards people with disabilities at the turn of the century, and this ideology dominated most of the care and treatment programs that were established for children with physical disabilities in Ontario during the early years of the twentieth century.

It is this social construction of children with orthopaedic disabilities (crippled children) that will be explored in this article. In doing so, the article explores how children with physical disabilities came to be seen as having further deficits, such as mental defects. In addition, the article examines how this image of mental defect was adopted and promoted by medical specialists, such as orthopaedic surgeons, and became part of the care and treatment programs established for crippled children

in Ontario during the late 19th and early 20th centuries. The article pays particular attention to the development of educational and vocational training programs for crippled children, and especially to how these programs reflected the social image of the crippled child as being both physically and mentally defective.

There has been a growing body of literature, in recent decades, that supports the argument that physical and intellectual disabilities are socially constructed (Albrecht & Levy, 1981; Finkelstein, 1981; Friedson, 1965; Gliedman & Roth, 1980; Liachowitz, 1988; Oliver, 1990; Scott, 1969; Wendell, 1989). This view stems from the contention that disability represents much more than the identifiable/measurable biological impairment(s) of the individual. Albrecht and Levy (1982), for example, while maintaining that disabilities do have an objective reality, concluded that the overall consequences of disability are determined by the social meanings associated with it:

Despite the objective reality, what becomes a disability is determined by the social meanings individuals attach to particular physical and mental impairments. Certain disabilities become defined as social problems through the successful efforts of powerful groups to market their own self interests. Consequently, the so-called objective criteria of disability reflect the biases, self-interests, and moral evaluations of those in a position to influence social policy. (Albrecht & Levy, 1980, p. 14)

A review of the literature pertaining to the care of crippled children during the late 19th and early 20th centuries supports Albrecht and Levy. This literature suggests that the everyday experiences of this population were shaped by the social meaning of disability. Disabled persons including crippled children were viewed as social misfits, and during much of the 19th century they were either hidden at home or placed in institutions such as insane asylums, jails, workhouses, and orphanages.

Although hospitals and other institutions for crippled children later replaced the asylums, workhouses, and orphanages the stigma of disability remained. Many

professionals, such as orthopaedic surgeons, educators, and social workers maintained the stigma of disability through their activities and interventions, which perpetuated many stereotypes about crippled children including the doctrine that crippled children were not only physically disabled but they were intellectually impaired as well.

By 1940, the lives of disabled people including crippled children had become dominated by the medical profession (Enns, 1981; Stone, 1984). Although the shift towards medical control did bring about a more humane and charitable approach in addressing the needs of crippled children, long held stereotypes remained. For example, the orthopaedic care and treatment of crippled children went beyond the traditional realm of medical and surgical intervention to include an educational component. The introduction of education programs can be seen as a progressive move, but in reality these programs incorporated the prevailing opinion that physical impairment went hand-in-hand with intellectual impairment. As a consequence of this principle, the education offered to most crippled children was heavily influenced by nonacademic vocational trades training.

What seems clear is that the social meanings linked to disability were of utmost importance. In the case of crippled children, because these children had a physical impairment they were also treated as though they had an intellectual impairment. This connection between the physical, intellectual and moral was made despite the fact that there was no evidence to suggest that having a physical impairment automatically lead to these other impairments and attributes.

#### **Historical Roots of the Medicalization of Disability**

Disability as a distinct category of people is dominated, in contemporary society, by medical professionals and para professionals. But an examination of the development of disability suggests that recognizing disability as a medical problem is a relatively recent phenomenon. Stone (1984) argued that legal and administrative conceptualizations of disability dominated service provision for people with

disabilities from the early 1600s to the early 1900s. She claimed that disability originated as a social/legal concept to separate deserving poor from non-deserving poor persons. Lay magistrates were used in England to determine eligibility for relief and had responsibility for distinguishing persons with disabilities from ablebodied people. Magistrates, during the 17th and 18th centuries, allocated beggar's licenses to those deemed disabled, and judges had responsibility for determining compensation benefits for injured workers in the 19th and early 20th centuries.

In the early years of the 20th century, disability began to be thought of in terms of constituting a medical category (Stone, 1984). The medical profession was increasingly recognized as having scientific expertise, which, interestingly, came about at a time when public charity was also trying to establish its scientific credentials. Stone tied the origins of the clinical concept of disability to the convergence of scientific medicine and the introduction of social benefits during the early 20th century: "Clinical medicine offered a model of illness that gave legitimacy to claims for social aid, and it offered a method of validation that would render administration of the category feasible" (p. 91).

It is important to understand how and why the medical profession gained control of the evaluation of disability and clinical judgment replaced many of the intrusive and adversarial mechanisms used in determining eligibility for social welfare benefits or for workers' injury benefits. The medical profession came to be seen as having a scientific basis. This recognition resulted primarily from germ theory which set out the biological explanation for diseases, and from other medical discoveries, such as the stethoscope, the microscope, and later the discovery of X-ray photography. Such medical developments contributed to the image of the medical profession as scientific and objective.

The discovery and development of these devices also allowed medical practitioners the opportunity to actually peer inside the body and, in doing so, to observe its internal workings. "It seemed to be a more powerful kind of investigative device that magnified, and made visible, the formerly invisible" (Stone 1984, p. 105). As a result, clinical medical judgment became increasingly recognized, and this

eventually expanded to using medical opinion as an acceptable means of evaluating claims for disability assistance. "Although the applicant for social aid would actually be undergoing a mandatory examination for the purpose of determining his motivation and ability to work," suggested Stone, "the test had all the trappings of a voluntary, patient-initiated, therapeutic encounter" (p. 107).

Although physicians began their involvement with persons with disabilities as part of a process of determining eligibility for social and compensatory benefits, the process of evaluation was broadened to include other needs. For example, when the "Cripple Classes" were opened at the Wellesley Public School in Toronto in April, 1924 (Minutes of Toronto Board of Education, April 15, 1926, p. 95), orthopaedic specialists from the Toronto Hospital for Sick Children examined the children and determined who could be in the class. Moreover, it was these same surgeons who prescribed the number of hours of schooling, physiotherapy, and occupational therapy each child could receive per day. In time, orthopaedic specialists became concerned with the psychological well-being of the child and part of the assessment for the Cripple Classes included referring the children to psychiatrists for evaluation.

By the late 1920s and early 1930s, the education and vocational training of crippled children became a central component of the child's care and treatment, and orthopaedic specialists acquired significant influence over the type of education and training provided to crippled children in Ontario. Thus, we find that the involvement of medical practitioners, especially orthopaedic specialists, in the lives of crippled children went far beyond the provision of medical care and treatment (Annual Reports, Toronto Board of Education, 1927 to 1935).

## **The Mind-Body Connection**

During the late Victorian era and during the early years of this century, the attainment of good health was considered to be a moral obligation and a measure of one's character. Haley (1978) argued that the pursuance of good health, at least

for the urban middle class, was a primary concern of the day. The topic of health, according to Haley, outranked war, famine, politics and science as topics of discussion. People hiked, swam, went to spas, took medication for all ailments, dieted, followed practices of holistic medicine, and sampled new medical techniques such as hydrotherapy, heliotherapy and electrotherapy. "Total health or wholeness...was the dominant concept for Victorians, as important in shaping thought about human growth and conduct as nature was to the Romantics" (p. 17).

It was this desire for good health that molded Victorian bourgeoisie images of themselves as whole, moral, and spiritual persons. Furthermore, it was also these same desires for good health and the connection of good health to good virtue that helped create bourgeois images about persons who were diseased, sick, defective, or insane. Although Victorian intellectuals and professionals were aware that sickness and disability were not necessarily the fault of the individual, they still believed that one's character was molded according to one's bodily makeup and physical health:

Victorian intellectuals insisted on the reality of a spiritual life higher than that of the body, but in one way or another they all thought physiologically: they adapted the well knit body as their model of the well formed mind and the mind-body harmony as their model of spiritual health. (Haley, 1978, p. 4)

These Victorian beliefs about disabled persons, including crippled children, were well developed by the late 19th century. In many ways, it was these ideals that laid the foundation for many of the care and treatment programs developed during the final decades of the century and during the early years of the 20th century. Although there were many beliefs underpinning attitudes toward the "cripple classes" two dominant ideas appear to stem from the rise of scientific medicine, which, by the end of the 19th century, was focusing on the interconnections between body systems. First, the development of physiology investigated the internal workings of the body and revealed the interrelationship between various organs and systems. Second, there was a growing connection between the sciences of physiology and psychology

which suggested an interdependence of the mind and body. In essence, these "systems theories" in one way or another promoted the belief that a healthy body bestowed a healthy mind and an impaired body held an impaired mind.

Many professionals referred to the psychological characteristics of the crippled child as a "mental warp," which they considered to be an impediment to the child's physical and psychological development. This view was perpetuated by Gwilym Davis, President of the American Association of Orthopaedic Surgeons, in 1914. Davis argued that "cripples as they grow acquire what has been called a mental warp which is in the highest degree detrimental to their development and progress" (p. 2). A similar view was held by John E. Fish, in a speech to the National Conference on Charities and Corrections in 1920, where he stated that physical impairment and mental problems went hand in hand. Dr. Fish concluded that "when a crippled child has acquired an irritable condition of the nervous system, a warped and crippled mind, he presents a pathetic picture indeed" (Fish, 1920, p. 225).

Still, the latter part of the Victorian era witnessed a major turning point regarding the care of crippled children. Although cripples were not recognized as equal citizens, the perception of cripples as totally dependent persons requiring institutionalization gradually changed to a perception of cripples as potentially trainable and curable. This conceptual shift was reflected by the rapid increase in services for cripples, including the rise of orthopedic surgery, the development of special hospitals, group homes, and the establishment of educational and training programs for crippled children.

This did not mean, however, that this was a golden age for cripples. Orthopedic hospitals and training facilities may have replaced the almshouse and workhouse, but a negative public and professional attitude still prevailed. The ongoing cruelty faced by disabled persons was discussed by early 20th century disability theorists Sullivan and Snortum (1926) who concluded that "while the overt cruelty toward the handicapped tended to decrease with each tide of civilization, the prejudices and innate prepossessions that marked earlier times persisted" (p. 2).

Crippled persons were still viewed as a defective class, and the primary objective in the care of cripples was to prevent cripples from becoming social parasites. It is in this vein that the development of programs, hospitals and convalescent facilities for cripples is best understood. During the late 19th and early 20th centuries, the image of the cripple as a potential or actual burden and the image of the cripple as having emotional, psychological, and character problems dominated all care and treatment programs for this population.

### The Economic Burden of the Crippled Child

In the culture of the late 19th and early 20th centuries, economic independence was as important as physical and mental well-being in the conceptualization of crippled children. Social support for dependent and defective people was influenced by concepts of Christian charity, but it was also influenced by the Protestant work ethic, particularly the values of self-sufficiency, industry, and morality.

It was considered a moral duty to be a self-supporting, economically contributing citizen, and a degradation to be a burden to one's family, friends, or community. The inability to succeed in a physical sense was considered indicative of the person's inability to succeed in a spiritual sense, and thus morality was tied to issues of work, religion and social dependence.

Socio-economic considerations regarding the causes of poverty and pauperism, concerns for morality and character, the work ethic, attitudes about the healthy body and mind, and the desire for a sound economy and secure nation influenced public and professional attitudes toward disabled persons and orthopaedic surgeons contributed to this negative stereotype of crippled children.

Gwilym Davis, M.D. (1914) wrote as follows:

A cripple is a menace to himself and community and is apt to become a burden on his relatives, his friends and the public. The aim then is to improve his physical condition and character and to make him, to as great an extent possible, self supporting, self respecting, self reliant, and able and willing to take and perform his part in communal life. (p. 1)

As with children with intellectual impairments, the image of the crippled child as a burden superceded concerns for the individual child's care. Moreover, the concept of burden implied concerns about the overall effect of being a burden on the family, the community and the state. For example, at the annual general meeting of the National Conference of Charities and Corrections in 1898, Dr. W. B. Platt, an orthopaedic surgeon, discussed his concerns regarding the dependency of crippled children. These concerns went far beyond the immediate consequences of providing medical care and treatment to the individual. He argued that crippled children, through their mere existence, had the potential of creating widespread economic consequences for society. "[W]e must consider the value of [the crippled child's] labor to the State, which is entirely lost, and the value of the labor of those who are employed to care for him, and who would otherwise be adding to, and not consuming, the resources of the State" (Platt 1898, p. 402).

The theme of economic liability of crippled children continued for many decades and orthopaedic surgeons can be found making speeches and writing about the economic burden of crippled children well into the 1930s. In a speech to the Toronto Rotary Club in 1934, the distinguished Canadian orthopaedic specialist Richard Harris, spoke of the importance of helping crippled children become economically independent adults. He spoke of the important role that orthopaedic surgery played in meeting those ends, stating that "the development of surgery through the introduction of anesthetics and antiseptic surgery laid open the road for the rehabilitation of the crippled" (Rotary Voice, Vol. 16, No. 813, Mar. 21, 1934). In addition, he also pointed out the importance of providing education and vocational training as part of the follow up care and treatment for crippled children. "Crippled children," he maintained, "must be taught to make a living by use of their brains rather than physical exertion, and therefore education is essential. Without proper guidance many such cripples might fall by the way."

Orthopaedic surgeons promoted themselves as having the expertise to help crippled children, but claimed to be considerably more. Abt (1924) argued that "we are not solely the medical attendants of these cripples, but to a certain extent their guardians" (p. 45). Frederick Watson, nephew of Sir Robert Jones, the eminent British orthopaedic surgeon, even referred to orthopaedic surgeons as divine beings: "...to crippled children, the orthopaedist is a messiah" (Watson, 1930, p. 46).

Instead of staying within the parameters of surgical intervention and medical care, orthopaedics took their intervention a step further and became involved in treatment that emphasized a reconstructive or rehabilitative component. The orthopaedic care and treatment of crippled children went far beyond the straightening of bones, the cutting of muscle, the severing of ligaments and tendons, and the application of splints and braces. Orthopaedic surgery exploited the social concern for the self-sufficiency of cripples and made economic independence a central theme in its approach.

The question is why these surgeons became interested in the economic self-sufficiency of crippled children. One possible answer, of course, is that orthopaedic surgeons, like many of the professional and middle classes pitied the crippled children's misery and dependency, and wanted to do what they could to remedy the situation. Another possibility is that orthopaedic surgery, like many branches of medicine, was trying to gain credibility within not only the medical fraternity but also the public, and the possibility of helping to reduce any form of dependency, especially social dependency, granted the profession a substantial level of credibility. Considering the poor state of affairs within orthopaedic surgery during the late 19th and early 20th centuries, orthopaedic surgeons needed to use every opportunity available to enhance their credibility and their profession. This was achieved through speeches, lectures and publications by orthopaedic surgeons and it appears that the theme followed a similar pattern: emphasize the social costs and problems of crippled children and emphasize the role of orthopaedic surgery in eradicating these concerns.

### The Provision of Educational and Training Services

During the late 19th century and up to the onset of World War II, there were very few differences in the philosophies underpinning the educational and training programs for crippled children in Ontario, the United States and Britain. The professionals concerned about the care, treatment and education of crippled children, whether in Toronto, New York, Boston or London, professed very similar ideals and promoted very similar approaches. Two themes dominated: first, the education was rarely to be continued past the level of junior high school; second, the education of crippled children was to emphasize trades training above academic studies.

Orthopaedic surgeons began expanding their authority into the realm of education and trades training in the late 19th century, and by the early 20th century orthopaedic surgeons had an influential role. The status of orthopaedic specialists as experts continued to evolve, and soon crippled children had to be evaluated by orthopaedic specialists before they could enter educational programs. In addition, many orthopaedic specialists before and after World War I were involved in planning educational and training programs for crippled children. Since the early years of the 20th century orthopaedic surgeons had argued that education was an essential component of the crippled child's care and treatment. Some orthopaedic surgeons such as Gwilym Davis suggested that without education the benefits of surgery would be lost. "There still remains a factor," Davis maintained, "which if ignored will render most of the previous surgical work useless and that is education. By education is meant training. Training not only of a limb, but of the body, the mind and the formation of character" (Davis 1914, p. 2).

In 1911, legislation was introduced in Ontario to address the educational needs of physically disabled and intellectually impaired children. *An Act Respecting Special Classes* granted permission to local school boards to establish special classes for intellectually impaired and physically disabled children, but the legislation did not make the introduction of these special classes compulsory for the schools.

Although this legislation was introduced in 1911, there had been special education

for disabled children since 1896, when some basic education was provided for the children at the Bloorview Home for Incurable Children in Toronto. Although the province may have recognized the need for providing educational opportunities for disabled children, it left the decision to introduce special education up to the local authorities, and the province took no direct responsibility for funding or providing education for crippled children. Not until the mid-1920s did school boards in the larger urban centres of the province establish orthopaedic classes for crippled children. For example, in Toronto "Cripple Classes" were introduced at the Wellesley Public School in 1926 and "Sunshine Classes" for crippled children were established in Ottawa in the same year.

In 1914, the act was amended, and the educational needs of intellectually impaired and physically disabled students were covered under *The Auxiliary Classes Act* of 1914. This made admission into the auxiliary classes more rigorous and scientific, as each child had to be interviewed by the principal of the school and the local inspector of schools. In addition, the child also had to be examined by the chief medical officer for the school board.

The Auxiliary Classes Act governed the provision of education for crippled children from the mid-1910s to the onset of World War II. The act indicated which types of classes were to be considered special classes, and these included open-air classes, hospital classes, sanatorium classes and ambulance classes. In 1927, other classes were covered by the act, such as industrial classes, aural education classes for deaf children and Braille classes for blind children. In 1930, auxiliary education was expanded to include children in rural areas, children in small towns and villages and children who were unable to leave their homes, in which case home instruction was provided. The changes to the Auxilary Classes Act also included transportation to and from schools for disabled children (Borthwick, 1979).

The changes to legislation that offered the best opportunities for education for the crippled children were those changes pertaining to home instruction by visiting teachers and the provision of transportation. However, since the legislation did not make special education for physically and intellectually impaired child compulsory

for the schools, many communities did not introduce any special educational opportunities for crippled children. The lack of educational and training opportunities for crippled children was so stubborn a problem that the executive committee of the Ontario Society for Crippled Children was expressing its concerns about it well into the 1930s.

While educational programs were made available to crippled children in the larger urban areas after the mid-1920s, the quality of the education was suspect. The Toronto Board of Education was so concerned about the poor quality of education provided for crippled children that the board appointed a Committee to review the efficiency of preparation of disabled young people (Ontario Society for Crippled Children 1941, minutes of Mar. 18. 1938). This committee found that the education of crippled children was limited to the elementary and junior high school levels and did not include secondary education or preparation for post-secondary education. As a result of these discoveries, the Toronto Board of Education recommended that the education of crippled children be expanded to include secondary education.

By the early 1920s, charitable organizations were established as a means of providing for the needs of crippled children. The Ontario Society for Crippled Children, for example, was established in 1922 and the Society undertook the responsibility of providing services to crippled children across the province. Initially, these services were related to the medical care of crippled children but by the early 1930s the Society became involved in the development of educational and training programs. The Vocational and Educational Committee of the Society supported the Toronto Board of Education's recommendations calling for the establishment of secondary and post-secondary education programs for disabled adolescents. But although the Society as a whole supported the establishment of more educational programs for crippled children and adolescents, it did not support academic education that would lead to college or university training. Thus, the Vocational and Educational Committee began to advocate a utilitarian approach to education, which had as its objective the training of disabled youth for employment. "A university education," it was argued, "is desirable but the cultural as such should not displace the utilitarian. No false hopes should be created, but earning a living is of cultural value" (Ontario Society for Crippled Children 1940, minutes of Oct. 21, 1938).

It was maintained that the education and vocational training of crippled children should centre on trades training, which was considered of greater value to the disabled youth and to society. There was never any mention of the actual wants and desires of the disabled youth. The educational experience of crippled children did not have and was not intended to have any intrinsic value for the physically disabled child or adolescent.

The Society began lobbying the provincial government for funding for educational and training programs for physically disabled youth in 1936, and the Society's efforts continued throughout the remainder of the 1930s and the 1940s. Despite these efforts, the Society was not successful at getting the province to commit itself to establishing a residential facility or getting the government to support more educational and training programs in the Depression. Not until 1949 was a residential training facility opened for physically disabled youth in the province, and even then the facility was built and subsidized by funds from Variety Clubs International. Again we see the reluctance of the government to become directly involved and a service club organization stepping to fill the gaps.

The ideology and the attitudes of professionals, including orthopaedic surgeons, educators and social workers, regarding the educational needs of crippled children had changed little in the early 20th century or until the 1940s. Many of the concerns and issues raised before World War I recurred throughout the 1920s, 1930s and 1940s. Never in all this time was there any consideration of academic secondary or post-secondary education for crippled children and adolescents. University and college education were considered inessential, as professions requiring post-secondary education were considered beyond the reach of this population.

The educational programs that were developed for crippled children were based on an ideology that viewed crippled children as worth saving, but at the same time morally delinquent. This belief was evident in educational programs for crippled children in Ontario and was similar to the philosophy underpinning crippled children's education in both England and the United States. As a result of the concern about the moral qualities of crippled children, their education focused on character development and the instilling of good moral values. Education and training "endeavored to supplement the work of the hospitals, to strengthen and renew the weak ones and to educate them in habits of industry, order, cleanliness, self respect, and self reliance and to apply such mental, moral, and religious training as would render them true, honorable and useful citizens" (Willard, 1909, p. 780).

The decision to steer crippled children into trades training programs was based on a utilitarian ideology that stressed the need to prepare crippled children to become employable adults, therefore reducing the potential for the child's becoming dependent on family, friends or the community in later life. On the whole, the purpose of education was not to encourage the crippled child to strive for secondary education and then university or college, but to help the crippled child to become economically independent. Trades training and vocational education were seen as mechanisms for teaching crippled children the work ethic and the importance of industry and self-sufficiency.

### Conclusion

By examining the care and treatment of crippled children we can see how the definitions and categorizations of crippled children came to establish the parameters of their reality. This article shows that the manner in which crippled children came to be defined as being intellectually impaired, as potential burdens to family and state, as mendicants, as immoral, or as social misfits set the tone for their care and treatment. By linking physical disability to many other personal attributes, professionals involved in the care and the treatment of crippled children were able to introduce programs and treatment plans that went far beyond the treatment of impaired limbs and deformed bodies. The care and treatment of crippled children came to include treatment not only of their physical being but came to include the treatment of their emotional, psychological, intellectual and moral being as well. In brief, from the late 19th century to the onset of World War II, the care of crippled

children was determined by cultural influences, such as the concerns for good health, good moral character and the desire for individual self-sufficiency.

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## Broca's "Discovery" of Brain Localization in Aphasia<sup>1</sup>

### Gary Woodill and Marie-Therèse Le Normand

Much of the history of neurology is in the tradition of "great man" history, or history which privileges the role of "heroic discoverers" in the production of scientific knowledge. Moreover, it is a history which is decidedly "Whiggish" (Butterfield, 1931; see also, Hall (1983), promoting a view of science as fundamentally the "march of progress" of ideas and methods. These themes are common, and particularly problematic, in the history of aphasia. Yet, the lessons that can be learned from an historical analysis of aphasia can be applied to other areas of disability, to disability itself, and to much knowledge in other fields.

## **Precursors to Nineteenth Century Aphasiology**

Descriptions of aphasia have been documented in the literature from Hippocrates through the Renaissance to the beginning of the 19th century (Benton, 1964; Benton & Joynt, 1960). The major shift in the view of aphasia in this period was from the idea of the ventricles of the brain being responsible for holding the spirit or fluid of the soul/mind to the idea that the physical "stuff" of the brain was directly connected to thinking and behaviour.

Many of the accounts of aphasia up until the mid-19th century reported aphasia accompanied by right hemiplegia, often as the result of an injury to the left side of the brain. It became known by the 18th century, through the work of Pourfour du Petit and Morgagni (Benton, 1964), that the nerves

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controlling each side of the body were crossed when reaching the brain (i.e., the left side of the brain controls the right side of the body, and vice versa). Still, before Marc Dax's paper in 1836 (first published in 1865), Gustav Dax's *Mémoire* in 1858, and Broca's paper in 1865, no one seems to have made the deduction that speech was controlled by the left hemisphere of the brain.

Starting with anatomical dissections of the brain in the 17th century, the view that the brain structure, and not the brain cavities, was the site of the mind became predominant. Yet, there remained the idea of the "sensorium commune," the place where sensory input was integrated and sent back to the body (Greenblatt, 1984). This integration was carried out by the "soul," whose seat was the brain.

At the beginning of the 19th century, there were two main interpretations of brain functioning. One view, represented by Flourens, was a "holistic" model which held that the mind functioned throughout the entire brain. The other view, represented initially by Gall, was a "localization" model which held that the mind was divided into distinct "faculties" which each had a specific site of functioning in the brain. As well, at that time, there was a doctrine of symmetry, whereby it was thought that each side of the brain was the functional mirror of the other side.

#### From Gall to Broca

Franz Joseph Gall, founder of the science of *phrenology*, began the localization debate at the beginning of the 19th century by pinpointing the centre for speech, one of the "37 organs of the mind," in the frontal lobes of the brain. He based this hypothesis on the fact that he noticed that, when he was growing up, most of his schoolmates who had exceptional verbal memory also had protruding eyeballs, pushed out, Gall thought, by overdeveloped frontal lobes. As Young (1970) commented, "It was from a mixture of accurate

52

description, confused methods, and rank nonsense that the idea took root that memory for words was situated in the frontal lobes" (p. 137).

In 1825, Bouillaud, a French professor and admirer of Gall, published a paper in which he "placed the faculty of articulation in the frontal lobes of the brain, which he considered to be the organs of the formation of words and memory..." (Bateman, 1890, p. 18). Bouillaud's paper was based on 114 cases of loss of speech associated with disease of the anterior lobes.

There were many clues pointing to the localization of speech functions on the left side of the brain, particularly when aphasia was accompanied by right hemiplegia. This was not recognized, however, as a pattern even though it was reported in a number of case studies before the 19th century and by Littré in 1828. Dr. Marc Dax, from the French village of Sommières, near Montpellier, presented a paper in 1836 locating lesions specifically in the left hemisphere of the brain based on 40 observations of right hemiplegia accompanied by aphasia. But this work apparently never became known until revealed by his son in 1863, two years after Broca's presentation on possible left frontal lobe involvement in aphasia (termed by Broca "aphemia") to the newly formed Anthropological Society in Paris. Hynd (1988), citing Benton (1984), suggested that "one reason, perhaps, for not making this connection was the fact that those interested in aphasia during the 18th century were primarily interested in those aphasias presenting more dramatic symptoms (e.g., subtle linguistic problems or paraphasias), which were often not accompanied by motor involvement" (p. 31). Another reason was that the literature already had reported many cases which did not fit the pattern of left hemisphere involvement.

## Broca's "Discovery"

There are two opposing stories about the young man Paul Broca and his "discovery" of left hemisphere localization of aphasia. In one story, Broca is

the brilliant scientist whose creative genius is responsible for this "discovery." In the other story, Broca is a competent young man, who, through a combination of luck, opportunism, and self-promotion, became famous for confirming a piece of the puzzle which had already been suggested by others.

According to Bateman (1890), in what he describes as the "ne plus ultra of pathological topography," Broca defined the site of lesion in aphasia as the posterior part of the third frontal convolution of the left hemisphere, based on two cases in 1861 and a further eight cases described in 1865. Collins (1898) wrote, "In the beginning of the second half of the 19th century two patients were admitted into the Bicêtre Hospital in Paris whose disorders of speech, thanks to the scientific zeal and clinical insight of Broca, surgeon to that institution, have contributed immeasurably to the understanding of speech in both health and disease" (p. 17). Most recently, Code (1989) claimed that "the presentation of these famous cases to the scientific community constitutes the traditional birth of modern aphasiology and the beginnings of neuropsychology" (p. 4).

Caplan (1987) contended that "the first scientific studies of patients with acquired disorders of language were presented in the last half of the 19th century. These began with an address by Paul Broca before the Anthropological Society of Paris in 1861" (p. 43). He further stated that after Broca's analysis of his first two patients "...came the now famous conclusion that the foot of the third frontal convolution was responsible for spoken language" (p. 46). He continued that "...the 1861 paper by Broca is the first truly scientific paper on language-brain relationships...it relies on a detailed case history and excellent gross anatomical findings at autopsy" (p. 46). On the issue of left hemisphere localization, Caplan recounted that "in 1865, Broca published a second important paper on language disorders, the first to call the attention of the neurological community to the fact that aphasia followed lesions of the left hemisphere and not the right" (p. 46). Caplan concluded that "it is reasonable to regard him [Broca] as the founder of the field" (p. 47).

54

In the more critical view of Broca's "discovery," it is mainly his "canonization," rather than his abilities, that are discounted. Young (1970) commented that "the quality of the evidence of his original case was very dubious indeed...his main contribution seems to have been a propaganda victory rather than an original discovery" (pp. 134-135).

Two of Broca's severest critics at the turn of the century were Pierre Marie (1906) and his student, admirer, and collaborator, François Moutier (1908). Moutier argued that Broca had no evidence for his assertions concerning the left frontal third convolution's role in language. Berker, Berker and Smith (1986) reviewed Broca's 1865 paper (in the course of translating it into English), and had a number of criticisms of both Broca's version of events, and of subsequent histories which have been written on Broca's achievements. They also engaged in a bit of "character assassination" by requoting Critchley's quote from Gardner that "in 1871, Paul Broca, a French neurologist with a broad skull, wrote five volumes to prove that the broader the head, the better the brain and that the French had particularly broad heads". They added that "Broca also applied the 'science' of craniometrics to 'prove' the intellectual superiority of men over women as well as the white races over blacks" (p. 1071).

We have, therefore, two distinct views of Broca given in the literature. Reading the published literature on the history of aphasia does little to help resolve this dispute. The literature is full of multiple versions of events, of repetitions of obvious errors, and of such a wide range of interpretations that it is obvious that much fiction, with the best of intentions, no doubt, has been written on the history of aphasia.

# How Did Broca Become Interested In the Problem Of Localization In Aphasia?

There are at least three versions of this story in the published histories of aphasia. Critchley (1970) wrote:

Perhaps the most important single date in the history of aphasiology is 4th April, 1861, when Ernest Auburtin, the son-in-law of Bouillaud, delivered before the Anthropological Society of Paris...an address entitled 'on the Seat of the Faculty of Language'. This was a well-reasoned plea for correlating the anterior lobes of the brain with the faculty of speech, based upon his own clinical experience and a formidable accumulation of data from the literature.

The secretary of the Society was the brilliant young surgeon Paul Broca, who approached Auburtin after his lecture and invited him to a joint consultation at the Bicêtre hospital. There had just been admitted to his service a man named Laborgne, an old hemiplegic and speechless mental defective with a septic infection of the leg. A day or so later, Laborgne died. At autopsy a superficial lesion was to be seen in the frontal lobe. Broca demonstrated this specimen at the next meeting of the Society, but no great interest was aroused. A month or two later, however, another such case cropped up in Broca's service. Once again, post-mortem inspection of the brain revealed a lesion in the same place. This was the case of Lelong.

The appearance of this second specimen created a sensation at the *Société d'Anthropologie*...The arrogant Dean, Professor Bouillaud, at first looked askance at Broca, calling him 'the St. Paul of the new doctrine' and 'one of the organizers, subinventors, augmenters, revisers, and correctors' of Gall's pioneer and magnificent discoveries'.

Almost against his will Broca found himself proclaimed a protagonist in the matter of cerebral localization and a pioneer in the philosophy of language and the problem of speech-loss. (p. 61-62)

Lord Brain's (1965) version of the same events is closest to the majority of the recountings of this period:

In February 1861, before the recently formed Société d'Anthropologie, Gratiolet, who had previously exhibited a primitive Mexican skull, discussed the significance of the volume of the brain. Auburtin, the pupil and son-in-law of Bouillaud, opposed the view that the total volume of the brain gave an exact measurement of intelligence, and opposed Gratiolet's view that the functions of all parts of the brain were the same. Broca, who was Secretary of the Society, joined in the debate.

The discussion aroused so much interest that it was continued at subsequent meetings. Auburtin reported a case in which haemorrhage into both frontal lobes caused no symptoms beyond loss of speech, and another in which pressure with a spatula upon the exposed frontal lobe caused immediate interruption of speech. He localized in the frontal lobes 'the faculty of co-ordinating the movements peculiar to language'. Broca happened to have under his care in the surgical wards of the Bicêtre a patient suffering from loss of speech, and he asked Auburtin to see this patient with him. The patient died within a week, and Broca demonstrated the brain at the next meeting of the Société d' Anthropologie, showing a cavity the size of a hen's egg involving the left frontal and to some extent the parietal and temporal lobes. He concluded, however, that 'the lesion in the frontal lobe was the cause of the loss of speech'...Broca's work was accepted by Bouillaud as confirming his conception of cerebral localization. (p.35)

Berker et al. (1986) offer a somewhat different version again:

In the February 1861 meeting of the Anthropological Society, Broca, in the tradition of Flourens, was holding forth on the relationship between brain volume and intelligence. In rebuttal, Aubertin cited his father-in-law Bouillaud's studies and repeated claims that speech was localized in the frontal lobes. Aubertin's rebuttal prompted Broca's challenge on April 12 that should the patient Tan not have a specified frontal lesion, would Aubertin then forever renounce his father-in-law's doctrine? Aubertin demurred and insisted on first examining the patient. However, after examining Tan and confirming the loss of speech, Aubertin accepted Broca's challenge. Tan, assuring his place in history, died on April 17. Broca performed the autopsy and, while noting widespread cerebral disease and considerable loss of brain substance, he declared, "The loss of speech...was a consequence of a lesion of one of the frontal lobes." Broca concluded, "Our observation confirms thus the opinion of Mr. Bouillaud, who places in these [the frontal] lobes the seat of the faculty of articulate language. (p. 1065)

From the same sets of "facts" available in the records of the period, three different historians have constructed three different stories. Each has a different version of how Broca became involved in the debate over localization, each has a different story on the relationship between Aubertin and Broca, and each has a different story on Bouillaud's reactions to Broca's "discovery." There are other variations as well. For example, Marie (1906) stated that after Broca's findings, Bouillaud "covered Broca with flowers."

# When Did Broca First State Definitively That the Faculty Of Speech Was Located In the Left Hemisphere?

A large number of publications state that in 1861 Broca located the faculty of articulate language in the third left frontal convolution in the brain. However, Berker et al. (1986) noted that Broca's papers in 1861 and 1863 only

tentatively discussed the possibility of left hemisphere localization, and that Broca only *definitively* pinpointed the location of articulate language in the third left frontal convolution in his 1865 paper, "Sur le siège de la faculté du language articulé". Lecours, Lhermitte and Yves (1978) supported this position, noting that "it was only in 1865, within a few weeks of the publication of Dax's article, that Broca clearly stated his conclusions concerning the lateralization of lesions causing aphemia..." (p. 12). Riese (1947) attributed this to Broca's critical approach. "Though in both of his famous cases the *left* hemisphere was involved, Broca did not realize immediately the correlation of aphasia with brain lesions of the left side, and when he finally concluded that speech disturbances result from involvement of the left hemisphere alone, he made no attempt to explain this coincidence; he called it a 'strange fact'" (p. 325).

This is an important point. If Broca only came to a firm conclusion on left hemisphere predominance in language functioning, then it is likely that he was influenced by the literature, and by the discussions at the time on left-hemisphere dominance. Certainly, by 1865 Broca knew about both Marc Dax's paper, as he discussed it in his article.

# Was Broca the First To State Publicly That the Left Hemisphere Was the Site Of Language Functions?

Greenblatt (1984) wrote that, although Broca "confirmed the localization of 'language' in the frontal lobe," he actually "discovered the lateralization of language in the left hemisphere. There is general support for this statement in the literature, but a number of writers disagree with this conclusion. Code (1989), for example, reviewed the literature and concluded that "in fact, Broca was not the first to suggest that aphasia followed only left hemisphere damage" (p. 4).

This subject was of interest to Broca himself, although he denied, in his 1865 paper, that he was interested in "questions of priority." However, Berker

et al. (1986) noted that, although Broca *claimed* to have no interest in who discovered left hemisphere localization first, after hearing about Marc Dax's 1836 paper from his son Gustav Dax, he went to great lengths to prove that Dax's paper may never have been presented, and that, in any case, he (Broca) could not have known about it.

Gustav Dax also wrote a *mémoire* on left brain localization. There are two stories in the literature on when this work became known to Broca and the other neurologists in Paris. In the most common version, Dax's *mémoire* is published in 1865 in *La Gazette Hebdomadaire de Médecine et de Chirurgie*. But this mémoire had been written in 1858, and presented locally in the south of France in 1858 and in 1860. Dax then sent his work to the Académie de Médecine in Paris in 1863, which is the time when Broca likely became aware of it. There are several stories associated with this report. The first story, by Edward Seguin in 1884, mixes the Dax story with another version of how Broca became interested in the localization of speech:

A report upon a memoir of Dr. G. Dax (a son of the other Dax), in the *Société d'Anthropologie of Paris*, in the spring of 1861, brought about a most animated debate between Bouillaud and Auburtin in defense of localization; Lelut, Gratiolet, and others against the hypothesis. One of the results of this discussion, was what M. Bouillaud afterward called the "brilliant conversion" of Broca, who brought forth his specimens, and carried localization to its extreme limit... (p. 29)

Another version of this story is told by Riese (1977):

Lélut, charged with the report on M. Dax's Observations tendant à prouver la coïncidence constante des dérangements de la parole avec une lésion de l'hemisphère gauche du cerveau [in fact, he was charged with reviewing G. Dax's report with this title], had already declared that the brain, mysterious organ, would

become still more mysterious if the two hemispheres were to subserve different functions... Bouillaud, not satisfied with Lélut's categorical refusal to admit two different functions for two symmetrical organs, recalled the difference in performances made by the right and the left hand and the distinction between right- and left-handedness, the latter believed by him to be exceptional. Would it not be conceivable that were left-handed as to certain acts, e.g. language? These words indeed marked the birthday of the doctrine of left cerebral dominance, since for the first time speech was linked with handedness. They were spoken at the meeting of the Académie Impériale de Médecine on April 4, 1865. At a later date, May 30, 1865, Baillarger referred to the fact that all nations are right-handed, that we write with the right hand; these facts and the difference in circulatory arrangements between the right and left hemispheres as well as the early development of the left frontal convolutions, seemed to throw some light on the strange fact that in 15 out of 16 cases of aphasia the left hemisphere was the site of the lesion. (p. 49)

Note that in the above account, Broca's name is not even mentioned, although in his 1865 article, many of the same points on handedness and cerebral dominance are raised. However, Broca was apparently present, and Alajouanine (1968) says that "he (Broca) didn't speak of localization solely in the *left* hemisphere until the discussion in 1864-65 at the Academy of Medicine of Dax's mémoire" (p. 38).

## The Struggle over Terminology

Broca named the loss of speech he observed in his first two patients "aphemia." Trousseau, in his *Clinique Médicale* (1862 edition, according to Moutier (1908), 1864 or 1865 according to others) and his series of lectures at the Hôtel Dieu in

1864, renamed this syndrome "aphasia," claiming that the word "aphemia" meant "infamy" in modern Greek. Broca countered with a lengthy defense of his choice, but also proposed "aphrasia" as an alternative.

Ryalls (1984) is the only writer in the literature who links the fight with Trousseau over terminology to the revelation of Marc Dax's 1836 manuscript. He wrote:

In the same period as the philological argument on the term aphasia, Trousseau (1865) cites a Doctor Dax from Marseille as having first discovered the principle of left hemisphere lateralization for speech in 1836. Broca again felt obliged to defend himself. In any case certainly some of the wind may have been taken from the sails of Broca's philological argument, when Trousseau credited Dax and not Broca with the theory of lateralization. (p. 363)

## The Struggle Over Evidence

Bateman (1890) described how evidence could be interpreted in different ways depending on which theory of brain localization one wished to support. A 42-year-old man was admitted to the Hôtel Dieu in March 1865, under the care of Broca's rival Trousseau. This man was obviously aphasic, and his autopsy revealed a large cyst which had destroyed all of the left hemisphere, *except for the frontal convolutions*. This was the area which Broca had identified as the site of language in the brain. Bateman related what happened next:

This examination was made in the presence of Professors Trousseau and Guillot, and whilst showing the care with which this subject in being investigated by the French faculty, it possesses an additional interest from the fact that when the autopsy was completely finished and the brain mutilated by the successive slices that had been made, M. Broca arrived, and declared that the postero-external part of the third frontal convolution was yellow and softened, and that it had been thought healthy because it had been looked for where it did not exist. (p. 35)

It is also interesting to note that while Broca's patients, and other cases of aphasia used to support his site of localization in aphasia, had damage ("lesions") to their left frontal lobes in the region of the third convolution, many also had damage to other parts of the brain. As Caplan (1987) explained, "...injuries to the brain such as stroke, trauma, and tumour do not leave neat areas of destruction ("lesions") in particular locations of the brain. Stroke follows patterns of vessels, trauma depends on its cause, and tumors grow locally and spread via the blood-stream" (p. 13).

This shows that the search for the sites for cerebral localization were mainly theory driven, resulting in a selective reading of the "evidence" used to support a given theorist's claims. In fact, Marie (1906) and Moutier (1908) were, later, to insist that Broca did not actually find true lesions in the brains of the first two aphasic patients he examined.

### The Marshalling of Cases

In the decade following Broca's 1861 paper, the field of aphasia research became "data rich and theory poor" (Caplan, 1987, p. 49). Case after case was cited in the medical literature, either supporting Broca's claims, or disputing them. It became clear that while many cases confirmed Broca's findings, many did not. From Bateman's (1890) review of the literature of the cases of aphasia up to 1869, we can see that the number of cases disconfirming Broca's claims was somewhat larger than those that supported him. That is, the evidence against left frontal lobe localization in the 19th century was as strong or stronger as the evidence for Broca's "discovery."

What, then, is the explanation for the strong positions taken on both sides,

and for the explosion of case studies on aphasia that followed? Moutier (1908) listed 1488 items in his bibliography on aphasia, while Von Monakow (1914) had over 3000 references in his study of aphasia in the 19th century. Though few studies have explored this phenomenon, part of the answer lies in the political sphere.

## **Aphasia and French Politics**

Politics in France during the 19th century were extremely volatile (Lough & Lough, 1978; Plessis, 1985). Napoleon Bonaparte ruled at the beginning of the century, having overthrown the Directory in 1799. In 1814 Napoleon abdicated, to be replaced by the first restoration of the Bourbon Monarchy with the accession of Louis XVIII to the throne. Napoleon returned in 1815, only to be forced into exile after the defeat of the French at Waterloo. Louis XVIII was returned to the throne, and when he died in 1824, he was succeeded by Charles X, his brother. In 1830 Charles X abdicated, and was replaced by Louis-Philippe, Duke of Orleans. A revolution in 1848, and the declaration of the Second Republic, was followed in 1851 by a coup d'état by Louis Napoleon (later proclaimed Emperor Napoleon III), nephew of Napoleon Bonaparte. When Napoleon III was taken prisoner in 1870, the Third Republic was declared, which lasted shakily into the twentieth century. During this time, as first monarchists and then republicans came into power, and supporters of the groups not in power were often harassed, imprisoned and/or executed. In general, the monarchists were the conservatives, interested in the return of both the power of the king and of the Catholic church, while the republicans were the liberals and radicals, wanting change, democracy and protection of basic freedoms.

The position one took on intellectual issues could be seen as a sign of support for one side or another in France's see-saw world of 19th century politics, or one's allegiance to one side or the other could determine whether or not you received a university or government post. In the area of physiology, Jacyna (1987) has shown how the medical profession grew in power from 1770 to 1830, and how ideas like the materialism of the body threatened the

established order by: (1) giving the medical profession the leading role in the developing "science of man," and (2) denying the spiritualist or idealist view that the body was simply the "seat of the soul." Thus, it is not surprising that after Broca's second paper in 1861, "localization of speech became a political question; the older conservative school, haunted by the bogey of phrenology, clung to the conception of that the brain 'acted as a whole'; whilst the younger liberals and republicans passionately favoured the view that different functions were exercised by the various portions of the cerebral hemispheres. During the next few years every medical authority took one side or other in the discussion" (Head, 1926, p. 25). The views of Marie (1906) on the influence of politics on Broca, as noted previously, are similar:

The battle began to become heated between spiritualism on the one hand, and materialism on the other, for that was the name by which they tried to brand the free-thinkers. Now, to the spiritualists, there seemed to be something that outraged the dignity of the human soul in a doctrine that tried to localize and restrict psychical functions and intellectual faculties to certain parts of the brain...Political passions were aroused, also, and for a little while, among the students, faith in localization was part of the republican credo. If we have insisted a little lengthily, perhaps, on the different aspects of the question of localization, it is in order to better understand the prevailing state of mind which influenced the many and ardent partisans of Broca; how to resist those who bear you in triumph! (Marie, 1906, quoted in Schuell, Jenkins & Jiménez-Pabón, 1964, pp. 14-15)

As a final note, two other figures in the history of aphasia, Marc and Gustav Dax, were also affected by the politics of their times. Critchley (1970) told us that both men were left out of the official history of their native town, Sommières, by Boisson, the town archivist. Boisson was an *Orleanist*, someone who favoured the reign of the Duke of Orleans, while Marc Dax

was a *Legitimist*, a person who favoured the reign of the Comte du Chambord, whom Charles X named as his successor when he abdicated.

### The Differentiation of Aphasia

Before Broca, the term for loss of speech was *alalia*, and several authors had tried to make distinctions between different types of alalia. Lordat (1843), the Montpellier professor who had himself experienced aphasia and had recovered, distinguished between *alalia* (mutism) and *paralalia* (imperfections of speech). But during and after the period when Broca first reported his findings, there was an upsurge in this type of differentiation of symptoms into particular syndromes.

After Broca's initial designation of the syndrome of "aphemia," and Trousseau's renaming it "aphasia," loss of speech quickly became differentiated into various types, in order to fit the data showing that many cases did not conform to Broca's findings on brain localization, or simply as a creative act of forming taxonomies. Trousseau, Broca's rival, in his 1864 lectures used a classification system of three types of aphasia, but Head (1963) says that these bore no relation to any fundamental principles, but were supposed to correspond to 'clinical entities'. Such fictitious classification of disease is one of the familiar methods adopted by popular teachers for stamping their image on the history of medicine. He added nothing that deserves to be remembered" (p. 28).

It is likely that many of the other taxonomies of aphasia which sprang up in the next twenty years deserved the same comment. In 1864, Jaccoud divided alalia into five types (Falret, 1866); in 1865, de Fleury published as article in which there is a taxonomy of 12 types of acquired speech loss: aphrasia, dysphrasia, paraphrasia, aphasia, dysphasia, paraphasia, alalia, dyslalia, paralalia, aphthongia, dyphthongia, and paraphthongia. Moutier (1908) listed many of the other taxonomies, including one of 18 types of aphasia by

Grasset. Greenblatt (1977) suggested that there is evidence that Hughlings Jackson distinguished between motor and sensory aphasia before he knew about Broca's work, but Harrington (1987) has recently suggested that Jackson was in possession of at least one of Broca's early papers on aphasia, probably a copy sent by Broca himself. In any case, Jules Baillarger, in France, in a 1865 paper, distinguished between "simple aphasia," with a loss of speech, and "aphasia with a perversion of the faculty of language" (Lecours et al., 1978). Hécaen and Dubois (1969) pointed out that Jackson insisted on the importance of the work of Baillarger in the development of his conceptions of speech. This seems to negate Caplan's (1987) claim that Jackson's "...work is so much a product of his own genius that it in fact borrowed little from that of other workers of his era" (p. 89). Jackson was also greatly influenced by the philosopher Herbert Spencer (1820-1903), "who introduced the notion of hierarchical organization in the nervous system, where each evolutionary stage added a new level of brain and consequently a new level of neurological and cognitive complexity" (Code, 1989, p. 7). This hierarchical organization is found in Jackson's concept of "levels of representation," whereby language is represented in different levels of the brain, with the higher levels controlling the lower levels.

Broca himself distinguished four categories of speech loss in 1869 (Henderson, 1986). These were:

- 1. Alogia, or loss of speech as a result of the loss of general intelligence;
- 2. *Verbal amnesia*, or the loss of words as a result of the loss of the memory of words;
- 3. *Aphemia*, or the loss of speech as a result of the alteration in the special faculty of articulate language;
- 4. *Mechanical alalia*, or the loss of speech as a result of incapacitation of the mechanical agents of articulation. (Broca, 1869, quoted in Henderson, 1986)

Henderson (1986) contended that Broca's description of *verbal amnesia* "is clearly recognizable as Wernicke's aphasia" (p. 611). Yet, in most histories

of aphasia it is Wernicke, a physician in Vienna, who has received the credit for first describing *fluent* or *sensory* aphasia. Moreover, Wernicke located the difficulties in sensory aphasia as being caused by "a lesion in the posterior aspects of the first temporal convolution in the left hemisphere" (Hynd, 1988, p. 37).

It is of historical interest that Wernicke was largely given credit for distinguishing between motor and sensory aphasia, when Jackson may have been the one to originally differentiate between the two. Perhaps because Jackson never published a widely circulated monograph and reportedly refused to even consider such a venture, lest "my enemies would find me out," Wernicke's monograph gained attention and thus firmly established him as the person who demonstrated the difference between various aphasia syndromes (Hynd, 1988).

This illustrates that the process of being named the "discoverer" of a phenomenon in science often depends on the ability to publicize one's findings, and on whom historians choose to remember and whom they forget. In 1906, Pierre Marie, wrote a paper entitled "The Third Left Frontal Convolution Plays No Special Role in the Function of Language". Marie accused Broca of being swayed by social interests and the politics of the day. However, Marie believed that *he* was above such things in formulating *his* view of aphasia. He wrote:

Such is my concept of aphasia based on facts observed without any preconceived notion, without intervention of any hypothesis. However different this may be from the classical doctrine, I have the conviction that this conception is the truth. Moreover, this conviction is corroborated by the fact that a part of the evidence which I give has been verified in passing by different authors; to the contrary, this opinion surprised some observers who are just as distinguished. The authors did not know how to separate themselves from the pernicious influence

which is always excited by doctrines considered as classical. These doctrines are seen as facts; they are not interpreted with enough independence of spirit. Certainly, the famous motto of Montaigne "What do I know?" ought to be practiced by each person. And when it is a question of dogmas, whatever their nature, established or transmitted by men who have gone before, is it not just to apply to these men, fallible as we ourselves are, and yet more ignorant, the same motto, and to ask one's self: "What did they know?" (Marie, 1906, quoted in Berker et al., 1986, p. 1071)

### **Discussion**

The theme of "discovery," common in the history of science and of geography, is among the most problematic in the histories of aphasia. In geography, the concept of discovery has been termed "the Pre-eminent Right of the First Trespasser", or "how genocide became a founding myth" (Hazelrigg, 1989). In the natural or medical sciences, "discovery" has been much more protected, tied as it is to the realist view of metaphysics and the role of the scientist as uncovering a concealed reality. There is, claimed Schaffer (1986), "an heroic model of discovery in which analysis concentrates on the inspired genius: hence the long debate on the creativity of the scientist". Schaffer listed the troublesome aspects of this concept of discovery: "(a) the isolation of discovery in time and space; (b) the authorship of discovery; (c) the preconditions of work which generates discovery; (d) the process by which discovery is recognized" (p. 391). In the case of Broca's "discovery" all the above problems apply, giving an vivid illustration of the "politics" of scientific work.

The history of aphasia in the 19th century illustrates many of the points made in the new relativist view of science, and the history of science, as a socially-mediated human production. On the level of the production of scientific knowledge itself, we can see that it is influenced by preconceived philosophical/theological ideas, that it is also influenced by human desires

for power and recognition, that it is moved in certain directions according to the political forces of the day, and that it is born/made in the midst of intense social interaction and debate, attacks and support. It is not necessarily (or perhaps even usually) a rational process based on the careful collection and examination of evidence, but the application of preconceived positions and theories, using whatever means are available to find support for one's position.

This case study also supports Kuhn's (1970) views that "normal science" is something practised at the "leading edge" by an "invisible college" of only a few intensively competitive individuals, with the vast majority of practitioners content to solve the minor "puzzles" or accumulate countless examples in support of the "dominant paradigm." Finally, it illustrates that much of conceptualizing in science is the application of metaphors from the physical world, often the world of technological invention. The concept of aphasia changed from a *pneumatic* or *hydraulic* model to an electrical model as new technology developed. Present day neurologist use computers or holograms as brain analogues.

On the level of the production of the history of scientific knowledge, our case study makes it difficult to disagree with Ashmore (1989) that all writing is fiction. The multiple versions of most stories, the selection of "facts" to fit the view of history and of science that the writer holds, and the opposing interpretations of the same events illustrate that the writing of history is also a socially-mediated enterprise.

When Marie re-examined the brain of Broca's first patient, he claimed that he could find no lesion. As Walther Riese (1977) commented, "The historian interested in the doctrine of methods in medicine will notice the very strange and significant fact that there can be disagreement and argument between the most eminent observers about the very existence of a gross lesion, the argument reflecting the critical character of macroscopic observation as of an undebatable criterium in empirical research" (p. 44). Taking a view that science is a *social product*, makes these findings somewhat less strange.

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# The Eugenic Legacy

#### John P. Radford and Deborah C. Park

A law suit for wrongful sterilization, brought in by Leilani Muir against the Alberta government in June 1995, has focused attention on an aspect of the treatment of people with developmental disabilities that has until now received little public recognition. Parents, professionals and other caregivers are often no more than vaguely aware of the incidence of such surgical practices in the past. Yet, involuntary sterilization became almost routine in some jurisdictions in North America during the interwar period, and it persisted into the 1970s. Together with the asylum (to which it is closely linked), involuntary sterilization infused a *mentalité* that dominated discourses of "mental deficiency" or "feeblemindedness" in Britain and North America for more than half a century.

The legislation under which Leilani Muir was sterilized was rooted firmly in the ideology of the eugenics movement. The Alberta Eugenic Sterilization Law, passed by the provincial legislature in 1928, provided the legal framework for the sterilization of persons declared in danger of transmitting mental deficiency to their children or deemed incapable of intelligent parenthood.

On admission to the Provincial Training School for Mental Defectives in Red Deer in 1955, Muir's diagnosis was recorded as "mental defective: moron." Brought before the 4-member Alberta Eugenics Board two years later, she was approved for sterilization "to eliminate the danger of procreation, with its attendant risk of transmission of the disability to progeny." Muir claims that she was told at the time that she was only having an appendectomy, the same "explanation" for surgical intervention that has echoed repeatedly through innumerable such cases over the decades. At the time of the operation, she was 14 years old. The sterilization law was repealed in 1972.

## **Eugenics In the Modern Era**

Over the past decade, a copious literature has developed on the eugenics movement, especially in Britain and the United States. The most comprehensive comparative studies are those by Kevles (1985) and Trombley (1988). More recently, a number of accounts have appeared for other regions of the world (e.g., Stepan, 1991). McLaren (1990) has demonstrated the pervasiveness of eugenic thought in Canada through most of the 20th century, and has placed the Canadian eugenicists firmly in the Anglo-American tradition. Such accounts leave little doubt about the influence of eugenic ideas on social policy, and indicate that these policies were not far removed from the infamous measures aimed at "purifying" the population of Nazi Germany (for a full explanation of these links, see Kuhl, 1994).

The eugenics movement rested on the assumption that most human attributes, including intellectual ability, are inherited. Its origins in the modern world are customarily traced back to late Victorian England. Francis Galton, who originally coined the term *eugenics*, was an amateur social reformer, statistician, and geographical explorer, who argued that medical improvements since Malthus had interfered with "survival of the fittest" mechanisms by prolonging the lives of those who would formerly have died in infancy so that they survived into their reproductive years.

Galton claimed that intervention was necessary to ensure the biological integrity of "the race." Since infanticide and euthanasia were morally unacceptable, Galton championed a search for ways of discouraging the least fit in society from reproducing themselves as rapidly as they appeared to be doing. This he referred to as negative eugenics, and it came to encompass sterilization, segregation, and other measures.

At the same time, worthy citizens (essentially the middle and upper middle classes), in danger of being overtaken numerically by the poor and unenterprising, were to be encouraged through positive eugenic policies (such as tax incentives) to have larger families. A recent exhaustive study based on the records of the Eugenics

Society (Mazumdar, 1992) has shown how this class-based premise became the foundation for a eugenic imperative which had an enormous impact on people with developmental disabilities. Merit was largely equated with intellectual ability, poverty with idleness and stupidity.

In its guise as social hygiene, the eugenics movement effectively blended new hereditarian ideas (especially those stemming from the rediscovery of Mendel in 1900) with public health concerns that had been evolving since Chadwick's reforms in the 1840s (Jones, 1989). The need to foster a superior population, especially an efficient workforce and an effective military, appealed to social reformers from a variety of social standpoints, holding political affiliations ranging from Tory to Fabian Socialist.

Much of the energy of the eugenicists was directed at urging authorities to "weed out" supposed "mental defectives" from the general population, and to subject them to controls of various kinds. Significant amounts of professional expertise—medical, legal and educational—were devoted to "ascertainment" of the incidence of defect and its treatment. In 1904, the British government established a Royal Commission on the Care and Control of the Feebleminded, that reported on its extensive research in 1908. The resulting Mental Deficiency Act of 1913 was less than the eugenics lobby had hoped for, but it did make local authorities responsible for "dealing with" their mentally deficient populations, and it also established a national Board of Control. Subsequent government inquiries (especially the Wood Committee of 1929) indicated that the problem was even greater than the Royal Commission has suggested. One major result was the building by local authorities of large numbers of asylums and "colonies" during the interwar period.

Although much of the earliest intellectual energy of the eugenics movement originated in Britain, implementation was so rapid in the United States, from the turn of the century onward, that lobbyists in interwar Britain found themselves pushing for measures which had been widely adopted in the United States before 1914. These included sterilization programs, for which the Eugenics Society campaigned from the mid 1920s onwards. The Brock Committee report of 1934,

despite raising the alarm that 250,000 "defectives" remained "at large" in England and Wales, recommended against compulsory programs, while urging support for "voluntary" eugenic sterilization.

There were a number of areas of eugenic policy implementation in which the United States led Britain. Even before the turn of the century, several states had built publicly-funded asylums on a large scale. Contemporary discussions reveal that, whatever their previous rationale, the newly expanded mental deficiency asylums (generally referred to in the U.S. after 1890 as "training institutions") increasingly reflected policies designed to control the "breeding of the unfit." When members of the British Royal Commission for the Care and Control of the Feebleminded visited many of these institutions in 1905, they were amazed at the sophistication of the diagnosis and treatment programs and the scale of operation. Their itinerary included a visit to the first asylum built explicitly for the detention of feebleminded women of childbearing age at Newark, NJ, a location that epitomized the institution as a eugenic control mechanism. Impressive as such places were to the unsophisticated commissioners in 1905, they represented only the beginning of a multi-faceted program of controls. There was much more to come.

Already the Carnegie Institute had been persuaded in 1904 to support the establishment of a Eugenics Record Office at Cold Spring Harbor, NY, though this did no more than allow the Americans to keep pace with record-keeping in England and Wales. Four additional developments placed the American Eugenicists well ahead of their British counterparts: the standardization of terminology, the introduction of intelligence testing, the revival of family pedigree studies, and the implementation of involuntary sterilization programs.

The first three of these can, in large measure, be credited to H. H. Goddard at the Research Laboratory of the Vineland Training School, New Jersey. In 1910, Goddard proposed that the term *feebleminded* be used to encompass the whole range of "mental defect"; *idiots* be defined as those having a mental age of 2 or less; and that *imbeciles* describe those with a mental age of 3 to 7. More significantly, he proposed that the umbrella of feeblemindedness be broadened to include people

with mental ages of 8 to 12. Lacking a label for this category, which had hitherto escaped recognition, he invented the term *moron*. Much attention subsequently focused on the moron (the equivalent British label for this category was *feebleminded*, a term that was never used generically), since it was this higher functioning group that came to be seen as the most prolific and constituting the greatest social menace.

But how to measure, classify, and categorize? How to sort out the idiots and imbeciles from the morons, and especially the morons from the "normal" population? Two years earlier while travelling in Europe, Goddard had encountered the Binet-Simon intelligence test. It was this that he now pressed into service, and within the next few years, through mass marketing ventures by others, various versions of the test (particularly the Stanford-Binet) became the stock-in-trade of educators throughout the United States (Gould, 1981).

Goddard's other contribution was to inject new scientific authority into family pedigree studies. This he achieved by publishing *The Kallikaks* in 1912, a study that purported to trace two lines of offspring originating with "Martin Kallikak" the fictitious name of a real soldier in colonial America. One legitimate family line turned out (in research largely conducted by Goddard's assistant Elizabeth Kite) to contain mainly success stories, or at least solid citizens. The other, supposedly descended from a relationship between Martin and a feebleminded tavern-girl, was shown to consist mainly of epileptics, criminals, and alcoholics, reproducing successive generations of poverty.

The effect of this study, which achieved considerable exposure, was to link mental deficiency with hereditary tendencies towards criminality, and (more impressive) to imbue this correlation with the authority of scientific measurement and accuracy. Numerous similar studies ensued. Rafter (1988), reading these studies as works of literature, found them to be explicitly class-obsessed documents that persistently conflate the constructs of "feebleminded stock" and "poor white."

## **Eugenic Sterilization Programs**

It is within this context that a fourth major American innovation—eugenic sterilization—can best be understood. In the mid-1890s, Dr. Harry Sharp of the Indiana State Reformatory at Jeffersonville perfected the procedure of vasectomy, which facilitated male sterilization without castration. This development had the effect of reducing the level of public opposition to sterilization. By 1907, when Indiana passed a law that specifically sanctioned the sterilization of "confirmed idiots, imbeciles and racists," he had performed the procedure on 465 males (Trombley, 1988, p. 51).

In the early stages, priority was given to sterilizing men, for it was they who were overpopulating the custodial institutions. Also, it was not until after 1910 that salpingectomy was perfected (originally in Germany) to produce a comparably safe (though still more intrusive) procedure for females (Reilly, 1991). During the interwar period, as legislation sanctioning the sterilization of the "unfit" or "deficient" of both sexes was passed in a number of jurisdictions, the balance in the incidence of sterilization swung towards females.

The necessity of sterilization grew out of the growing conviction (integral to the original eugenic argument but newly reinforced) that a hereditary underclass of mental defectives, prone to crime and vice in addition to poverty, was reproducing itself at an alarming rate. The prospect of institutional placement for these masses seemed impossibly daunting. Sterilization, it was often argued, allowed greater individual freedom than eugenic segregation. It was also, as Sharp himself asserted in the *Journal of the American Medical Association* (1909), a lot cheaper.

The issue of reproductive control of those deemed feebleminded has generally been presented as one of sterilization versus segregation (Radford, 1991; Tyor, 1977). A different perspective has recently been used by Trent (1993), who argued that the link between the eugenics movement and the segregated asylum was more tenuous. Focusing his attention on the writings of the American asylum superintendents, Trent found that their use of sterilization was less a response to outside pressures

from the eugenics movement than a means of preserving internal asylum order and asserting their professional authority. This perspective raises issues around professionalism similar to those discussed in the context of mental illness by authors such as Andrew Scull. Although this is an interesting and challenging thesis, it appears to discount unduly the wider processes of control evident in the construction of feeblemindedness (Radford, 1994). Trent's subsequent book (Trent, 1994) presents a more balanced view.

Whatever their precise link to the closed institution, involuntary sterilization programs grew steadily in the United States. Yet there was also opposition, especially from those who argued that the practice, being cruel and unusual punishment, was unconstitutional. In 1927, a test case in Virginia established the constitutionality of the various state eugenic sterilization laws. The career of Carrie Buck and the case of Buck *vs* Bell have received much attention in recent years, and Chief Justice Holmes' opinion that "three generations of imbeciles is enough" has become a slogan for critics of eugenic sterilization, as it formerly was for its proponents. Following this Supreme Court decision, sterilization laws were perpetuated or newly enacted in 30 states. By 1944, a total of 46,608 recorded sterilizations had been performed under these laws, 40 per cent of them in California and one tenth in Virginia. Of these, 17,958 (42%) were performed on males and 24,650 (58%) on females (Birthright, Inc., 1944).

### The Canadian Dimension

One year after the landmark U.S. Supreme Court decision of Buck *vs* Bell, Alberta became the first jurisdiction in the British Empire to pass a eugenic sterilization law. Data compiled directly from the Alberta Eugenics Board case files throughout the period during which the law was in effect record 948 sterilizations of males and 1,154 of females (for full details see Park, 1995). The data were compiled from records relating to operations performed at Edmonton Guidance Clinic, the Red Deer Training School, the Provincial Hospital, Ponoka, the Provincial Mental Institute in Edmonton, and the Provincial Mental Institute in Oliver. The figures

cited here are 349 fewer than the number arrived at by McLaren (1990), possibly because the balance were carried out beyond this particular legislation. The emphasis on the inheritability of mental deficiency is shown by the fact that only 114 males and 256 females diagnosed as psychotic were sterilized under the eugenic legislation through the entire period.

Perhaps the most startling revelation from our compilation from the Alberta data is that close to 40% of the females and fully 48% of the males sterilized on the grounds of supposed mental deficiency were operated on after 1955. The annual totals for females varied within a fairly narrow range, while those for males varied more widely. Nevertheless, the peak years for both sexes occurred during the late 1950s and early 1960s (Park, 1995). Presumably, there are large numbers of survivors who, like Leilani Muir, are now in their late 40s and early 50s.

The eugenic heritage in Canada is, however, much broader than Alberta's sterilization measures. The most comprehensive treatment remains that by McLaren, who has documented the intimate relationship between Canadian developments and those in Britain and the United States, and also to a degree with German practice. The Boer War recruitment scare which revealed large numbers of deficiencies among the military-age male population was felt in Canada as well as in England. The immigration scare was felt here as strongly as it was in the United States. Canada also experienced the same alarming inflation of statistics on mental deficiency, and the same financial pressures for an alternative to eugenic segregation in asylums. Roman Catholic opposition to eugenics, although international in scope, was especially significant in Canada, and not only in Quebec.

Yet in pressing the sterilization option, Alberta was extreme rather than unique in Canada. The only other province to enact a sterilization law was British Columbia, in 1933. Since the records for that province were either lost or destroyed, it is impossible to estimate how many sterilizations were carried out under this Act. Surviving documents for the Essondale facility indicate that 7 men and 57 women from there were operated on. Thirty-nine of the women had been diagnosed as mentally defective (Park, 1995).

Ontario, on the other hand, opted for segregation on a significant scale. Its institution at Orillia, opened in 1876 as the Orillia Asylum for Idiots, was the first large specialized institution for the "feebleminded" in Canada. Based largely on experience and praxis in neighbouring U.S. states, it acted as a prototype for similar institutions throughout Canada (Radford & Park, 1993). Ontario did, however, come close to enacting a sterilization law. The Ross Commission of 1929 recommended it. Members of the newly formed Eugenics Society of Canada, based in southern Ontario, called for government intervention in sterilization and birth control in the early 1930s. H. A. Bruce, prominent in earlier years as the founder of the Wellesley Hospital in Toronto, lent the authority of his position as Lieutenant Governor (1932-1937) to the cause, which was also endorsed by the Ontario Medical Association. In addition to public health officers and other medical proponents, support came from birth control advocates and psychologists, and from among prominent industrialists, educators, and the protestant clergy—a similar mix to that found in Britain (Jones, 1986; McLaren, 1990). The Ontario initiative was stalled, partly by significant public opposition (especially among Roman Catholics) but also because of a fear of resulting law suits (Archives of Ontario: File on Sterilization). No official program of involuntary sterilization of "mental defectives" was therefore enacted in Ontario. It is certain, however, that large numbers of sterilizations were performed on adolescents on the basis of parental consent, a practice which became an issue in the 1970s.

# **Current Implications Of The Eugenics Legacy**

This review of a selection of the most prominent recent literature on the eugenics movement, supplemented with reference to some of our own current work, leads us to suggest three areas of the eugenic legacy which may be usefully contemplated by those with interests in current policies in developmental disability.

First, eugenic sterilization programs were only one of several sets of eugenic measures discussed, and in many cases enacted, during the course of this century. They were a part of what Mazumdar (1992) has rightly referred to as a eugenics

"problematic"—an organized body of ideas that permitted some questions to be asked, but disqualified others. Specifically, the large custodial institutions that either emerged from expansion of previous asylum models or were constructed on completely new extensive sites, were as much eugenically inspired as were programs of involuntary sterilization. The decline of both involuntary sterilization and segregation since the 1970s reflects the dissolution of this problematic, at least in its traditional form.

Second, the eugenics movement can only be fully understood in the context of wider social forces. The rapidity of the diffusion of eugenics in the United States has often been linked with the support it received from Progressives. Similar thrusts were important in Canada. But the remarkable characteristic of the movement was its attraction for people from a wide range of political perspectives. Often they had little in common other than their interest in what they often called "race betterment." They tended to be middle or upper middle class, but some were ultra-conservatives, others avowed modernists. Belief in the efficacy of science and the role of professionalism was general. There was no single eugenics movement, even in one nation at one point in time. The only unifying characteristic was the conviction that the future of society required the regulation of reproduction to control the incidence of genetically-based propensities to crime, alcoholism, prostitution, sexual deviancy, delinquency, and inefficiency, and of the feeblemindedness that seemed common to all of these supposedly hereditary social ills.

Finally, although many historians argue (or assume) that eugenics is now a dead issue, it is not at all clear that the questions raised or even the solutions posed earlier this century have disappeared from either the public forum or professional agendas. Arguments that eugenics was always a pseudo-science, never taken seriously by respectable geneticists, that even if it was influential at one time it was already waning in the early 1930s, that even if it did survive the Depression, it was permanently discredited by the action of the Third Reich; all of these have recently been challenged. Some see a resurgence of eugenic notions in the 1990s in the debate over *The Bell Curve* (Tyor, 1977), others in the Human Genome project (see position papers in Kevles & Hood, 1992), still others in recent cutbacks in welfare

and public sector budgets in many jurisdictions.

Although society now deplores the use of the old labels, it may still be capable of tolerating some of the old principles, at least in modified form. The believe-it-ornot tone evident in some of the media reports of the circumstances surrounding Leilani Muir's incarceration and sterilization suggests that they may be missing the point. Many of the reports lay great stress on the fact that Ms Muir has recently taken tests which show that she is near normal intelligence. Do they mean to imply that her treatment would have been excusable if she really had been developmentally disabled?

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## Bureaucracy And Ideology: A Case Study Of The Development Of Community Living Policy In Ontario In The 1970s

#### Tim Stainton

The idea of community living as the cornerstone of policy and services for people with developmental disabilities is now well established in most western jurisdictions. The 1970s can arguably be considered to be the formative decade of this policy.

It is sometimes thought that the positive vision of normalization and the work of President Kennedy's commission on mental retardation spurred significant policy change. But the widespread scandals that occurred in the 1970s in virtually every country and jurisdiction probably had more influence on the development of community living policy (Martin, 1984; Scheerenberger, 1983; Williston, 1971).

It was during the 1970s, also, that serious efforts by governments to implement deinstitutionalization began in earnest (Scheerenberger, 1983; Stainton, 1994). But despite these efforts, little in the way of actual deinstitutionalization was achieved. The reasons for this are numerous and complex and to some degree vary among jurisdictions. Some key factors stand out, however. First, these early efforts were largely reactive, focusing on the negative goal of deinstitutionalization rather than on the positive goal of community living. Second, there was confusion around responsibility and funding, with many institutions under health rather than community or social service auspices. There was also the reaction of institution staff unions and to some degree negative community reactions to the development of community living policy and practice. Finally, and more difficult to identify, was the role of the parents' movement and the increasing control over the direction of policy and service by the state at the exclusion of the parents' and other movements.

Ontario provides a good case study of this period for a number of reasons, but most notably: the existence of a well-organized parents' movement supported by

prominent reformers such as Wolf Wolfensberger and Bengt Nirje; an early recognition of deinstitutionalization as primarily a rights issues; and, finally, clarification of the key role of two government departments, community and social services and health services. Despite these apparently positive influences, early deinstitutionalization efforts in Ontario were not significantly more successful, at least in terms of numbers, than elsewhere. It is instructive to explore why this was the case, both for helping to explain the developments of the 1970s and for setting community living policy in the future. This article reviews the community living movement during the 1970s in Ontario. It also draws some tentative conclusions about the reasons for the early failure of this movement, and suggests implications for future policy directions in Ontario and elsewhere.

## The Williston Report: Indicting the Past, Charting the Future

In the space of two weeks, two very public tragedies would force the government of Ontario to review its policy on, and services to, people with developmental disabilities. On February 18, 1971 Jean-Marie Martel, recently discharged from a large institution, was found walking along a country road with gangrenous fingertips caused by severe frostbite. Martel had been placed on a local farm, a common practice that arose from local farmers looking for cheap labour and requesting workers from the institution. After a series of difficulties with two such employers, Martel ran off and was found suffering from frostbit. The numerous newspaper reports contained a catalogue of abuse and neglect (Williston, 1971).

On March 5, 1971, police were called to a farm outside of Ottawa where they found, hanging from the barn rafters, Frederick Elijah Sanderson, a 19-year-old Cree Indian, on leave from the same institution as Martel. As with Martel, he had been sent out to work on the farm and had made a series of complaints before his suicide. Unlike Martel, though, Sanderson was still under the formal supervision of the institution (Williston, 1971).

These two widely-publicized events resulted in the Minster of Health, who had

responsibility for the running of the institution, asking Walter B. Williston, a prominent Toronto lawyer, to investigate. The Minster gave Williston a broad mandate, asking him to go beyond the immediate cases and provide the government with some clear direction as to both government and public responsibility for such persons. He commented on why he had chosen an "experienced lawyer," stating, "as we move into this whole area of human rights we immediately get involved in fundamental legal issues, particularly those concerning the civil rights of citizen, whether or not they are retarded" (Williston, 1971, pp. 3-4). The document Williston produced stands as the most remarkable in the policy history of developmental disabilities in Ontario.

The tone of the report is set in its first paragraph, the "Statement of Principles and Objectives":

The problems concerning mentally retarded persons cannot be viewed in isolation. Civilized society must provide every child with the opportunity of developing to his optimum potential...Thereafter society must provide each with such assistance, protection, opportunity and shelter as will enable him to take his place as a contributing member of the community and to ensure him a decent standard of living so that he can walk through life with dignity...

The furnishing of the basic necessities and support to enable a person to function in society must be recognized as a basic human right to be provided for at public expense and not discharged as a matter of chance or charity...A "means test" which further culls out and earmarks the handicapped, should never apply...This is a moral and ethical responsibility...particularly to those who are not subject to custodial care, which may seldom be necessary at all...

Society should thus do everything in its power to enable the mentally retarded to live with his own family during his formative years and thereafter be kept within his own community. (Williston, 1971, p. 4-5)

Whether the government had wanted a brief this far-ranging is not clear. What is clear is that Williston was concerned with not only the abuse or neglect of two individuals, but the general neglect of a whole population and their rightful place as citizens. The report gives a detailed account of past and current policy and attitudes, the specifics of the two cases at hand, and a set of specific proposals for the reorganization of services and policy. Most notable were his call for large institutions to be phased down as quickly as possible, and what he explicitly terms his detailed 16-point "indictment of the present institutions."

The "indictment" included the standard catalogue of problems: overcrowding, custodialism, antiquated buildings, and isolation. But he also claimed that institutions of this type are not an economic way of providing custodial care. On another notable point, he stated that the institutions actually inhibit rehabilitation and community involvement, and make it more difficult for people to adjust to the community when released. This view was at odds with an argument frequently made by the institutions that they served as training centres to prepare people for life in the community. As his final point he stated:

I suggest that a century of failure and inhumanity in the large multipurpose residential hospitals for the retarded should, in itself, be enough to warn of the inherent weakness in the system and inspire us to look for some better solution. (Williston, 1971, pp. 67-68)

Williston's report was the first official statement in Ontario that the basic fault was not with the way institutions were run but with their very nature.

Among Williston's most important recommendations was a call for the institutional population to be reduced to 40% of current capacity, recognizing that institutions would have a role to play for some years to come. Another key recommendation was for support to parents to keep their children at home through a range of services and benefits. He noted that "the ability of the community to sustain its mentally retarded persons within its boundaries is dependent on the quality and quantity of family support, crisis intervention, rehabilitation services, educational, vocational

89

and recreational opportunities" (Williston, 1971, pp. 71-73). In other words, he was recommending a "comprehensive community service system" as it would come to be called. He called for a range of small community residences, with varying degrees of support and supervision, pointing out that these should be "a home to those who reside within." In addition to this, he called for a range of other supports, the most notable of which was for citizen advocacy programs and guardianship services independent of the service providers.

One of his strongest critiques (and recommendations) concerned the fragmentation of service delivery and policy. He noted that there were six different departments, several with numerous branches, involved in policy development and implementation. He called for a single department responsible for all services to handicapped persons and their families, and for a single fixed point of referral to be available to families to ensure that appropriate information be available to families. This idea would not come to the fore again for more than a decade.

While calling for strong central planning and coordination, he also called for regional self-sufficiency in the delivery of services, with each area developing its own network of services. The centre would provide the financial and specific regulatory mechanisms to aid local developments. On the actual management and delivery of specific services, Williston supported strengthening and extending the current trend of using local voluntary groups. In a remarkable passage he stated:

The Ontario Association for the Mentally Retarded has the expertise, the knowledge and the experience, it is reasonable to give them a major share in the responsibility for the management and delivery of services...It is unnecessary for the Government to build or operate residences, workshops or leisure facilities in the communities. It would be more appropriate for the government to give more economic support to organizations which are providing these services. (Williston, 1971, p. 98)

These comments marked an important shift which would continue to gain force

into the present. Although the early reluctance of the government to provide community services reflected a fairly classic residualist position, the idea of community services being funded by government but provided by voluntary groups reflects a significant departure from classical residualism. It recognized the government's responsibility to ensure support is provided through planning and funding. But it also recognized the limitations of large public services, with their consequent bureaucracies, and the strength of local voluntary bodies and the intimacy and concern that can be achieved by them. What results is a somewhat unique mix of the traditional residualist and the institutionalist positions that would continue to evolve into the present day in Ontario and provide a fertile context for innovation in community service development.

Williston's report represented a catalyst for changes that would occur over the next two decades. Although generally acclaimed, its recommendations were not fully accepted initially. Over the next few years, however, many of the ideas he brought forward would come to the fore in policy. But Williston's report did not appear from a vacuum; there were other significant forces influencing the pace and direction of change.

#### **Normalization Pioneers**

The concept of normalization had been around since the late 1950s, but did not begin to receive wide attention until the end of the 1960s. Two of the key figures in the development and dissemination of the normalization philosophy were in Ontario by 1971. Bengt Nirje, former executive director of the *Swedish Association for the Mentally Handicapped*, was then the coordinator of training in the Ontario government's Ministry of Health. He had been brought over by the head of the Mental Retardation Services Branch of the Ministry of Health, an early advocate of change within, if not dissolution of, the institutional system. Nirje was one of the originators of the normalization concept, but was not radically opposed to all institutions (Nirje, 1976). In general, he took a moderate approach to change but was an important influence within the Ministry at that time and his very presence

suggests a favourable disposition to the basic principles of normalization.

Far more radical and influential, was Wolf Wolfensberger, who began a 2-year tenure as visiting scholar at the National Institute on Mental Retardation in Toronto in 1971. His influence and presence had radicalized many parents' views of the institutions, to which he was totally opposed (Wolfensberger, 1972). His uncompromising, overtly value-based approach changed the nature of the debate, and provided what amounted to an ideology for the nascent community living movement. The presence of these two men ensured that "progressive ideas" on community support for people with developmental disabilities were well known in Ontario at a very early stage, and provided to some extent the catalyst for a strong community-based deinstitutionalization movement.

## **Economics and Ideology: The Emergence Of ComSoc**

The government's response to Williston was rather disappointing: initially to scale down the largest facilities by transferring people to smaller institutions closer to their home regions (Simmons, 1982). At the time, though, there was in progress a general reorganization of the government to improve its efficiency in light of the rapid growth since World War II. As part of this process, Robert Welch was appointed Minister of Social Development Policy. Welch had both personal and professional contact with the Ontario Association for the Mentally Retarded, and, as such, was somewhat personally interested and sympathetic to mental handicap issues (Simmons, 1982). In an effort to rationalize several reports on the future directions of policy on mental handicap, Welch appointed a task force that produced, in April 1973, a paper *Community Living for the Mentally Retarded: A New Policy Focus* (Provincial Secretariat for Social Development, 1973).

This paper was essentially the government's response to Williston. It spelled out for the first time the government's commitment to the idea of normalization, and represented a reorientation away from institutions toward community-based services. It contained a frank assessment of the failings of the existing policy, many of which

echoed Williston. Most important, it considered alternative administrative structures, rejecting the idea of a Ministry for the Handicapped on the basis that this would in itself be institutionalizing, "segregating handicapped citizens from other citizens in Ontario" (Provincial Secretariat for Social Development, 1973, p. 19). In the end, the suggestion of transferring the institutions to the Ministry of Community and Social Services (ComSoc) was accepted in the summer of 1973 (Anglin & Braaten, 1978; Simmons, 1982).

The transfer was not, however, a purely, or even in the final analysis primarily, an ideological decision. Under the Canada Assistance Plan, people with developmental disabilities who lived in institutions under the Mental Health Act of 1967—the majority of people in institutions—were not eligible for federal government costshared funding. The transfer from Health to ComSoc in essence made all those people eligible for 50% cost-sharing with the stroke of a pen (Anglin & Braaten, 1978; MacCoy, 1990; Simmons, 1982).

But the transfer away from Health responsibility was significant for other reasons as well. Most notably, it limited the problems of co-ordination and competition for funds which would plague British service and policy development (Glennerster, 1983; Korman & Glennerster, 1990; Tyne & Wertheimer, 1980). The conflict between the institutions and those in favour of community-based services did not, however, disappear.

The Developmental Services Act (DSA) came into effect in April of 1974 giving ComSoc responsibility for all mental retardation facilities. This Act also provided a broad umbrella under which ComSoc could institute programs beyond those authorized under other legislation-Homes for Retarded Persons Act and The Vocational Rehabilitation Act—and allowed for full funding of such programs. What had been a relatively small Ministry with some 2,000 staff ballooned to some 12,000 staff, the majority based in the institutions (Williams, 1984).

The result was somewhat paradoxical given that the goal of the process was to reorient services to the community, yet it gave ComSoc a heavily institution-based staff and budget. The implications of this would be diffuse but pervasive, and continue to effect policy into the present day. Although this situation was somewhat unique to Ontario, the issue of bureaucratic responsibility for deinstitutionalization and the fate of institution-based staff has been problematic in most jurisdictions.

A new Facilities Division in ComSoc was established, with a director transferred from Health. A division with responsibility for community services development was also established with a far more radical vision and a staff drawn largely from community- based services (Simmons, 1982). In May of 1974, ComSoc released a discussion paper, *A New Mental Retardation Program for Ontario*, drafted largely by the Community Services Division. This paper set out the basic goals and approach of the new policy. The most radical aspect of this statement was a call for the return of 50% of the current institutional population to the community within five years. In the end, a reduction of only 1.5% was achieved (Simmons, 1982).

The other major development was the proposal to establish 19 District Working Groups (DWGs) to oversee local community development. But the DWGs were often bypassed or ignored by ComSoc and by the mid-1980s had little role in service development or coordination (Simmons, 1982). The result, however, reflected the deep gulf between rhetoric and result which would characterize much of the next 15 years. This also was typical of early attempts at deinstitutionalization. In Britain, ambitious targets set in 1971 met much the same fate (Tyne & Wertheimer, 1980).

The period from 1974-6 was a period of internal struggle and confusion at ComSoc. Many of the programs brought in reflected the strong beliefs of the relatively small community development branch as opposed to those of the facilities branch (MacCoy, 1990; Simmons, 1982). The initial successes would not continue, however.

Although the 1970s was generally a time of restraint within ComSoc, mental retardation services were explicitly exempted from this policy (Williams, 1984). This allowed some of the innovations to proceed, but for a variety of reasons, progress was slow. The conflict between the Community Services and Facilities Divisions continued. By 1976, the initial optimism was waning, and consensus on

the direction of policy both internally and externally was weakening. In 1976, the head of the Community Services Division, along with other progressive people, left ComSoc and the bureaucracy became increasingly filled with career civil servants who had no particular commitment to community living or developmental disabilities, and perhaps a greater concern for economy (Simmons, 1982). The sheer number of institutional staff would also ensure that they would increasingly inundate the ComSoc bureaucracy through internal promotion, while the vast majority of community program staff were, by design, not Ministry personnel.

There were other factors that fostered a less enthusiastic program of deinstitutionalization in the 1970s. The Ontario Association for the Mentally Retarded had begun to lose much of its influence, and government policy-making was increasingly an in-house affair. The role of the parents' movement in Ontario was one of the key factors that spurred early movement towards large scale deinstitutionalization. As the bureaucratic machinery developed and consolidated its control over policy and planning, however, the voice of the parents' movement was increasingly unwelcome. While the parents' movement in the United States was as strong as in Ontario, it was far less developed in Britain. This difference did not have a marked effect on the pace of deinstitutionalization in the three areas, but it did effect the quality of community services, in general engendering a more radical and innovative approach to service development than has been seen in Britain.

Within government, there were differences of opinion on exactly what role the institutions should play. In many communities, there was resistance to the building of group homes, and, in some cases, these were blocked by local by-laws. Again, this was a phenomenon that was typical across jurisdictions and represented an additional break on community support development. Finally, there was the increasingly active resistance to deinstitutionalization by the Ontario Public Service Employees Union (Simmons, 1982). All of the above factors would continue to hamper progress towards community living into the present day in Ontario, as was the case in most western countries.

95

Despite the rhetoric, the government's major effort at phasing out the large institutions was to build smaller mini-institutions throughout the province, despite opposition from DWGs and the Ontario Association for the Mentally Retarded (Simmons, 1982). The institutions also began to show more creativity in responding to the threat to their existence both by creating "normalizing environments" within, and by proposing themselves as "centres of expertise," a concept supported by ComSoc through the promotion of "resource centres" (Coalition Against Institutions As Community Resource Centres, 1986; Simmons, 1982).

By the end of the decade there had been no significant reduction in the numbers of people in institutions in Ontario, and there had been a net increase in the number of institutions. There was, however, significant development of sheltered workshops, and to a lesser degree of community residential places (Simmons, 1982). Although the several complex and interacting factors discussed above all contributed to the failure to reduce institutional populations significantly, one overriding reason was that the difficulty of maintaining a clear value-based policy direction in developing community services and knowing what services to develop was very much underestimated.

#### Conclusion

The 1970s, then, was the formative decade for the community living movement in Ontario and elsewhere. It was a time when initial optimism gave way to a more realistic assessment of the challenges ahead. Despite the general failure of community living policy in the 1970s, many valuable lessons were learned. These encouraged successes in the 1980s when the actual phase-down of institutions would begin in earnest, spurred in part by concern for economy as much as any deep commitment to community living.

Some aspects of Ontario's experience were similar to experiences of other jurisdictions, while others differed. The value in Ontario's experience as a case study comes both from these similarities and differences. This holds true not only

for the history of community living policy, but also for the process of policy making and the translation of ideology in practice.

Clearly, the fact that initially deinstitutionalization was a reactive movement, engendered by widespread scandals, hindered the development of effective policy and programs in Ontario as it did elsewhere. However, Ontario was somewhat unique in both the level of organization of its parents' movement and the ideological resources at its disposal with the presence of Wolfensberger and Nirje. Despite this, bureaucratization of policy and planning, and the vested interest of those associated with institutional services limited progress towards community living in Ontario which showed no significantly different results than elsewhere during this period.

Where Ontario has shown significant positive differences has been more in the area of service delivery, a factor attributable to the policy of voluntary, community responsibility for publicly funded services. This structural factor is perhaps most in evidence in comparison with Britain where public authorities have, until recently, been responsible for planning, funding, and delivering community services, and where innovation and progress as been much slower.

While community living is now the dominant policy norm in western society, much remains to be done. Significant numbers of people remain in institutions, often now renamed as resource or specialist facilities. The parents' movement has now been joined by a growing self-advocacy movement, which is perhaps the most positive feature of recent changes. The key lesson of the 1970s, which remains only partially learned, is that policy must flow from the people most directly involved. Government will continue to play a key role as funder and monitor of development, but a rational centrist approach to policy development has proven itself an ineffective instrument of positive change. More important, the 1970s demonstrated that the state has as often as not been a major brake on progress. The public scandals in state facilities which gave rise to the community living movement should lend a note of caution to any further attempts at large scale state run services and bureaucratic control over policy.

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# Quality of Life:

## AN INTERNATIONAL CONFERENCE FOR FAMILIES AND PROFESSIONALS ON DEVELOPMENTAL AND RELATED DISABILITIES

# June 6-8, 1996 Toronto, Ontario, Canada

# **Conference Objectives**

- To bring together health professionals, researchers, government policy makers, educators, medical residents, clinical trainees, graduate students, caregivers, families and persons with a developmental disability from local, provincial, national and international settings for whom quality of life issues are relevant.
- To review through presentations, major current quality of life topics.
- To communicate, through posters\displays, the most significant quality of life projects and programs - both international and local.

- To address major challenges and to plan effectively for the future through carefully organized, focused and small group discussions.
- To share and integrate knowledge, points of view, and to learn from international and multicultural experiences through large, multiperspective panel discussions.
- To create a network of resources relative to quality of life—both materials and people—using conventional and electronic means.
- To disseminate the results through appropriate publications

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## **Conference Format**

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# Mailbag

# Reflections On Historical and Present Conditions In Developmental Disabilities

I think that it is vitally important that this journal has dedicated this issue to the topic of history. Too many of us in the field have not taken the time to understand the history of the people we serve. Historically, persons labelled with developmental disabilities have been subject to ridicule, segregation, inhumane treatment and even death. History has aligned persons labelled as developmentally disabled with criminals and those with mental illness. In this century, they have been identified by IQ scores, segregated from home and community, and congregated into large institutions. There is still much injustice that needs to be righted and more understanding that needs to be garnered.

But the pendulum has swung. The past 25 years have seen the most dramatic shift in understanding, humanity, and inclusion of persons with developmental disabilities, that has occurred in history.

The past 25 years had been the most positive growth period in the field of developmental disabilities in all of its history. At no time in history have individuals with disabling conditions been provided such widespread academic, social, and financial support. At no time in history has there been a more radical positive shift in how society treats persons who are labelled as developmentally disabled. The mere use of the above descriptor is indicative of a change! A change to seeing persons first, a change in the recognition that the diagnostic epithet is a label not the person, and a change in understanding the nature of disabling conditions. I am not suggesting in any way that we have reached a pinnacle in our support or treatment of persons with developmental disabilities. However, the direction has been positive.

There is an old adage that those who do not learn from the past are doomed

to relive it. Without revisiting it and learning from it, we may once again risk making the mistakes of the past. In the past month, I have been told of two separate instances of political figures in two areas of North America who have made astounding reversals on the direction of government policy on institutions. In both cases, the politicians suggested that government should reconsider the closure of institutions for people with developmental disabilities. The stated rationale was that some people have a better quality of life in institutions than in communities.

The role of institutions and the care and treatment provided there has been an issue of hot debate over the past quarter of a century (Foster, 1987). Although the debate has continued as to whether institutions play a role in the continuum of services for some individuals, both sides agree that institutionalization should not be the first choice (Foster, 1987). So from what frame of reference could this reversal of history be considered?

The attitudes toward the treatment of persons with development disabilities has been a shifting tide according to Stroman (1989). Institutions of the mid-19th century were benevolently erected as a means of protecting and educating persons with developmental disabilities. However, by the 1880's and throughout the 1920's persons with developmental disabilities became the scapegoats for much of society's ills. They were blamed for crime, delinquency, alcoholism, unemployment, prostitution, and insanity. Simmons (1982), quoting from the Ontario Sessional Papers, noted that "the mere presence of a feebleminded person is a threat to the moral stability of normal people" (p.87), and therefore, it was considered that they should be segregated from society.

The overriding reason for institutionalization was to separate persons with developmental disabilities from society. Through the 1920's to the 1950's the field of developmental disabilities made few changes. However, by the time of increased affluence of the 1950's, there began to grow a more positive view about persons with disabilities. This culminated in the 70's and 80's

with the growth of normalization, deinstitutionalization, and community living.

Scheerenburger (1983) suggested that attitudes about the role of people with disabilities and their place in the community has changed significantly over time. Decisions have been based on "scientific" evidence, later found to be faulty. He suggested that many of the decisions were based more on the needs of the professional community rather than the needs of the individuals.

The classic text on History of Mental Retardation (Scheerenburger, 1982) provides a valuable understanding of the treatment of persons with disabling conditions over the ages. Simmons (1982) made a similar contribution to the understanding of social policy develop in Ontario in his text *From Asylum to Welfare*. These books provided strong evidence for examining the decisions made for people with developmental disabilities in light of the social, political, and economic influences of the time. It is important to realize that the same economic and political pressures that caused the mistakes and atrocities in history could occur again.

I recall vividly one of my first visits to an institution for children with severe physical and cognitive disabilities. It was an old and ill-kept building. I walked through room after room of that urine-wrenching building to witness children aged two to twenty-one warehoused in the most deplorable conditions. There were children enclosed in cribs too small for their growing bodies, contorted in shapes that could never be repaired. When I attempted to interact with one of the children I was met with a blank and lonely stare. Not only their small bodies but also their minds were atrophying from neglect. There was little human contact except for the provision of the most basic of sustenance care. In the corner of the room, I found one young man tucked away in what had been a closet, with the top of the door removed.

They explained he had to be kept secluded because he was a behaviour problem. He would constantly touch people and was always trying to escape.

I remember thinking that he and I would have been kindred spirits because I was sharing his quest. In the next room, I found a very young man playing with what I thought was a ball. He threw it and then scooted along the floor to follow it, and then repeated the process again. I was heartened to see a bit of childhood normalacy in this place, until I realized that his ball was actually a piece of faeces!

I remember being horrified that this could happen. How could society let this happen to these children? The truth was that for much of society, these children were unknown. They had been placed there away from society, so we did not have to see or know of their needs. If these children were nameless, faceless, and voiceless then we did not have to recognize that individuals were being treated in this way. I was thankful that institution was closed shortly after my visit. I was thankful that *normalization* (Wolfensburger, 1972) had been written about and that deinstitutionalization was beginning. Once people with developmental disabilities were returned to our community that they no longer would be seen as these faceless and voiceless individuals that we as society had shut away, then surely this type of atrocity could not happen again.

Blatt and Kaplan (1966) exposed readers to a rare glimpse of the bleakness of the lives of persons with disabilities living in institutions in their classic work *Christmas in Purgatory: A Photographic Essay on Mental Retardation*. Through the compelling and silently descriptive medium of photography, the desolation and loneliness of the life experience of many people with disabilities was exposed.

For the most part, history has blatantly disregarded how people with developmental disabilities have experienced the decisions that society has made on their behalf. One of the most shocking awakenings for society came from Geraldo Rivera, before he became the daytime talk show host. As a young reporter, Geraldo conducted a piece of reporting that forced change in the lives of people with disabilities forever. He uncovered the deplorable treatment of an person with developmental disabilities at the

Willowbrook institution in New York. The story, with footage, was shown on public television and the silence was broken. In 1975, the Willowbrook decision (New York Sate ARC vs Carey) recognized the rights of persons with disabilities to be protected from harm. He had given a face to the injury and a voice to the victim.

One of the main reasons why people with disabilities are such easy victims to the changing attitudes and social policy is that they have been largely voiceless in their own history. It is interesting to note that the history of developmental disabilities, with few exceptions, is the history of the services to developmental disability, not of the personal experience of those so labelled. Perhaps our failure to provide reference to the experience of persons with developmental disabilities is important because it reflects history's blatant disregard for how they were experiencing the decisions that we in society made for them.

I recently read an excellent historical account of the life of John Lovelace, a man with developmental disabilities—*Pieces of Purgatory! Mental Retardation In and Out of Institutions* (Smith, 1995). The book chronicles the life of John Lovelace and his experiences with the services for the developmental disabilities. It brilliantly weaves together one man's history of institutionalization, deinstitutionalization and reinstitutionalization, with the experience of behaviouraltering treatments and sterilization.

The book challenges us to examine whether the evolution of services over the past years has forgotten the impact of policy and change upon the lives of the individuals whom they support. Although we have come a long way in the past quarter of a century, there is so much yet to be achieved. From the perspective of the individuals we support, we still have a long way to go.

One of the few books that describes the history of developmental disabilities from the perspective of the individual who experienced it is *I witness! History and a Person with a Developmental Disability* by David Hingsburger (1992). This book

is a stirring account of Noreen's experience, as a person with a developmental disability, in a Canadian Institution and now in the community. The richness of this historical perspective is threefold. First, it is an actual account of the history as told by an individual with a disabling condition. Second, it is a deeply personal account that demonstrates clearly the impact of social policy and service provision on the life of the person for whom it was designed. Third, it is a remarkably uplifting text which provides the story of courage, determination, and achievement of a very special woman, who happened to carry the label of developmental disability.

I have been a service provider in the field of developmental services during this period of incredible change. As we review the past 25 years it is difficult to deny that our heritage is rich. However, unless we understand it, we may neglect some of the important lessons learned. History has reflected much about the relationship between economic and political times and the treatment of persons with disabilities. We cannot stand on the accomplishments of the past and be satisfied with how far we have come. There is still so much that needs to be done. However, there is an ever-present danger, particularly in these times of economic constraint, that there could be again a shift in the tides of opinion and conscience. Those of us who are witnesses to the change in positive direction and who can remember or learn from the past should be giving a voice to the history of persons with disabling conditions, so that history will not be repeated.

Today, people with developmental disabilities are more a part of our community. Although the effort to provide a voice to their lives is a slow process, as long as they remain a part of the community and an ever present force, the struggle can persist.

#### **Dorothy Griffiths**

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## **Film Reviews**

### by Judy Koch

Recently, I saw the vidoetapes of two films Dumb and Dumber and Nell. Films such as these potentially impact on the image that people with developmental disabilities hold in their communities at large. They will also affect people's perceptions of psychiatric survivors, and possibly perceptions of people who have learning disabilities. It is important that publications dealing with these disabilities comment on films of this type.

Dumb and Dumber is a story about two men who go across the country to deliver a suitcase left behind by a woman who flew to a city in Colorado. It is a slapstick comedy full of their misadventures and close calls with fate. At the end, they get rewarded by cops for (inadvertently) helping them catch some criminals. Throughout the movie, the two friends manage to avoid many dangerous situations, as well as constantly facing being broke but managing to keep going. They have many lucky breaks that could only happen in Hollywood movies. At the end of the movie, they appear to have learned something when a group of women in bikinis riding in a truck offer to take them along as male escorts, but they refuse.

It is not clear if these two men have developmental disabilities (or at least an intellectual challenge), but their misadventures could happen to people who do, at least in Hollywood movies. On the whole, the movie can be seen as an ableist view of developmentally disabled people. An ableist view implies two things: (1) looking at the world solely from the perspective of a non-disabled person rather than from the perspective of the person with disabilities, and (2) looking down on people who have disabilities. This movie is meant to be a comedy, and, unfortunately, the ableist view is essential as the source of the comedy. We laugh at (not with) the two bumblers, because, from the non-intellectually challenged perspective, their bumbling is dependent upon their being "dumb."

People with all disabilities as well as other concerned individuals should speak out

against this movie and should consider refusing to see either the video or the movie if it is shown at second run theatres.

Nell is a video about a woman who is raised in the wild by a mother who is disabled. She is discovered by a group of doctors and other professionals. A man and a woman go to study her and try to help her for a period of a few months. They become her friends and discover that she knows a type of English. Some teenage boys discover her one day and the word gets out. The local newspapers run sensational reports on her. A psychiatric hospital takes her in to "protect" her. The man who discovered her takes her out of the hospital and there is a court hearing on whether she should be in the custody of the hospital or not. Her protectors get her to testify and translate for her towards the end of the hearing. She ends up remaining free of the hospital.

This film is also very much a Hollywood fantasy, since this woman has a "knight in shining armor." This seldom happens in real life. In real life, women from other cultures sometimes end up in psychiatric hgospitals full a racist staff who try to separate them from their culture and "westernize" them. There are no guardian angels to take them out. Thus, this movie is a distortion of reality also. Although it is the better of the two movies, it should also be on the list of movies that should actively be discouraged.

There have been a number of movies dealing with people who have various types of intellectual disabilities since the disability rights movement got going. Unfortunately, they have mostly represented distortion of the reality of the lives of people with disabilities. It is time we did something about this.

Judy Koch is a member of the Disabled Women's Network, Toronto.

## **Book Reviews**

James W. Trent, Jr. *Inventing the Feeble Mind:* A History of Mental Retardation in the United States, Berkeley CA, University of California Press, 1994. 356 pages.

## Reviewed by Dennis Raphael

In Inventing the Feeble Mind, James Trent does much more than provide a history of "mental retardation" in the United States. Through an analysis of how the idea of "feeble-mindedness" has been constructed within the United States, he provides the reader with an intensive introduction to critical social theory and how such an analysis can transform the way in which we consider social issues. Trent also identifies the forces, sometimes societal, sometimes personal, which served to shape the frameworks within which "mental retardation" has been defined, and acted upon, in the United States. His analysis extends from pre-revolutionary America to the present.

### Mental Retardation as a Social Construction

Early on, Trent explicitly states that his analytical framework is drawn from social constructionism and critical sociology. He views terms such as "mental retardation" to be social constructions: "Mental retardation is a construction whose changing meaning is shaped both by individuals who initiate and administer policies, programs, and practices, and by the social context to which these individuals are responding" (p. 2). Focus upon these constructions is not an idle intellectual exercise. These ideas have served to justify, at various times, institutionalization, deinstitutionalization, sterilization, segregated education, non-segregated education, or any number of additional policies and procedures directed towards individuals perceived to be "feeble-minded."

Additionally, Trent positions himself as favouring "...a conflict and revisionist

approach to a generally older 'progressive' humanitarian view of the history of social problems" (p. 279). Concerning the history of "mental retardation" in the United States, Trent sees "institutional policies and practices forced on groups of people who have intruded in the interests and values of powerful and usually conservative native populations" (p. 28). In his analysis, Trent focuses upon a multitude of factors which serve to define the ideas which exist in differing times and places.

At one level, Trent considers the role of economic crises in shaping views concerning the educability of "feeble-minded" persons and their return to the community. For example, such views varied as a function of relative economic growth and employment shortages and surpluses. An extensive review and presentation of documents details how professional prestige considerations shaped the building and maintaining of institutions. During the mid and late 1800's, superintendents spread the view that the protection of society required the incarceration of the "feeble-minded." These activities served to increase their prestige and assure them increasing control over the expanding "feeble-mindedness" domain. Similarly, physicians gradually gained professional dominance of the field from educators during the late 1800's, leading to the "medicalization of mental retardation." More recently, in the United States, psychologists in universities have gained control over the research agenda from psychiatrists and superintendents. Trent examines the impacts these developments have had upon the field in general and persons with "mental retardation" in particular.

But the story of "mental retardation" in the United States and how it has been constructed, is also a story of individuals. An entire chapter documents the tremendous impact of Edward Seguin and how his message of the educability of even low functioning individuals served to energize the American education and medical community to improve the lives of individuals so identified. The visionary views and documented successes of Charles Bernstein during the first two decades of this century in returning hundreds of individuals to the community--at the height of the eugenics movement--also gives one pause to consider the power of individuals to effect change.

A particularly fascinating story is the impact that conscientious objectors during World War II had upon social policy. Many worked in custodial institutions and, upon the war's end, they exposed the appalling conditions found in these institutions. These former conscientious objectors even formed the National Mental Health Foundation to promote better care. Additionally, the important roles in reform played by Roy and Dale Rogers, Pearl S. Buck, and Geraldo Rivera, among others, in recent decades, are also considered.

### **Book Contents**

The book consists of seven chapters. Chapter 1, Idiots in America, traces how "mental retardation" moved from being a family and local problem to a state and social problem. At this point, Trent develops the idea that mental retardation as a state problem served a variety of societal needs. In the second chapter, Edward Seguin and the Irony of Physiological Education, Trent considers the impact of Seguin's emphasis upon methods and tools of education rather than the ends of education. In the third chapter, The Burden of the Feebleminded, he considers the growth of institutions and the role of superintendents in shaping policy towards the "feeble-minded." Trent musters available documents to describe the daily life of attendants and "inmates" in the fourth chapter, Living and Working in the Institution, 1890-1920. The available letters between inmates and their parents, as well as letters from former inmates to institution authorities, are a focus of this chapter.

Chapter 5, The Menace of the Feebleminded, documents the process by which American society now construed persons with "mental retardation" as a threat. This discussion includes the rise of the eugenics movement, the impacts of economic crises, and the changes occurring in American society. Chapter Six, Sterilization, Parole, and Routinization, develops the argument that sterilization of inmates was a means of maintaining, first, institutional control, and then, social control, as overcrowding led to a need to safely parole "inmates" into the community.

Finally, in the last chapter, The Remaking of Mental Retardation: Of War, Angels,

Parents, and Politicians, the unique forces which converged at the end of World War II to first promote institutionalization, then deinstitutionalization, are described. In one of many ironies, Trent depicts how, following the second world war, famous individuals such as Pearl S. Buck, by admitting to having "mentally retarded" children, served to set the stage for the increased institutionalization of children and toddlers.

## **Evaluation and Lessons**

The book is extremely well-written and draws upon a decade of work by the author. It should be of special interest to researchers and educators, and students learning about issues related to developmental disabilities at either the undergraduate or graduate level. It may also be useful to those involved in formulating governmental social policy and agency-level practice. The book will be enjoyed by anyone who wishes to gain an introduction to critical social theory. This may include front-line workers with an historical bent or other citizens who wish to gain a broader understanding of the history of disabilities.

Extensive documentation is provided in the form of detailed notes, and references are numerous. Consistent with work in the critical social science tradition, extensive verbatim statements and quotes are provided within the text. These statements serve to provide a rich sense of the personal constructions concerning "mental retardation" held by individuals during the periods considered by the book. Reading this book is a transformational experience: one will not view the issue of "mental retardation" in the same light after reading it. One also becomes aware of the wide shifts which are possible in public policy approaches over very short periods of time.

What I take away from *Inventing the Feeble Mind: A History of Mental Retardation* in the *United States*, is an increased awareness of the impact of societal forces, specifically, economic forces, in shaping constructions of disability. In Ontario, we are awaiting expected extensive budget cuts and I wonder how these may impact upon how we construct the image of persons with developmental disabilities. Trent

specifically comments on the impact of the capitalist, market-orientation on the treatment of the issue of "mental retardation" in the United States. What effect will the Common Sense Revolution--the proposed agenda of Ontario's newly elected Progressive Conservative government--have on our social constructions concerning persons with developmental disabilities?

Similarly, I found myself, as a psychologist, reflecting upon the role that professionals play in defining the domains of interest and research. Trent points out that, traditionally, focus has been on well-defined, measurable characteristics of the individual. He criticizes this particularistic and technical approach since it is associated with the following:

The problem with this focus in the history of mental retardation is that it has kept our gaze on the person labelled mentally retarded. In so doing, research questions and policy formulations have almost always placed the burden of change on the retarded person. It is her medical-pathological flaw that must be understood, his intelligence measured, her behavior modified, or his social maladjustment reshaped. None would argue that there are no needs particular to some people with intellectual disability. Yet most needs of people labelled mentally retarded are the same as those of people not labelled mentally retarded: meaningful work and economic security, fulfilling personal and community relations, dignity, and a measure of control over one's life. By restricting the gaze to the person with 'it', issues of the maldistribution of resources, status, and power so prominent in the history of the lives of most mentally retarded (and mentally accelerated) people remain muted (p. 274).

In closing, I heartily recommend this book. While it is focused on the United States, the lessons it contains are relevant to Canada and elsewhere. Its appearance on the scene may be especially timely.

#### **Endnote**

Throughout the book, Trent employs the period-terms (e.g., idiots, morons, feeble-minded, inmates, etc.) used to refer to persons with mental retardation in the United States (developmental disabilities in Ontario). He does so since he believes that a tradition of condescension, suspicion, and exclusion continues to be informed by these earlier terms. "That history is unavoidably manifest in the words we now find offensive, and so I have intentionally used them throughout the book." He also points out: "While our contemporary phrases appear more benign, too often we use them to hide from the offense in ways that the old terms did not permit" (p. 5).

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Stainton, Timothy. Autonomy and Social Policy: Rights, Mental Handicap and Community Care. Brookfield, VT, Ashgate Publishing, 1994. 233 pages.

### Reviewed by Judith Sandys

In these increasingly rights-conscious times, many of us struggle with how best to secure for people with intellectual disabilities the rights that most of us take for granted. We struggle to give people choices and options and, as much as possible, to involve them in the decision-making process. Nonetheless, we recognize that today most people with intellectual disabilities have relatively few choices and options and that, all too often, decisions which effect them are made by the service systems upon which they depend for support and assistance.

In his book, Autonomy and Social Policy: Rights, Mental Handicap and Community Care, Timothy Stainton grapples with these weighty questions from both a theoretical and an applied perspective. The book is divided into two very distinct sections, the first of which focuses on political theory and the second of which seeks to apply this to the realm of social policy and, more specifically, to social policy relating to people with intellectual disabilities.

Stainton defines his goals in Part One as seeking "to analyze the concept of autonomy and establish a theoretical base for the application of autonomy to social policy" (p.2) using the techniques of normative political philosophy. Stainton defines autonomy as "the capacity of the individual to formulate and act on plans and purposes which are self-determined." He devotes considerable energy to specifying the variables inherent in this definition and argues for the concept of autonomy as a core political value.

The issues addressed in Part One are of great importance and the treatment of them very thorough and thought-provoking. For those who have the time and inclination to delve into this type of scholarly material, the rewards will likely be substantial. For those unfamiliar with political theory, though, the going will be challenging. Some readers may find the presentation of the material somewhat daunting. By way of an example, Stainton states that: "autonomous execution consists in the conscious initiation and management of action aimed at the realization of plans and purposes, which is both dispositionally and occurrently consistent with our valuation system" (p. 33).

Some readers may be tempted to skip to Part Two, where the focus turns specifically to the issue of disability. Stainton notes that it is misleading to speak of "disability rights" or the "rights of the disabled" as if these rights somehow stem from a different source than the rights of everyone else. Rather, we are concerned when people with disabilities are denied their rights or are unable to exercise them and we want to consider what has to be in place in order to secure these rights. Stainton identifies two sets of actions associated with disability rights: "First, compensatory actions to redress historical disadvantage; and, second, positive action to ensure

that people with disabilities are able to fully exercise their rights" (p. 121).

In Chapter 7, entitled "Autonomy, rights and disability: The social construction of exclusion," he examines some of the policies which, historically, have contributed to the exclusion, and sometimes elimination, of people with disabilities, including the development of institutions and the eugenics movement. The next chapter moves to the present. Reviewing legislative initiatives in Britain, Stainton notes that despite increased use of the language of rights, paternalism is still very prevalent. He provides a succinct summary of recent legislative changes in Ontario, and concludes: "While Ontario has gone further in making real structural changes towards a rights based reality, incoherence and inconsistencies remain" (p 149). Further, he suggests, in both Britain and Ontario, "there is no overall perspective on what a truly rights based system entails and how such a system might be implemented" (p. 159).

Outlining what such a system might look like is the focus of the following chapter, Chapter 9. It is this chapter that will be of primary interest to many readers. Here, Stainton seeks to explore strategies which will, potentially, enhance people's autonomy. The components that comprise Stainton's ideal system include: (1) advocacy, provided through a supportive personal network, which helps the individual to identify and demand needed services and supports; (2) service brokerage, wherein a neutral party is available to help mediate between the individual and the service system, so as to ensure that appropriate services are indeed provided; and (3) individualized funding, which ensures that funds are attached to and controlled by the individual (assisted by her/his personal network and service broker), rather than to and by service systems. Stainton provides a brief, clear summary of the essential characteristics and potential benefits of these various components. He cites some (limited) research which suggests that while people feel controlled by traditional case management approaches, service brokerage and individualized funding lead to increased autonomy. Without question, the ideas that Stainton presents are worthy of serious consideration. There is no doubt that, used creatively, these kinds of approaches can have a major, positive impact on people's lives.

Nevertheless, there is the risk that this very brief and largely uncritical presentation of advocacy, brokerage, and individualized funding will leave the reader with the impression that they are easy to accomplish and that they invariably lead to positive outcomes. Unfortunately, neither is the case. Promoting effective advocacy is a major challenge and service brokers may not mediate effectively. Individualized funding does not always produce positive outcomes and, indeed, creates many of its own challenges. Further research is needed to explore the benefits and limitations of these approaches, the safeguards that are necessary, and the conditions under which they are most likely to produce positive outcomes.

This interesting and thought-provoking book has made a most valuable contribution in terms of explicating a theoretical base for the development of these approaches as well as providing a clear description of the components of a service system which places autonomy at its core. It challenges us all to continue to explore better ways of securing the rights of people with intellectual disabilities.

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