

A brief history of The J.P. Das Developmental Disabilities Centre

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The J.P. Das Developmental Disabilities Centre celebrated its 40th anniversary on September 1, 2007, followed by The University of Alberta's 100th anniversary celebration in 2008. The year 2008 also brought the appointment of a new Director for the Centre. As the immediate past Director of the Centre, I would like to record some of the history of the Centre at this time.

It is difficult to write with objectivity about any organization or endeavor with which one has been closely involved for many years and about which one holds strong views. Nevertheless, upon my recent completion of my extended term as Director of the J.P. Das Developmental Disabilities Centre and the recent fortieth anniversary of the Centre, this seems a good time to recount some of the history of the Centre.

In writing this article, I have taken the liberty to use first-person narrative in sections that are essentially self-reports of a participant-observer. This avoids the stilted convention and false objectivity of writing about oneself in the third person. Kent Cameron contributed much of the material on the early years of the Centre, which came from documents in the Cameron family archives, which include many papers of his grandfather, Don R. Cameron, the founder and first Director of the Centre for Study of Mental Retardation, today known as the J.P. Das Developmental Disabilities Centre.

The history of the J.P. Das Developmental Disabilities Centre is, above all, a story of a Community-University Partnership. From its earliest stages, The Centre has worked closely with community-based organizations, most notably the Canadian Association for Community Living and the Alberta Association for Community Living, and this relationship continues today, in 2008.

Formative History

The forces that led to the creation of the J.P. Das Developmental Disabilities Centre began to take shape in post-World-War-II Canada. In the first half of the Twentieth Century, North American society had responded to people with intellectual and developmental disabilities largely through eugenics, exclusion, and institutionalization. Families were isolated and often lived in shame. It was not uncommon for parents to deny the existence of their children with disabilities. After the war, the widespread repudiation of eugenic ideas and practices, which were associated with Nazi racial policy and extermination programs, led to rapid change in social conditions.

The Joseph P. Kennedy, Jr. Foundation, founded in 1946 in honor of Senator Joseph Kennedy's son, who was killed in World War II, played an important role in raising awareness of the needs of people with intellectual disabilities and their families. The Foundation was influential in advocating for research on intellectual disabilities, and would influence the directions of the J.P. Das Developmental Disabilities Centre in various ways in the decades to come.

Another development was the emergence of widespread parent and family advocacy on behalf of children and adults with intellectual and developmental disabilities. Across North America, local advocacy organizations sprang up in the 1950s. In 1953, Dale Evans' *Angel Unaware*, was among the first parental accounts published of having a child with an intellectual disability. It proved to be a major influence on parents of children with disabilities throughout the English-speaking world to speak out and openly advocate for their children. Royalties from the book, which sold millions of copies, were donated to the organization of a national advocacy organization, which further fueled the movement (Sobsey, in press).

In 1958, local organizations across Canada forged a national Federation then called the *Canadian Association for the Mentally Retarded*, a national organization that would play a major role in the creation of the J.P. Das Developmental Disabilities Centre less than a decade later.

Around the same time, other events at the University of Alberta were moving ahead. In 1942, the Faculty of Education was established at the University of Alberta. In 1945, the Province made teacher training a university responsibility and the University of Alberta Faculty of Education moved to the Edmonton Normal School. By August 1950, the Department of Educational Psychology was established in the Faculty, and by the early 1960s courses were taught in special education. Don (Donald R.) Cameron, who had previously been employed by the Alberta Department of Education with responsibility for services to children with multiple disabilities, joined the Educational Psychology Department in 1962, with a mandate to develop resources for teaching children with special needs. By 1964, the Faculty had established a minor in special education, and the Special Education Area within the Department of Educational Psychology was under development (Clarke, 1982).

A confluence of the interests of the Canadian Association for the Mentally Retarded and the University of Alberta was beginning to form. The Association had a strong interest in building Canadian capacity for research to better the lives of people with intellectual disabilities, and the University had a strong interest in developing scholarly research to support its professional training in pediatrics, special education, and other programs related to children and adults with disabilities.

International influences in the 1960s also played an important role in establishing the context for the establishment of a new Centre. On February 5, 1963, U.S. President John F. Kennedy delivered a powerful speech to the U.S. House of Representatives on the need to address the challenges of mental retardation and mental illness. In this speech, he emphasized the need to:

... strengthen the underlying resources of knowledge, and, above all, of skilled manpower which are necessary to mount and sustain our attack on mental disability for many years to come. (Kennedy, 1963, p. 2.)

In concrete terms, this led to the *Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963* (PL 88-164), signed into law less than a month before Kennedy was assassinated on October 31, 1963, that provided for the construction of university affiliated research centres and mental retardation research centres across the United States. As of 2008, 67 American Universities have University Centers for Excellence in Developmental Disabilities, at least one in every state. In addition there are another 21 Intellectual and Developmental Disabilities Research Centers that grew out of this Act. These centres are actively involved in research, training, and community service in their states. The development of these centres in the United States provided a template for the creation of a Canadian centre. These University Affiliated Centres operate with many more staff members and much larger budgets, but the J.P. Das Developmental Disabilities Centre has a similar mission and has made substantial contributions to work in this area.

Early Years

In the mid-1960s, the Canadian Association for the Mentally Retarded (CAMR), now the Canadian Association for Community Living (CACL), and the University of Alberta began discussions on establishing an interdisciplinary research centre to address five interrelated goals:

1. provide a supportive environment for studies of mental retardation;
 2. encourage the application of scientific findings that could lead to prevention, education, and habilitation of mental retardation;
 3. disseminate and publish research and applications;
 4. train students; and
 5. act as a resource for government and public agencies.
- (University of Alberta, 1987, p. 1)

G. Allan Roeher, from CAMR, and Don Cameron, from the University of Alberta, represented their respective organizations in creating a vision for the Centre.

CAMR made a lump sum grant of \$225,000 to the University of Alberta to establish the Centre, Other Foundations added \$20,000 during the early years of the Centre and small private donations added an additional \$30,000. The University of Alberta supplemented this with \$25,000 per year during the early years of the Centre (Centre for the Study of Mental Retardation, 1984). This was a very substantial investment for a fledgling, grassroots charitable organization like CAMR to make during its early years. According to the Canadian Consumer Price Index, it is equivalent to more than \$1.5 Million in 2008 dollars. In return, the University offered a promise of hope for better lives for Canadians with intellectual disabilities based on a foundation of quality research directly applicable to their lives. During the formation of the Centre, in an undated document titled "Promises to keep," Cameron wrote about how the new research centre could better the lives of children with intellectual disabilities.

The Centre began its operation on September 1, 1967, with plans for 3.5 full-time academic positions and one secretarial position. While the initial grant of a quarter-million dollars stretched much further in the 1960s and 1970s than it would today, staffing costs well exceeded funding and the original grant was depleted completely by about 1976. The new Centre was originally administered under the Office of the President of the University and later the Office of the Vice-President, Research. The Centre continued to report directly to the Vice-President, Research until 1990, when it was administratively placed under the Department of Educational Psychology in the Faculty of Education.

Services for people with developmental disabilities in the 1960s and 1970s were primitive by today's standards. The number of people institutionalized continued to grow until 1971 and the law mandating involuntary sterilizations was not repealed until 1972. Schools routinely denied educational services to children with severe disabilities until 1978, when this practice was eliminated by a court. In that case, *Shelley Joyce Marie Carriere v. County of Lamont No. 30 (1978)*, the Glenrose Hospital expelled a nine-year-old girl who had cerebral palsy because they claimed that she was mentally retarded and therefore was not suitable to attend their program, which only served children with

physical disabilities. Her local board responded by indicating that since no appropriate program was available, she was not entitled to education. The court, however, determined that School Boards must provide educational services for all children including those with intellectual and multiple disabilities. This was an important milestone in the evolution of educational services in the Province of Alberta in which the Centre played a significant role and which would later influence the direction of the Centre.

The 1980s and 1990s

The 1980s and 1990s were challenging times for the Centre. In 1984, it underwent a review by the President's Advisory Committee on Campus Reviews. The Committee found that the work done at the Centre had scientific merit but, more importantly, it had "immediate application to improving learning and achievement in mentally handicapped and learning disabled people" (University of Alberta, 1987, p. 1). The review recommended expansion of the Centre and this recommendation led to a small increase in the operating budget. Two salient changes followed this review.

First, on November 18, 1986, the Centre changed its name to the *Developmental Disabilities Centre* to reflect a broadened mandate to include the study of other cognitive disabilities along with the study of global intellectual disabilities. The change also reflected a growing social concern that the term *mental retardation* was considered to carry undesirable stigma. Canada's *National Institute on Mental Retardation* had changed its name to the *Roeher Institute* following the untimely death of its founder G. Allan Roeher in 1983, and the *Canadian Association for the Mentally Retarded* had changed its name to the *Canadian Association for Community Living* in 1985 for similar reasons.

Second, a Research and Services Unit was established in 1986. Although I had worked informally with the Centre since I came to Alberta in 1982, my appointment to head this unit in 1986 began my formal role with the Centre. The new unit worked with the Alberta Association for Community Living and others in the Community to establish the *On*

Campus program, a post-secondary education program for students with intellectual disabilities fully integrated with campus life at the University of Alberta. In 2008, *On Campus* continues to operate as an independent program at the University of Alberta closely linked to the J.P. Das Developmental Disabilities Centre (Brown, Fay-Verschuur, Logan, & Rossiter, 2007).

The late 1980s and early 1990s were particularly turbulent times for the Developmental Disabilities Centre and for the University of Alberta as a whole. The University was undergoing major financial pressures, which impacted heavily on the Developmental Disabilities Centre along with many other areas of the University of Alberta. Major financial and administrative changes took place. In April 1990, the Centre was transferred administratively from the Office of the Vice-President of Research into the Department of Educational Psychology in the Faculty of Education. The budget for the Centre was reduced by 25% and the remaining funds were absorbed into the budget of the Department of Educational Psychology.

Directors

Over the four decades of its operation, the J.P. Das Developmental Disabilities Centre has had five directors. Each of the first three has made important contributions to research and to practice in the field of developmental disabilities. I was honored to follow them as the fourth director. My contribution to the field and that of my successors will be evaluated by others in the years to come.

Donald R. Cameron Don Cameron, the Founder of the Centre, was its first Director until 1970. His vision of the Centre played a major role in setting future directions. Cameron had a pragmatic focus on improving services for people with intellectual and developmental disabilities, but he also recognized the importance of building effective and humane services on a firm foundation of high-quality research. While his own focus was on education, Cameron also recognized the need for interdisciplinary collaboration for meaningful research and effective service delivery.

Don Cameron retired from the University of Alberta in 1974, but his commitment to children and adults with developmental disabilities did not end there. While he continued teaching as a Professor Emeritus, he served as President of the Alberta Association for Community Living in 1975-1976 and as Vice-President of the Canadian Association for Community Living following that.

As President of the Alberta Association for the Mentally Retarded, Cameron wrote in an open Letter to the Minister of Education in 1975:

How long must the handicapped in Alberta wait for a forthright statement on their right to education? An increasing body of research and experience supports the proposition that no child is ineducable. Despite ability limitations, even the severely mentally retarded are capable of useful learning. "Educating the ineducable" is no longer a contradictory concept. (Cameron, 1975, p. 5)

As Vice-President of the Canadian Association on Community Living, he consulted on the previously mentioned Carriere case (*Shelley Joyce Marie Carriere v. County of Lamont No. 30, 1978*) that was critical to recognizing the right of all children, particularly those with severe and multiple disabilities, who were previously excluded, to education in Alberta. Cameron's continued involvement with AACL and CACL after his formal retirement and his involvement with critical events such as the Carriere case helped to fulfill the original promise of the Centre to conduct and utilize research to better the lives of people with intellectual and developmental disabilities. The following year Don Cameron (1979) wrote a short article discussing the impact of the Carriere case. Among the many issues he addressed was one that would have profound impact on my own life and career:

... the reverberations of the Carriere judgment have created an acute emergency in respect of a lack of teachers specially prepared and qualified to serve dependent and multiply handicapped children. (p. 5)

Two years later and a thousands of kilometers distance, I was recruited to come to Alberta to train teachers to educate those children.

Don Cameron passed away in 1998 at the age of 86. As of 2008, Cameron's grandson, Kent, is enrolled as a doctoral student in Special Education at the University of Alberta. Kent Cameron contributed much useful information about the formation and early years of the Centre based on his grandfather's papers.

Ernest E. McCoy E. E. McCoy, from the Department of Pediatrics, served as its second Director from 1970 until 1972. Dr. McCoy was also the Chair of the Department of Pediatrics at the University of Alberta from 1971 to 1985 and a major figure in the operation of the Alberta Heritage Fund for Medical Research from its inception in 1976 until 1995. Dr. McCoy has a particular interest in health care for children with Down syndrome and other developmental disability syndromes. He was Chair of the Joint University Megavitamin Therapy Review Committee in 1976 and a co-editor of the book *Down syndrome: Advances in medical care* in 1992 (Lott, & McCoy, 1992). He was also one of the founders of the Greenpeace Children of Chernobyl Project in 1990 and served as its medical director for several years.

J.P. (Jagannath Prasad) Das J.P. Das was appointed to the CSMR on January 1, 1968. He had previously been a Kennedy Research Professor at George Peabody College at Vanderbilt University in Nashville, Tennessee and was appointed as a University Research Professor, when he arrived in Alberta. Later, he received a cross-appointment to the Department of Educational Psychology. He was made the Director of the Centre in 1972 (Centre for the Study of Mental Retardation, 1984) and served as Director of the Centre until 1994. In 1995, he officially retired from the University of Alberta, but he has continued active research with the Centre as a Professor Emeritus.

J.P. Das served as Director of the Developmental Disabilities Centre for 22 years. In his roles, as Research Professor, Director, and Professor Emeritus, he has worked for the Centre for forty years, as of 2008, and brought honor and distinction to the Centre. Although he has studied a

broad range of topics, much of his research has focused on the nature of cognitive processing. In 1987, he was awarded the J Gordin Kaplan Award for Excellence in Research, the University of Alberta's highest award for excellence in research. In 1999, Dr. Das received the highest distinction awarded to Canadian scholars when he was elected to the Royal Society of Canada. In recognition of his contribution the Centre was renamed the J.P. Das Developmental Disabilities Centre at the 30th anniversary of the Centre in 1997. Professor Das' remarkable career spans virtually the entire four-decade history of the Centre, having been recruited during the first days of its operation and continuing to work actively with the Centre today in 2008. While his contributions to the Centre are too numerous to adequately record here, some observations and reminiscences are included in a following article in this issue.

Dick Sobsey In 1994, J.P. Das stepped down as Director of the Developmental Disabilities Centre, and I assumed the role of Director of the Centre at that time. My association with the Centre had begun shortly after I came to the University of Alberta in 1982. In 1986, I was Clinical Services Director for the Centre and I served as Editor of the *Developmental Disabilities Bulletin* from 1989 – 1992.

My research has focused on five areas related to developmental disabilities: (1) transdisciplinary collaboration of service delivery, (2) services for children and adults with severe and multiple disabilities, (3) understanding and preventing abuse and exploitation of people with disabilities, (4) effects of developmental disabilities on family function, and (5) ethical issues as they affect the lives of people with disabilities.

During my 22 year tenure with the Centre as Clinical Services Director, Director, and Associate Director, I endeavored to contribute to teaching, research, and community service consultation that would enhance the lives of people with disabilities. In teaching, I first published the text *Educating Children with Multiple Disabilities*, with co-author Fred Orelove from Virginia Commonwealth University in 1987. Now in its fourth edition, it has been used to train approximately 50,000 professionals working with students with severe disabilities over the last two decades. In research, I first presented the integrated-ecological model of violence

against people with disabilities, which has been widely accepted and applied in criminology and a number of other disciplines. In public service, I have frequently acted as an expert witness or engaged in public policy consultation. I am pleased to have had the opportunity to influence legislation in Alberta and beyond. I wrote the original draft of what became Alberta's Protection for Persons in Care Act, which came into force on January 5, 1998. I also co-authored a small section of the Alberta's revised Education Act that guaranteed every child with Special Needs a Right to a free appropriate education and replaced the original Section 29 of Bill 59 of the proposed Education Act of 1987 that would have denied education to children with severe disabilities who were deemed uneducable. Most recently, in 2008, California Assembly Speaker pro Tempore (Democrat) Sally Lieber introduced the Crime Victims with Disabilities Act (AB 2038), and Senator Joe Biden introduced the U.S. Federal Crime Victims with Disabilities Act (S3668), based, in part, on my research.

While I am proud to have played a role in these events that serve the needs of people with developmental disabilities as part of my work with the Centre, they are all the result of the collaborative efforts of many individuals and organizations, notably the Canadian Association for Community Living, The Alberta Association for Community Living, and the Joseph P. Kennedy, Jr. Foundation, which were formative influences in the creation of the Centre and valuable allies throughout its history.

For example, in 1987, 1989, 1990, and 1994, I coordinated four large conferences for the Severe Handicaps Alliance for Public Education, a coalition of organizations including the J.P. Das Developmental Disabilities Centre and the Alberta Association for Community Living. Since 2001, I have served on the Canadian Association for Community Living's Task force on Values and Ethics. During my time as Director of the Centre, the Joseph P. Kennedy, Jr. Foundation funded my research on sexual abuse of people with developmental disabilities, and I also worked with the Foundation on a number of other matters ranging from program evaluations to legislative planning. As of July 2008, I have stepped down as Director of the J.P. Das Developmental Disabilities

Centre, but I continue to work with the Centre as an Associate Director, with a focus on children and adults with intellectual disabilities.

Rauno Parrila In July 2008, Rauno Parrila was appointed as the fifth Director of the J.P. Das Developmental Disabilities Centre. His research is focused on psychological, linguistic, and social factors as they influence reading development and disabilities, and other academic skills. As of 2008, he is actively involved in the development of a strategic plan to set the future directions of the Centre. Rauno Parrila studied with Dr. Das at the Developmental Disabilities Centre as a doctoral student (1992 - 1996). After receiving his Doctoral degree, he worked as a postdoctoral fellow at Queen's University, and as an Associate Professor at University of Tromso, Norway, before returning to the University of Alberta in 2000.

Developmental Disabilities Bulletin

One of the first innovations under Dr. Das' Leadership was the publication of the *C.S.M.R. Bulletin*. Volume 1, Number 1, published in 1972-1973 was 22 pages in length. It opened with a brief foreword from Max Wyman, the President of the University of Alberta, and contained short articles from J.P. Das, E.E. McCoy (Chairman of Pediatrics at the University of Alberta), Perry Kinkaide (who was also first Editor of the Bulletin), and L. W. Krywaniuk.

The following year, the *C.S.M.R. Bulletin* became the *Mental Retardation Bulletin*. In the 1980s, it became the *Mental Retardation and Learning Disabilities Bulletin*, and in the 1990s, the journal began publishing under its current name *Developmental Disabilities Bulletin*. In 2008, the Journal continues to publish under the direction of co-editors Jack Goldberg and Lorraine Wilgosh. *Developmental Disabilities Bulletin* is now available in electronic full text through several publishers.

Advisory Boards

From its inception until the time that the J.P. Das Developmental Disabilities Centre was absorbed into the Faculty of Education, a

community advisory board guided the Centre and assisted in its work. The Board was actively engaged in many issues. For example, in 1987, the Government introduced a new Education Act. As part of the proposed Act, Section 29 would declare some students “uneducable” and exclude them from Alberta’s schools. The passage of this Act would have taken away the right to education of students with severe disabilities that the courts had affirmed in the Carriere case nine years earlier. The Advisory Committee of the Developmental Disabilities Centre joined with other community groups protesting this Section. Elizabeth (Betty) Stevens-Guille (1988, January 12), Chair, wrote the following to the Minister of Education on behalf of the Advisory Committee:

It has consistently been the position of the Centre’s Advisory Committee that any legislation, which excludes individuals from education suitable to their needs, is undesirable. For this reason, the Committee strongly objects to the proposed School Act, Section 29 of Bill 59.

Fortunately, the Government reconsidered this legislation in the light of this and many other protests. The Act was withdrawn and rewritten guaranteeing an appropriate education to every child in Alberta. In reframing the Act to provide for the right of all children in Alberta to education, the Minister of Education acknowledged the role of the Centre in formulating these provisions.

Secretary-Administrators

The administration of the J.P. Das Developmental Disabilities Centre was managed through much of its history by a series of competent individuals working under the official title of Secretary or Administrative Officer. Judy Maynes was appointed as the first Secretary to the CSMR on October 5, 1967 (University of Alberta, 1968). Anne Marie Thornberry, Barbara McGowen, Fran Russell, and Henny DeGroot followed. Each of them made substantial contributions to and left indelible influences on the Centre. Since the integration of the Centre into the Faculty of Education and the subsequent retirement of Henny

DeGroot, the staff of the Department of Educational Psychology has handled the administration of the Centre competently and efficiently.

Toward the Future

There are so many more aspects of the history of the Centre that might be recounted that it would be impossible to include them all here. In this paper, I have tried to collect some of them and add a few of my personal reminiscences. Dr. Das's reminiscences follow in a separate paper.

The future of the Centre remains to be written. It will be the product of the unique characteristics of the participants and the evolving University and Community contexts in which they will operate. It would have been impossible to predict the events and achievements of the past four decades, but looking back it is clear that the lives of Albertans with intellectual and developmental disabilities have improved over the last four decades and the J.P. Das Developmental Disabilities Centre made some contributions to that improvement. The next four decades may bring even greater improvements and the Centre may continue to help bring those changes about.

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