

Gaps and Silos

Persons with Developmental Disabilities Move to the Community

(Report of a Study Leave Granted by the University of Manitoba, July 2004 to June 2005,
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Preface

My first experience with developmental disabilities was in Wentworth St. Public School, in Hamilton Ontario where from Kindergarten to grade six, I was aware (and sometimes peeked in the door) of the “opportunity class”. I was told by my mother and older sisters that it was a special class with its own teacher for kids who were slow at learning. We had no interaction as students with members of that class. A few times, I heard the term “dumb-dumb class” from other kids but they were usually shushed and then ignored by the rest of us.

I went through two years of junior high and then high school (five years in Ontario, then) with no specific memories of experiences to do with intellectually disabled children or adults. We had no family members, including our known extended family of uncles, aunts and cousins, who had intellectual disability or “mental retardation” as it was usually referred to then (and still is in parts of the United States).

In first year pre-meds at Queen’s in 1956 we took a course in Psychology, which I remember primarily through the professor, Dr. Blackburn, who had a British accent and wore musty smelling tweed suits. In second year pre-meds we had an elective opportunity and I took a course, Abnormal Child Psychology, taught by a minute dynamo of a senior professor, Dr. Isobel Laird. I remember mostly about child development, some rather bizarre abnormal case descriptions, and doing a major assignment on the influence of musical rhythm on youth.

During the summer before first year medicine, I got a job working in the clinical laboratory of the Ontario Hospital at Hamilton “the Mental Hospital”. I developed skills at microscopic examination of centrifuged urine, counting red and white cells in a glass cell counter under the microscope, drawing blood from cooperative patients, and doing the chemical maneuvers necessary to measure blood sugar. The lab director, my boss, drew the bloods from the “difficult” patients, some of whom had to be visited on the wards and I usually guarded the lab in her absence. When Dr. Mackenzie, the visiting Toronto neurosurgeon, came to do “leucotomies”, I was allowed to leave the lab for the O.R. and observe. The O.R. nurse was very accommodating to me. Medical students were rarely seen in those parts.

Next summer, I returned to that hospital, a year of “medicine” under my belt. I was given a clinical job as an “extern” and because the medical staff was under strength I was given responsibility beyond my specific skill sets. I was “in charge” of the admitting ward (new patient histories, physicals, and initial orders), sat in on weekly conferencing of patients, and administered electroshock therapy one half day a week. Because I was a student doctor, I was permitted to eat in the doctors’ dining room where we were served a full course lunch on white table cloths, with several silver knives, forks and spoons at each place setting, and attended by waitresses in full regalia. I enjoyed the “doctor talk” with the real doctors on staff, some of it good medical learning, some an introduction to the personal life and stress of being a doctor, and some, quite amusing. The hospital medical superintendent’s son later became a student and eventually a colleague.

Also because I was a student doctor I was permitted a half day each week to do whatever I wanted. I chose to spend it with a group of chronically schizophrenic women on a locked ward, where I tried valiantly to lead them in group discussion and finger painting exercises and actually took them out on the hospital grounds for walks, before a mixed reception of various hospital staff. It was quite a parade; a young man in a long white coat and sporting a stethoscope shepherding seven or eight women in plain grayish dresses following along in stumbling, Parkinsonian (due to medication) gaits, most with their heads down looking at the ground and blinking when they looked up, through eyes unused to direct sunlight.

I returned to medical school and being short of funds lucked upon a room and board arrangement plus \$40 per month to work in the Sunnyside Centre for children with emotional disorders. I was the only male staff member with four full time women staff, two with advanced degrees in child psychology. I was, then, the only approximation of a “father figure”. The thirteen children ranged from age three and a half to fourteen, most of them abandoned or removed from their homes because of their own difficult behavior or having been subject to abusive behavior. One boy was considered autistic, several children had particular learning difficulties at school, and all were a challenge. A consultant child psychiatrist visited regularly. Once a year he and his wife had all children and staff for a hot dog and pop lunch during which the hosts set out the food in a stripped-down dining room for the children, while the staff sat at lunch with the hosts in another room with door closed. I had breakfast and dinner with the children every day and on every fifth weekend was on duty with one of the other staff. I spent my monthly \$40 on long distance calls with my girlfriend (and later wife) who was completing university at McMaster University in Hamilton.

Following internship, I joined a group practice in Orillia, Ontario, where there happened to be one of the Ontario Hospitals for the mentally retarded. Our practice had no direct involvement with that hospital during my two years there, although occasionally I would see a resident of that hospital who happened to be working for one of our farmer patients and needed medical attention. The Orillia Ontario Hospital became known as the Huronia Centre and remains one of the three institutional facilities in the province for persons with developmental disabilities, now scheduled for closure by 2009.

After two years as a salaried general practitioner, I had to consider buying into the practice or not. I had particularly enjoyed children in my medical experiences and decided to take a year of pediatric residency at Queen’s, to gain more experience and also to decide whether or not to pursue other than a general practice career. The residency year included a two month rotation at the Smith’s Falls Ontario Hospital which then held 2600 individuals with developmental disabilities, nearly all children. My duties were to provide general medical services on specific units. I occasionally attended case conferences to hear the discussions about individual residents. There was no learning program set out for me as a pediatric resident and my educational supervision was

remote, through my professors at Kingston. I still have notes of the patients I saw there and am embarrassed to read how biomedically-oriented they are and how lacking in comments about behaviour, learning and social development. I recall a heated discussion between a medical student and one of my professors at Kingston about the appropriateness of admitting one's child to such an institution. The student challenged the professor "what could you know about what it's like to be a parent of such a child?" and the response was "I have a child in Smith's Falls, I know quite a bit about what it's like!" The Smith's Falls Hospital is now known as the Rideau Regional Centre and is also scheduled for closure by 2009.

Three years later I had embarked on a career as an "academic family physician", Family Medicine being a newly minted "academic clinical discipline". I wanted to better prepare myself as a teacher, so enrolled in a Master's program in Educational Psychology at Michigan State University's Office of Medical Education Research and Development. The focus was on graduate and postgraduate education in medical school, so while there were courses on Educational Objectives, Curriculum, Psychology of Learning, Psychological Measurement and Statistics, and Educational Research, there was little content directly related to intellectual or developmental disabilities.

I then went through eighteen years of academic and clinical work at London Ontario's University of Western Ontario and Halifax's Dalhousie University in their respective Departments of Family Medicine. I recall no specific discussions or involvement to do with Developmental Disabilities. I was a clinical professor and eventually a department head and had specific interests in health promotion and disease prevention, death and dying, and teaching. While at Dalhousie, our clinic was next to the School of Speech and Hearing, so when David Shires and I decided to produce a departmentally written Family Medicine text, I recruited two faculty from Speech and Hearing (Beverley and Michael Seitz) to write a chapter with me on "The Chronically Disabled Child and His Family" (1). I chaired the Medical faculty's Committee on Undergraduate Medical Education for three years and cannot recall any discussion regarding the presence or absence of content related to developmental disabilities.

I returned to the University of Western Ontario in 1987 as Family Medicine Department Head and found myself on the Advisory Board for the Developmental Disabilities Program, chaired by the Psychiatry Department Head. I was able to encourage a department member to take the initiative in developing a case study for Problem Based Learning in the undergraduate medical curriculum, which involved a female with Down syndrome at three stages of life: at birth, pre-school and puberty. The same staff member, Dr. George Deagle, with Maria Gitta, the administrative officer for the program, undertook a needs assessment survey of local family doctors to determine their problems in providing medical care to persons with developmental disabilities. (2,3). I was also able to tease four 1 ½ hour seminars for Developmental Disabilities out of the Family Medicine Postgraduate Residency Curriculum time. I engaged Dr. Ben Goldberg (a

psychiatrist specialist in Developmental Disabilities) and later, Greg Gillies (a family doctor with a child with Pervasive Developmental Disorder) and still later Tom Cheetham (a family doctor who had practiced half time in Woodstock at the Oxford Regional Centre (for developmental disabilities) in teaching various elements of the seminar series. I also worked with Dr. Goldberg on an external audit review of the Oxford Regional Centre as it was undergoing its deinstitutionalization process, leading eventually to full closure. In 1993 I chaired a task force on the Role of Family Medicine in Developmental Disabilities for the Advisory Board of the Developmental Disabilities Program at the University of Western Ontario. In May, 1999, I conducted an external review of the Queen's Program in Developmental Disabilities in the Faculty of Medicine for Dean David Walker.

All of these experiences made me increasingly aware of the inadequacy of education at the undergraduate medical and postgraduate residency levels in Developmental Disabilities. In discussion with others in Family Medicine and with other health professionals (especially Nursing and Social Work) I learned that Medicine was neither behind nor ahead in preparing its graduates for providing good care to persons with developmental disabilities. None of these disciplines had an adequate undergraduate curriculum component in developmental disabilities. I particularly started to wonder about the transition of childhood to adulthood, as developmentally disabled children grew too old for the developmental pediatricians (the most appropriately prepared medical discipline for dealing with this population). Further discoveries would show that a gap not only existed in physician preparation to serve the population but in terms of access to various social programs as these individuals fall out of the hands of children's services.

In 1997 I took a six month administrative leave and traveled to the United Kingdom, the Netherlands, the World Health Organization at Geneva, Australia, New Zealand and in Canada to Nova Scotia and New Brunswick. This exploration of deinstitutionalization in these different parts of the world revealed a varied approach. Scotland and the Netherlands seemed then to be leading: Scotland, in money spent per capita and in service innovations, and the Netherlands with the provision of support funds going directly to the users to spend as they saw fit. I also saw the weakening of nurse preparation and physician involvement in providing services, particularly in Australia and Canada. The Advocacy Groups (led by INCLUSION) and the research groups (led by IASSID) were so far apart in their ideologies (normalization versus categorization) that they had stopped cooperating and their organizations' leaders were struggling with how to get them together again.

I prepared a workshop for presentation at the Family Medicine Forum in 1998 (the national meeting of the College of Family Physicians of Canada) only to have one person appear, besides the chairperson for the session. The competition of a choice of topics such as the Emergency Care of Acute Shoulder Injuries and other more biologically-oriented topics overtook the wish of practicing family doctors to spend three hours of an

afternoon on Developmental Disabilities. One of the realities is that most family doctors will have only 3 or 4 persons in their practice population with a recognized developmental disability if they are distributed evenly amongst practitioners. Some family doctors with special skills and interest end up having more such patients (so much so that in one Australian community, a third of such doctors did not want to be recognized by name for fear that it might attract other affected individuals to their practice). Developmentally disabled patients take longer to see (for which there is no corrective compensation), it is perceived that such patients are disruptive in the waiting room, some require special access facilities which cost money, and such patients, because of their complexity, are considered medicolegal risks for the doctor who feels inadequately prepared to look after them.

When I next moved to the University of Manitoba as Dean of Medicine in 1999 I joined the research committee of the St. Amant Centre for Developmental Disabilities. I was also a member of the St. Amant Foundation board. I shared, with a developmental pediatrician, the teaching of a three hour seminar on Developmental Disability for Psychiatry residents ...the sole half day of their 3 years core training dedicated to that topic. I gave a faculty development workshop to the Department of Family Medicine on Teaching Developmental Disabilities. There is no core time in the present residency program for Developmental Disabilities.

St. Amant hosts an annual three day meeting on Developmental Disabilities and I have presented at three of these. ("Primary Care Needs of Persons with Developmental Disabilities" in 2001; "Science's Promise for Persons with Developmental Disabilities and their Families" in 2002; and "The Challenge of including Developmental Disability in Health Professional Education" in 2003). The meeting attracts a wide range of service providers, government officials, educators and researchers.

During the Capital Campaign of the University of Manitoba, I was able to arrange the funding of a research award on Developmental Disabilities for medical and graduate students or Family Medicine residents undertaking studies on some aspect of discovery or service. It was named the "Susan Wright Bell award" to recognize a woman with Down Syndrome and her husband from London, Ontario, who have been an inspiration to friends and health care providers.

During my five years in Winnipeg, I became increasingly aware of the expanding group of what constitutes Developmental Disabilities. Added now to the mix of known syndromes and the unspecified developmentally disabled group is the wide range of disorders identified as Autism and Autism Spectrum Disorders. I was heartened that our medical students, on their own initiative had decided to establish a Medical Art show and had picked for their first clinical topic, "Autism". It was a great success, and the single most positive review came from an adult young man with Autism who on visiting the

show at the Fort Garry campus with his parents, said to them, “For the first time, I feel that somebody understands me”.

A further expansion is seen in the Fetal Alcohol Syndrome, Fetal Alcohol Effect and Fetal Spectrum Disorder group of conditions. University of Manitoba’s pediatricians are leaders in Canada, given the large proportion of FAS patients in this province. Dr. Ab Chudley chaired the group which developed for publication in the Canadian Medical Association Journal the first “Clinical Guidelines for Identification and Treatment of Fetal Alcohol Syndrome” (4). Unfortunately the group does not include primary care practitioners, doctors or nurses, and so the practical relevance of the guidelines lack some credibility and may not be endorsed by those who need to have them. Adding further to the numbers are those young people addicted to inhalants.

While the particular characteristics of the nature of the disabilities are yet to be defined, there are developmental disabilities associated with children who have AIDs. And the world disasters of famine, poverty and severe weather causing floods and tsunamis leave millions of children vulnerable to acquired social and cognitive disabilities. We can expect a further enlargement of the overall group of developmental disabilities.

It was roughly at this stage of awareness and involvement that I submitted my application to Vice President Kerr for support to study Developmental Disabilities as part of my 2004-5 administrative leave,. I think it fair to say that over a lifetime of clinical and academic experience I had kindled a significant interest in developmental disabilities.

Since completing my decanal term, I have reviewed the undergraduate medical curriculum at the University of Manitoba with Associate Dean Magwood and curriculum administrative officer, Pat McCullough, and while there is no explicit component in the curriculum labeled, “Developmental Disabilities”, there are a number of threads in various parts of the curriculum which address some aspect of the subject. (see analysis in Table 1).

Most recently, in March, 2005, this kindled interest became a personal concern with the arrival of our first grandson, Sean Alexander. At his birth the midwife/nursing team noted that Sean had some of the recognized characteristics of Down syndrome, which was quickly confirmed diagnostically. At nearly seven months, he is developing well and has avoided the major cardiovascular and neurological problems often associated with the diagnosis.

What Sean has given me is the absolute expectation that in further developing my kindled interest, I really know what I’m talking about. He, his parents and our whole family will be assisting me in determining that this will be the case. And so the final preparation of this review is undertaken, along with academic interest, with a true commitment of love.

Gaps and Silos, Persons with Developmental Disabilities Move to the Community

A Century of Interrupted Progress

Less than a century ago, most people with developmental disabilities did not reach adulthood. Infants and children died from the complications of their disability and from neglect. Those who did survive, children and adults, were often admitted to institutional settings (asylums or “psychiatric hospitals”). Many others remained with their families, sometimes hidden away and other times accepted into their local community, but as an unfortunate and sometimes vulnerable member. Children frequently were removed from their families on the advice of physicians and other health care professionals who generally had the wellbeing of the affected individuals’ parents and siblings in mind, by relieving them of the burden of care.

“In years past, children such as ours would very likely have been placed in institutions at an early age. Parents of babies with much lesser disabilities were often advised not to take them home. ‘Put her in a home and forget you ever had her’ they were told. And many did.”

(Burbidge, Mary, Forever Baby. Second Edition, H-Mark Press Pty. Ltd., Australia, 2001, p14).

“The epileptic should lead as normal a life as possible. If he is employed, he should avoid certain hazards—mental and physical. He should not work near moving machines, nor drive an automobile. He should avoid marriage because he is usually a poor provider and may transmit the disease. If he displays antisocial conduct, owing to mental retardation (which is not infrequent) or deterioration he should be placed in an institution.”

(Pemeranz,, Herman and, Koll,, Irvin S. The Family Physician.. Greystone Press, 1961,p175)

“My book (last updated in about 1950)declared grandly that the birth of a Down syndrome child generally destroyed the mother’s mental health, as well as the life of any older sisters that might be in the family (brothers, its said, were exempt, since they were not expected to fill a caretaking role). It gave absolutely false information about the inability of such children to control their bodily functions, and their antisocial inclinations. It listed the typical IQ for “mongoloids” as about 35, and by way of comparison, mentioned that the IQ of a chimpanzee is about 50 and that of the average oak tree is 3.”

(Beck,Martha, Expecting Adam, Berkley Publishing Group, New York, 2000, p112.)

Research was, for the most part, descriptive of clinical presentations (Gellis, Sydney S., Feingold, Murray, Atlas of Mental Retardation Syndromes, Visual Diagnosis of Facies and Physical Findings, U.S. Department of Health, Education and Welfare. U.S. Government Printing Office, 1968).

The institutions which admitted people with developmental disabilities generally had little in the way of effective therapeutic programs and served as holding places (their facilities and programs would stretch the concepts of residence or home). Attendants with varying capacity for caring and disciplining and with limited, if any, vocational training, fed the intellectually and physically disabled residents, dressed them, sometimes employed them to do manual labour and on occasion arranged entertainment such as field trips, music concerts, or sports events.

As recently as 1992, one institution in Australia had two units housing 93 residents with intellectual disabilities, each unit consisting of a brick building and an attached chicken-wire bound compound where residents were put out at dawn and from which they were taken in at dusk. These units were shut down under the direction of a forensic psychiatrist (whose prison practice of nearly twenty years had increasingly become dominated by inmates with varying kinds of intellectual disability and mental illness). The task was accomplished in one year. Twelve years later all but five of the 93 residents were living in community based, state-supported residential homes.

As health of the population at large has improved substantially because of environmental, nutritional, educational and social developments, so has health status improved for those with developmental disabilities and their longevity has increased. Some of that improved health is the result of specific biomedical advancements such as: assessment and surgical treatment of congenital heart abnormalities, diagnosis and remedies for thyroid and folic acid deficiency, successful medical management of previously fatal leukemias and diabetes, new interventions for seizures and other advances in chronic disease treatment.

In institutions built and constructed for children with developmental disabilities, administrators and providers of services found their residents growing into adulthood and the facilities and programs becoming less suitable.

In Canada, as in most other developed countries, the institutions were built as large, stone/brick buildings usually situated on a large piece of farmland on the outskirts of the main living area of the community. Their construction having provided work for planners and builders, the institutions and services served as economic centres for the communities employing administrative, professional, support and maintenance workers, paid for by provincial or state governments.

“There were brick walls and a gateway and a drive and gardens and trees, so that though it was the edge of London you might have been arriving at someone’s country mansion, Except the mansion had got mixed up with what looked like an old-style barracks block, with grilles on the windows, and, once through the main entrance, there was the usual sour-milk smell of Institution, the usual squeaky corridors leading off, the usual rattle of things being shifted by trolley.”

(Swift, Graham. Last Orders. Random House, U.S., 1996, p213.)

The farmland was cultivated by the residents under supervision to provide food for the institution. At Ontario’s Rideau Regional Centre, in 1972, the farm produced 433.5 tons of vegetables and was “paying its own way and a bit more” while gardens at some of the other institutions were being phased out because they cost too much. (Rideau Regional Centre Memory Book 1951-2001, 50th Anniversary, published by The Record News EMC, Smiths Falls, p16).

In the late 60’s and early 70’s came an increasing awareness that institutional placement was not the way for societies to manage this vulnerable population, that their quality of life could be better, that they were not achieving their social and educational potential, and that they should be integrated into general community life. Lobby and advocacy groups began to convince governments that a change was needed. In Canada, Human Rights legislation demanded equality of opportunity and, internationally, new developments in bioethics strengthened their case. The concept of “normalization” derived from works by Nirje (5.) and Wolfensberger (6.) became the theme for a new direction of community living for people with developmental disabilities.

By the 1990’s, deinstitutionalization had taken hold as the direction for future planning. One of the earliest movements was the simple “demonstration” of what could be done through the l’Arche communities (founded in 1964 on the practical and spiritual leadership of Jean Vanier) (<<http://www.larche.org.uk/founding.html>>). More politically determined groups of parents and advocates found support in organizations such as the Associations for Community Living and Inclusion International. They and other organizations rattled the chains of politicians and government officials. And WHO had redefined “health” as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (7). Government commitments were made to close institutions and resituate individuals into more “normal” living settings. So, hostels, group homes, government-supported housing and individually supported placements began to happen. “Normalization” was to be effected through “Deinstitutionalization”. The process proceeded at varying rates in different jurisdictions and it still continues.

A Study Leave Commitment

Granted an administrative leave by the University of Manitoba, I set out in July, 2004 to: review the current status of persons with developmental disabilities with particular emphasis on primary health care services and to update my clinical skills in family practice generally and with particular reference to care of persons with developmental disabilities and their families. To do this I planned to review relevant and current clinical literature; to work with experienced Family Physicians at Queen's University with expertise in developmental disabilities and Family Physicians in family practice at Queen's and Dalhousie universities; to visit Australian medical centres focusing on primary medical services to persons with developmental disabilities and their families; and to meet with other health professionals, academics and government officials involved in serving the needs of the developmental disability population and their families.

During the year, July, 2004 to June, 2005, I visited Ontario, Manitoba, Nova Scotia in Canada, and Victoria, Queensland, and New South Wales in Australia meeting with clinicians, academics and government officials and visiting sites of care. This was a focused tour, including leaders and institutions which from my previous visits and readings had proven to be representative of those on the upside of newer ideas and programs. Academic literature reviews were accumulated (8) and media scanned. Over ninety individuals (educators, ministry officials, clinical professionals, researchers, and individuals with intellectual disability and their families) were interviewed. All of the people I contacted made themselves available with two exceptions; an Ontario member of parliament who had an understandably busy schedule and a clinician in Queensland who had to deal with an urgent patient problem and cancelled. I attended three conferences in Toronto, Kingston and Brisbane. I gave four formal presentations in Toronto, Kingston, Melbourne and Brisbane.

I visited four group homes in Kingston and Napanee, Ontario and the Park Centre for Mental Health in Brisbane. I attended family practice clinics in Kingston at the Queen's Department of Family Medicine at the Hotel Dieu Health Centre and in Halifax at the Dalhousie Department of Family Medicine in the Abbie Lane component of the QEII Health Centre, and in the Rideau Regional Centre, I attended clinics and took part in medication reviews, and participated in various clinical rounds and seminars in Kingston and Halifax.

I also reviewed a number of artistic compositions and dramatic pieces that have come forth over the year that reflected on the lot of characters with developmental disabilities and on the works of artists who have achieved recognition while dealing with developmental disability (appendix I). And I scanned the media at the various sites (appendix II).

Questions Behind the Review

On reviewing literature about Developmental Disabilities there are a number of possible directions to take, including: what constitutes a developmental disability and how the definitions differ over time and over context; new additions to the group we call developmental disabilities; social, health and educational needs and services accessible; collaborative and multidisciplinary service models; educational preparation of providers of those services; government policies affecting persons with developmental disabilities and their families; vocational choices for persons with developmental disabilities; leisure & recreational choices for persons with developmental disabilities; and ethical decision-making for developmental disability, among others. The literature is substantial. For example, a recent review of health care for adults with intellectual disabilities in the community was supported by over 500 references of the past fifteen years. There are also many academic and clinical professionals, government officials and community agencies, involved in studying and providing services to the population.

To approach the volume of literature and the potential number of individual experts to interview, I decided to focus on three issues which my own experience had caused me to commit a major portion of a one year administrative study leave to Developmental Disabilities. As a family physician and a medical academic over a 40 year span, I had become increasingly aware of three outstanding realizations.

First, the deinstitutionalization process, while nearly 50 years in progress, had not been assessed from the medical perspective in terms of health outcomes as better, worse or unchanged. And in those studies that were reported, the evidence was not rigorous by today's standards.

Second, learning opportunities for doctors at all levels of education; undergraduate, postgraduate, and practice, were substantially inadequate in preparing them to provide good care to persons with developmental disability.

Third, a gap in service, particularly at the primary medical care level, existed for adults with developmental disability (once they had chronologically exceeded the biological age for which developmental pediatricians could sustain them as patients). To a large degree, this gap was due to the manner in which planning and implementing plans to deinstitutionalize residents from the large institutions developed over the last half of the 20th century. The planning had essentially gone on and the process enacted, with little or no participation by family doctors and almost as little participation by psychiatrists, the two medical provider groups who were to find themselves most called upon to provide medical services to the newly resituated, vulnerable and high needs population.

While there was a developing expert opinion being published in some parts of the world about the nature of the foremost primary health care needs of adults with developmental disabilities, none was in Canada,. Although it is reasonable to assume that these needs in the United Kingdom, Australia, New Zealand, the Netherlands and the United States, would not differ substantially for the population of persons with developmental disabilities in Canada, the comparisons had not happened. Further, the services available to meet those needs were likely to depend on different strategies and resources in the various health care, education and social service systems.

I decided to focus on what are the results of deinstitutionalization, what education exists and ought to exist in undergraduate medical, family physician and psychiatry residency programs and in continuing professional development of practicing doctors, and what are the most important primary medical needs of persons with developmental disabilities? These three questions remain central and readers will find themselves being brought back to them. In addition, the complexities of health care services organization, of medical education and of outcomes assessment will lead us through many references to other aspects, such as curricula of other health professional programs, specialty care needs and a wide range of subjective opinion as well as some objective evidence about deinstitutionalization's success or otherwise.

Inspirational Beginnings

Providing services to persons with developmental disabilities began in Canada with the story of Ste. Marguerite d'Youville who, in 1737, established the Grey Nuns (Congregation of the Sisters of Charity of Montreal). She dedicated her life to helping the unfortunate and the Grey Nuns dedicated their first hospital services to caring for the poor and disadvantaged. Les Soeurs Gris eventually founded over 150 hospitals and community-based institutional programs in North America. Among them was the Youville Epileptic Hospital (1939) in Winnipeg with the mandate to care for children with epilepsy and developmental disabilities. The St. Boniface Sanatorium (established in 1931 for treating tuberculosis) eventually assumed that mandate and became the St. Amant Centre for Developmental Disabilities in 1974. Sister Marguerite must be considered one of the earliest Canadians influencing the care of those with developmental disability. Her founding of the Grey Nuns made possible service programs such as those provided out of St. Amant Centre in Winnipeg.

The next most influential Canadian to effect changes in life quality for persons with developmental disabilities (over 230 years later) is Jean Vanier, the founder of L'Arche. L'Arche was and remains a leading example of community living. From beginnings in 1964 in a small French village, there are now 130 L'Arche communities in twenty-nine countries. In Canada, twenty-six communities are found in six provinces; nine in Ontario, one in Manitoba and three in Nova Scotia. Such communities include homes and supported apartments as well as day programs and workshops. L'Arche communities are for persons with learning disabilities (Vanier's term) and emphasize accepting them as valued contributors to society with the capacity to transform others. Examples of L'Arche communities in Canada include: a relatively small community in London, Ontario has two homes with eight core members and nine assistants and offers day programs in music and crafts; L'Arche Winnipeg has six homes and three supported living apartments with 28 core members and 26 assistants; and L'Arche Homefires in Wolfville, Nova Scotia has five homes, 23 core members and 15 assistants and has day programs providing weaving and candle making, a support program for people with high needs, and a seniors' program.

In Australia, L'Arche communities are found in Sydney, Canberra, Hobart, Brisbane, Melbourne.

I have attended two of Jean Vanier's public presentations, the second in Kingston, Ontario during that portion of my study year at Queen's (October 24, 2004). With his charismatic humanity, Vanier is a role model for any who are engaged or considering engagement with the community of people with learning disabilities.

Conversations in Three Canadian Provinces and Three Australian States

A review of Canadian and Australian leaders in the academic/service worlds of Developmental Disability and Medical Education raises many names. During the study leave, many made themselves available. Primary contacts were Dr. Walter Rosser, Head of the Department of Family Medicine at Queen's University in Kingston, Ontario; Dr. Dickie Yu, Director of Research at St. Amant Centre, Dr. Sharon MacDonald, Vice-President for Primary Care, Winnipeg Regional Health Authority, and Dr. Judy Anderson, Associate Dean, Academic, Faculty of Medicine, University of Manitoba; Dr. Richard MacLachlan, Head of Family Medicine at Dalhousie University in Halifax; Dr. Robert Davis, Director of the Centre for Developmental Disability Health Victoria in Melbourne; Dr. Nick Lennox Director of the Queensland Centre for Intellectual Disabilities in Brisbane; Ds. Michael Partington at University of Newcastle; and Dr. Trevor Parmenter of the Centre for Developmental Disability Studies in Sydney. These people introduced the author to many service providers and academics of various disciplines who are working diligently and effectively as leaders and coordinators or behind the scenes on committees and boards and directly in clinical services and programs. And, several are family to someone with a developmental disability.

In Melbourne, at the Centre for Developmental Disability Health Victoria, I met with: **Dr. Robert Davis**, General Practitioner and Director of the Centre; **Dr. Mary Burbidge**, General Practitioner, Liason with a regional Collanda Centre, promoter of a common "personal health record" and author of "Baby Forever" (about her own disabled daughter); **Dr. Jenny Torr**, practicing and teaching Psychiatrist who has successfully enrolled twelve Psychiatric residents in an elective course for Developmental Disability and teaches Masters students in a joint Monash/ U. of Melbourne graduate program; **Dr. Teresa Iacono**, Research Director, PhD in Speech Therapy, with a primary interest in interdisciplinary collaboration; **Dr. Donna Henderson**, General Practitioner and teacher, mother of a disabled child, key liason with the Royal College of General Practice in developing postgraduate education programs and actively involved in formulating "care plans" with GP's; **Dr. Jane Tracy**, General Practitioner, developer of an undergraduate Developmental Disabilities medical education program and editor of its CD (9) and mother of a disabled child ; **Dr. Jane Graham**, recently qualified psychiatrist who completed Dr. Torr's elective program.

Also in Melbourne, I met with the Heffernans. **Dr. Michael Heffernan** is a General Practitioner and Psychotherapist and former medical educator. **Nola Heffernan**, his wife, is a recently retired medical office administrator and housewife. **Dr. Mark Heffernan** is a General Practitioner and Medical Director of Chapel Gate Medical Centre which brings together fourteen General Practitioners and providers of other health services, including Physiotherapy, Podiatry, Psychology, Hypnotherapy, Yoga, Relaxation Massage, Quit Smoking groups, Dietetics, Acupuncture and Chinese Medicine. **Brett Heffernan** is a musician and part time delivery clerk who resides independently while dealing with a developmental disability.

In Brisbane, I met with **Dr. Nicholas Lennox**, General Practitioner and Director of the Queensland Centre for Intellectual and Developmental Disabilities (QCIID); **Dr. Peter Brooks**, Executive Dean (Health Sciences) for the University of Queensland; **Dr. Alan Lopez**, Director of the School of Population Health, University of Queensland; **Therese Rey-Conde**, MPH, Project Manager for QCIDD with interest in better use of health utilization data; **Nicci Edwards**, MPA, social worker PhD candidate studying psychotropic medication for challenging behavior and dual diagnosis; **Dr. Madonna Tucker**, educational psychologist, whose PhD thesis addressed Applied Behavior Analysis (ABA) interventions; **Dr. Patricia Oliver** who works with Private Industry on the use of neuroleptics in Adults with Intellectual Disability and Challenging Behavior; **Shamshad Issa**, an honours microbiology and MPH student, research assistant for Dr. David Harley on the neuroleptic study above; **Dr. Gillian Eastgate**, General Practitioner with expertise in Sexual Health, who conducts clinical assessments on referred individuals with developmental disabilities; **Dr. Paul White**, forensic psychiatrist who operates QCIID clinics, and leads the Dual Diagnosis program at the Park Centre for Mental Health on the Wolston Park Hospital site in northern Brisbane; and I had a telephone interview with **Dr. Louise Young**, an educational psychologist whose PhD thesis addressed the closure of the largest institution for developmental disabilities in Queensland (Challinor Centre).

In Newcastle, N.S.W., I met with **Dr. Michael Partington** and **Dr. Gillian Turner**, the former and present heads of Developmental Genetics at University of Newcastle. Dr. Partington was a Professor of Pediatrics at Queen's University in Kingston in 1965-6 when I was taking a Pediatric residency year. Dr. Turner is a recognized world expert on Fragile X Syndrome. I met with **Professor Shirley Schultze**, a retired academic nurse with strong community experience; **Dr. Cliff Hooker**, a philosopher and ethicist currently studying ethics in complex organizations; **Dr. Ralph Robinson**, a retired academic philosopher with experience in interdisciplinary collaborations; **Ms. Jean Hooker**, a special education school teacher; **Ms. Zeny Giles**, poet and short story author; and **Dr. John Giles**, retired professor of Mathematics and religious educator.

In Sydney, N.S.W., I met with **Dr. Trevor Parmenter**, the Director of the Centre for Disability Studies (C.D.S.), former president of the International Association for the Scientific Study of Intellectual Disability; **Dr. Seeta Durvusala**, director of the medical clinic at the Centre; and **Dr. Helen Beange**, MPH, Fellow of the Australian Faculty of Public Health Medicine, General Practitioner, a specialist in Developmental Medicine. Clinician at the C.D.S. and Australia's senior medical academic in Developmental Disability. I met with **Dr. Jill Gordon**, former general practitioner, medical educator and now a Humanities professor at University of Sydney; **Dr. Richard Gordon**, general practitioner; and **Ms. Mary Maddison**, a public mediator.

In Canada, at Queen's University and at Rideau Regional Centre, I met with **Dr. Irene Swift** (Chief Medical Officer at RGC and **Dr. Bruce McCreary**, consultant Psychiatrist, former Head of the Division of Developmental Psychiatry and Director of the Developmental Consulting Program; **Barbara Stanton**, administrative officer of the Developmental Consulting Program, **Dr. Deborah Elliott**, Head of the Division of Developmental Psychiatry; **Dr. Walter Rosser**, Head of the Department of Family Medicine; **John Huett**, Chief Executive Officer of the RRC; **Robert Seaby**, Chief Executive Officer of the Ongwanada Resource Centre; **Dr. Ian Casson**, Director of the Queen's Department of Family Medicine's Residency Program and physician to the Elizabeth St. Group Home; Elizabeth Christie, Family Medicine resident; **Cynthia Leblanc, R.N.** at Elizabeth St. Group Home; **Zwany Malino**, Occupational Therapist and activity Coordinator at RRC; **Monica Nagy**, Physiotherapist RRC; **Marilyn Knapp, R.N.**, Manager of Health services at RRC; **Dr. Robert Rae**, Psychologist, RRC; **Dr. Laura McKinnon**, Family Physician, Fellow in Developmental Disabilities in Queen's Department of Family Medicine; **Dr. Cynthia Forster-Gibson**, Family Physician-Geneticist, RRC; **Dr. Jeanette Holden**, Psychologist/Researcher, Genetic Aspects of Autism; **Dr. Helene Oullette-Kuntz**, Epidemiologist/Researcher, Principal Investigator for H.E.I.D.I. (Health Equity for Intellectually Disabled Individuals); **Dr. Dianne Delva**, Vice-chair, Department of Family Medicine and physician to one of the Ongwanada Group Homes; **Dr. Jeff Sloan**, Family Physician to two group homes in Napanee, Ont.; **Chris Carrier, R.N.** supervisor of seven group homes in the Ongwanada system. I had a telephone interview with **Professor Jennifer Curry-Roy**, Algonquin College teacher of Developmental Service Workers.

In Manitoba, I met with **Dr. Carl Stephens**, Chief Executive Officer of the St. Amant Centre for Developmental Disabilities; **Dr. Dickie Yu**, Research Director for St. Amant Centre; **Dr. Klaus Dittberner**, Medical Director for St. Amant Centre; **Dr. Eموke Szathmary**, President of the University of Manitoba; **Dr. Robert Kerr**, Vice-president, Academic, University of Manitoba; **Dr. Christine Blais**, Associate Professor of Disability Studies and director of University 1, the common first year undergraduate program at University of Manitoba; **Dr. Joanne Keselman**, Vice-president, Research, University of Manitoba; **Dr. Dean Sandham**, Dean of Medicine, University of Manitoba; **Dr. Judy Anderson**, Associate Dean, Academic, Faculty of Medicine, University of Manitoba; **Dr. Bryan Magwood**, Associate Dean, Undergraduate Education, Faculty of Medicine, University of Manitoba; **Pat McCullough**, coordinator of the Medical Undergraduate Curriculum; **Lynn Fisher**, Human Resource Coordinator, Faculty of Medicine, and mother of a daughter with Down Syndrome; **Dr. Johann DeVries**, Dean of Dentistry, University of Manitoba; **Dr. Doug Brothwell**, Department of Community Dentistry, University of Manitoba and dentist for the Manitoba Developmental Centre in Portage La Prairie; **Dr. Sharon MacDonald**, Vice-president, Winnipeg Regional Health Authority; **Dr. Larry Reynolds**, Head of Family Medicine, University of Manitoba and Winnipeg Regional Health Authority; **Dr. Samia Barakat**, Head of Psychiatry, University of Manitoba and Winnipeg Regional Health Authority; **Dr. Randy Goosen**, Psychiatrist and

director of Community Living Psychiatry Services in Winnipeg; **Dr. Patrician Martens**, Director of the Manitoba Centre for Health Evaluation and **Ms. Paulette Collins**, senior administrator of the Manitoba Centre for Health Evaluation. From the Ministry of Community and Social Service I met with **Ruth Loeppekey**, Director of Centralized Services and Resources, **Cheryl Busch**, Winnipeg Supported Living, and **Pat Danino**, Protection Coordinator.

In Nova Scotia, I met with **Dr. Richard MacLachlan**, Head of Family Medicine, Dalhousie University; **Dr. David Gass**, Director of Primary Care, Ministry of Health; **Dr. Harold Cook**, Dean of the Faculty of Medicine and **Brenda Patterson**, Director of Aboriginal Health Initiatives, Dalhousie University.

I have had several phone conferences with colleagues planning an invitational Colloquium on the Primary Care of Adults with Developmental Disabilities on November 7-11 at Surrey Place in Toronto. **Dr. Bill Sullivan**, Family Physician, Medical Director at Surrey Place and on faculty at University of Toronto, Colloquium chair; **Dr. Yona Lunsky**, Psychologist of the Centre for Addiction and mental Health and the dual Diagnosis Program in the Department of Psychiatry at University of Toronto; **Dr. Tom Cheetham**, Family Physician and Medical Director of Rideau Regional Centre and on faculty at Queen's University; and **Maria Gitta**, administrative officer for the Program of Developmental Disabilities at University of Western Ontario have all brought new insights forward in discussions concerning the Colloquium's organization.

Besides meeting with these individuals, on several occasions I met with groups of their colleagues. I participated in three conferences; presented personally to four groups and learned from the discussions that followed; was privileged to sit in on several problem-solving and planning meetings that had to do with academic planning, service planning, and administrative or political and policy discussions.

At the Expert Policy Forum on Specialized Resources for the Developmental Services Branch of the Ministry of Community and Social Services of Ontario, October 19, 2004, I presented "Next Steps in Building Capacity for Caring, Learning and Discovery; Ontario's 2005 Investment in the Next 25 Years for Persons with Developmental Disability and their Families" (appendix III). Also presenting there were Jerry Kirkpatrick, General Manager, Moncton Community Residences Incorporated; Randy James, Team Director, Developmental Disability Mental Health Services, Interior Health Authority, B.C.; and Elspeth Bradley, Associate Professor and Postgraduate Education Coordinator in Intellectual Disabilities, Department of Psychiatry, University of Toronto.

At The Dean's Symposium, celebrating Queen's medical school sesquicentennial, November 25, 2004, I presented "Canadian Medical Schools' Covenant with Society" (appendix IV) in a series of debates exploring the future of Medical Schools in Canada. Other presenters were Dan Burns, former Ontario Deputy Minister of Health, Lorne Tyrrell, past Dean of Medicine, University of Alberta; Roger Strasser, Founding Dean of the Northern Ontario School of Medicine; Carol Herbert, Dean of Medicine, University of Western Ontario; John Kelton, Dean of Medicine, McMaster University; David Naylor, Dean of Medicine, University of Toronto; and Peter Walker, Dean of Medicine, University of Ottawa.

In Australia, I presented "What's Happening in Canada re: Developmental Disabilities, Especially in Primary Care?" to the Centre For Developmental Disability Health Victoria on April 6, 2005; and "The Challenge of Determining Accurate Data Sets for Identifying Persons with Developmental Disabilities" (appendix V) on April 26, 2005 in the School of Population Health Seminar Program, University of Queensland.

I was welcomed in attending a number of department meetings, task force meetings, staff meetings, resident seminars, CME presentations, some or all of which related to Developmental Disability services, educational programs and research.

All of the individuals who met with me gave generously of their time (ranging from 30 minutes to two hours or more) and were candid in their discussion. They identified their participation in the academic and service worlds of Developmental Disabilities, commented on their hopes for change and reported on their frustrations and difficulties. Except for particular factual contributions referred to elsewhere in this report, in what follows here I have not attributed opinions and concerns to individuals but have tried to consolidate their experience and expertise in general reflections and summary comments that sustain the richness of what they said while providing an appropriate degree of anonymity. I am most grateful to them.

The following is a distillation of key messages and reflections of the over ninety experts interviewed individually and others' contributions during meetings and conferences during the period September, 2004 to June, 2005.

Gaps and Silos

(Developmental Disabilities: Services and Academic Programs, emphasizing three Australian states and three Canadian provinces)

Most of the reasons for not achieving the desired success for deinstitutionalization, appropriate health professional education and an effective health service for persons with developmental disabilities fall into two categories; gaps and silos. Gaps are breaks in the continuity of implementation of services and programs. They include absent services or service components, absent academic programs or program components, and gaps in continuity of services and academic programs that might otherwise be sufficient if not permitted to lapse over periods of time or disappear across geographic jurisdictional boundaries. Silos are the regulatory boundaries or impermeable margins that define administrative structures such as government ministries, academic disciplines, self-defined groups of individuals with particular beliefs or prejudices, provincial or state and municipal divisions, service program managers and collective bargainers, and other administrative groups that tend toward jurisdictional control and budgetary protection.

My interviews listed above and many group discussions left me with the following messages, most of which were repeated by various individuals and reinforced at various meetings.

1. Developmental Pediatricians provide the bulk of services to children with Developmental Disabilities and a substantial proportion of the teaching about them to medical students.
2. Once children with Developmental Disabilities grow past the age served by Developmental Pediatricians, as young adults, they face a gap in medical and social services which may never be adequately filled.
3. While some 70% of people with Developmental Disability do not have Psychiatric Illness requiring specialists' interventions, Psychiatry as a discipline has been designated a leading home for academic and service programs, mostly by default. Aside from Psychiatry and Developmental Pediatrics, Family Medicine and other relevant consulting specialties such as Neurology, Orthopedics, Ophthalmology, ENT, Dermatology, Dentistry, Rehabilitation Medicine have shown limited interest, have received few incentives and have been lacking in supportive resources to accept their appropriate roles.
4. Some in senior government and academic positions are surprisingly uninformed or ill informed about the health status of persons with developmental disabilities and the services being provided.

5. The gaps in health and social support services are mostly due to government administrative departments' failure to integrate needed resources in serving individual and family needs. These bureaucratic silos impair access and resist monies being shared effectively.
6. University and Health Care System departmentalization similarly creates silos of turf protection, resisting integration particularly where sharing resources and recognition are expected.
7. Politically lead initiatives often proceed with limited or insufficient comprehensiveness of consultation with experienced system administrators, front line providers and users of services.
8. Family physicians have been essentially unengaged in developing service and academic programs for people with Developmental Disabilities, and those family doctors who do commit to providing primary medical care to them are remuneratively penalized for doing so and have to learn on the job. For the most part they are doing a good job.
9. Support services and consultant services available to primary care providers are irregular and not reliable in most settings.
10. Incentives for health service providers to offer 'best care' to persons with Developmental Disabilities are not equivalent remuneratively to those serving other vulnerable or disadvantaged populations. And persons with Developmental Disabilities are not formally recognized by professional medical organizations as "disadvantaged".
11. Health system organizations and methods of payment to providers are not conducive to integrated, interdisciplinary practices.
12. Attempts at encouraging general practitioners in Australia to apply for "Integrated Care Plan" financial support have had limited success.
13. Disincentives for health service providers are found in the extra time required to assess and manage patients/clients and their families, anticipated waiting room disruptions, necessary physical upgrades in clinical facilities to facilitate access, medico-legal risks of caring for those whose health status is complex and who are difficult-to-communicate-with, and an awareness of being inadequately educated to provide optimal services.
14. The knowledge base upon which we can further our understanding of Developmental Disabilities hangs on fragile infrastructures for research and education.

15. Basic or core education about Developmental Disabilities for most health professions ranges from little or none to reasonably adequate but is dependent on individual curricular priorities and faculty champions and is inconsistent across health science centres. No accreditation guidelines specifically address the need for education about Developmental Disabilities in basic Undergraduate or Postgraduate Medicine, Nursing, Psychology, Social Work, Rehabilitation Programs. There are islands of appropriate special education in a few exceptional programs.
16. Several of the “champions” presently committed to academic and service programs have personal experience of a family member with a Developmental Disability. It is likely that recruitment into the field will be easier if students and professionals with family experience can see career paths opening up. They’ve already passed important hurdles of attitudinal readiness and personal commitment.
17. Accurate determinations of the prevalence and incidence of Developmental Disabilities remain difficult. Although earlier identification and earlier treatments are reducing numbers somewhat, increased numbers are seen as more premature newborns survive to face complications, Autism and its variants have become more clearly recognized, Foetal Alcohol Syndrome and Effect continue to be increasing and the developmental delays associated with new illnesses (HIV, AIDs) and world disasters (war, poverty, Tsunamis) are becoming more apparent. The overall likelihood is a net increase in the proportion of people with developmental disabilities.
18. While there are now more accurate “diagnoses” being made for those with Developmental Disabilities, there remains a large minority (about 45%) of people with Developmental Disability that is “undiagnosed” or “undifferentiated”. This undifferentiated group is subject to particular challenges related to eligibility for certain government benefits, to lack of a “scientific” interest in them by academics, and to lack of specific “advocacy” group sponsors. Also, because they are more likely to be in a higher functioning cohort, they are more likely to be in the least supervised community settings and hence are less protected from discriminatory and bullying behaviours, either as victims or perpetrators.
19. Comments and behaviours expressing the attitudes of the public, health professionals, health professional students and some academic and service leaders continue to be tinged with stigmatizing labels and beliefs about people with Developmental Disabilities.
20. The media express both condemnatory and laudatory reports as various government schemes are changed and criticized. Little in the public media addresses the educational and research deficiencies.

21. There remain a number of misperceptions or myths that inaccurately describe the problems of Developmental Disability. An example would be the reported higher incidence of dental caries which in fact is a lower treatment capability.
22. Human Rights legislation and the increasing sophistication of biomedical ethics are influencing the direction of service provision and academic supports. The drive for “normalization” and resulting initiatives in “deinstitutionalization” can, to a large part, be attributed to these changing attitudes and public policy. Issues of consent are particularly concerning for health service providers, particularly in emergency situations.
23. There are no attractive career paths for health professionals prepared to consider a vocation that emphasizes service to persons with Developmental Disabilities.
24. There are health profession students showing interest in the field of Developmental Disabilities for whom learning opportunities are variable from school to school.
25. Research funding opportunities have improved in the past decade but monies available in Social Science government research agencies remain proportionately smaller than for Biomedical Sciences and Engineering Sciences.
26. A serious deficiency in health professional expertise is forecast due to retirements, loss of secure positions through deinstitutionalization, and lack of career paths and incentives in the field of Developmental Disabilities.
27. As deinstitutionalization proceeds, health professionals with substantial experience and expertise are being lost to the alternative systems of care expected to develop.
28. The effects of deinstitutionalization are not well documented, opinions vary, and where deinstitutionalization is still ongoing the process faces vocal opposition.
29. Some deinstitutionalization strategies have failed to consider personal or family preferences in placing individuals in community settings.
30. There remains a case for sustaining a core institutional centre of expertise for the most complex individuals in each state or provincial jurisdiction, especially those who have long histories of having been cared for in well resourced settings.
31. Successes in health care and academic systems are poorly communicated with others and hence not emulated.
32. Academic and service leaders often acknowledge the problems of establishing some degree of priority for Developmental Disabilities but fail to implement supportive actions.

33. Best practices in pharmaceutical interventions have not been established. Strategies for discontinuing outdated or no longer necessary medications are poorly developed and new medications are prescribed without adequate evidence or withheld for inappropriate reasons.
34. A study reviewing the “burden of care” of persons with developmental disabilities to their families, and the health care systems has not yet been completed and reported.
35. While most acknowledge that interdisciplinary approaches to management are preferred, few have been successfully implemented. An “anti-medical model” attitude persists amongst many non medical professionals, although there is no common understanding of what constitutes “the medical model”.
36. Advocacy groups continue to distrust scientifically-based health professions and deny the latter any credit for the improved health status of persons with Developmental Disabilities.
37. There continues to be a stigma for having a Developmental Disability, in some cases very explicit but more often implicit and often unconscious on the part of the stigmatizer.

Methodological Challenges in Studying Developmental Disabilities

In many ways the population of persons with developmental disabilities is difficult to study. It is not homogeneous being comprised of nearly 1000 diagnostic syndromes and a large undifferentiated group. The common characteristic, intellectual disability, has wide ranges of definition (IQ's and functional assessments determine degrees of disability which currently are qualified as profound, severe, moderate, and mild). Those in each of these categories are often considered differently when determining the suitability of various service categories. Comparative studies are difficult considering the changing living arrangements in moves from institution to community, and the variable options for community living. Community size and distance from specialized resources are further considerations. The nature of caregivers varies from family members (nuclear or extended) to volunteers and professionals (all with variable education and experience). Finally, and most important, each person with a developmental disability is unique, with individual qualities that determine independence and social capability.

As well, since the process of deinstitutionalization has been introduced gradually over some forty years and has, for the most part, been applied initially to the least disabled, there are layers of severity and complexity that are changing over time as the process has proceeded, with varying support needs and increasing lifespan expectations. Assessing a public service which is provided by a range of professional and academic disciplines and is subject to varying political policy environments makes for fundamental difficulties in determining reliable scientific or moral comparisons. It is difficult to tease out what are the “ long-term consistent influences” (9) of importance in judging the effects of deinstitutionalization.

Bengt Nirje, in 1969, described three components of disability: the primary medical or physical condition which was usually the most visible and the most open to biomedical advances; the broader environment of living conditions, daily routines, economic status and prevailing social attitudes; and the identity of the person, affected by the physical condition and comprising a self-image reflecting the broader environment. He advocated for the disabled to have daily, weekly and yearly routines, access to ordinary housing, ordinary economic circumstances and usual life opportunities.(5) Wolf Wolfensberger put forward “The Principle of Normalization in Human Services” underpinned by a philosophy of abandoning the stereotypes and ideologies of difference and substituting the principle of inclusion. (6) The adoption of “normalization” as the rallying cry for the advocates of persons with developmental disability was the primary force behind the promotion and implementation of the deinstitutionalization process.

Bjannes et al, in 1981, observed that systemic differences in normalization exist among large care facilities and community placements. (10) In large care facilities there was a greater emphasis on components of client normalization; in community placements the greater emphasis was on environmental normalization. In assessing deinstitutionalization at that time he concluded that the primary emphasis appeared to be on environmental normalization instead of a community-based, comprehensive, interdisciplinary service system that adequately supported normalized client outcomes. He and Butler (11) categorized community care facilities as: custodial (with little achievement of normalization and where residents might actually regress); therapeutic (where there was an active ongoing attempt at enhancing normalization); and maintaining (in which there was little change in residential outcome effects).

Eyman et al in 1977 had written “the social-psychological characteristics of a residence, rather than its setting or location influence the behaviours of the residents”(12). Bjannes and Butler, also in 1977, warned “It cannot and should not be assumed that a community care facility is *a priori* a normalizing environment.” (11)

Clarke and Clarke argued that “Intellectual Disability is a social and administrative rather than scientific concept” (13) and Parmenter, on reviewing the evidence to support deinstitutionalization noted that “in large measure, the movement to deinstitutionalization was more motivated by social, moral and political forces, than empirical research” (14). Further, Parmenter had previously declared, “to a degree, social policy initiatives outstripped the capacity of the research community to inform policies and practices”.(15)

Perhaps the evaluation of the effects of deinstitutionalization may best be determined by assessing whether or not the desired social, moral and political standards have been met. What have been the viewpoints of the evaluators who have set out to show whether or not deinstitutionalization achieved what its proponents and implementers intended? What are the standards, the criteria, the parameters? What models or constructs have been employed to assess outcomes? What dimensions of these models were chosen? What have been significant methodological issues? And given where we find ourselves in the process in 2005, how ought we to direct our evaluation efforts from now on?

Methods used to examine outcomes of deinstitutionalization on those subjected to it have been described as: traditional group designs measuring the relative impact on the process and outcomes; studies that seek to determine predictor variables for successful outcomes; life history interviewing; and examining community attitudes towards community residences (16).

O'Brien lists five targets to be achieved for the individual with Intellectual Disability: community presence (using ordinary, mainstream resources); choice (supported in making one's own decision about day-to-day matters as well as major life events); competence (opportunities encourage the reaching of one's full potential by developing a range of skills); respect (the right to occupy a valued role); and community participation (realizing a part in one's network of friends)(17).

In Scotland, national aspirations set out in the 2000 Joint Future Group Report were: better outcomes for people who use community care services and their carers; better use of government resources; better management of services (encouraging innovation); and better systems with less bureaucracy and duplication. The first, better outcomes for users and carers, was considered under four divisions: (i) supporting more people at home, as an alternative to residential and nursing care, through locally agreed joint service developments; (ii) assisting people to lead independent lives through reducing inappropriate hospital admission, reducing time spent inappropriately in hospital and enabling supported and faster discharges from hospital through service developments; (iii) ensuring people receive an improved quality of care through faster access to services and better quality services; and (iv) better involvement of carers. (18).

What Studies Show

Of the variety of studies assessing the effects of deinstitutionalization, many report improvements in quality of life measures such as greater variety and stimulation of physical surroundings, more involvement in decisions, privacy, more enjoyable meals, (41), improved adaptive behaviour, participation in employment, opportunities for integration, contact with relatives (19), lifestyle satisfaction (20), happier, healthier, more independent people (21), more participation in grocery shopping (22).

Some studies reported quality of life indicators which did not show improvement. These were mostly having to do with a limited choice of accommodation, unimproved opportunities for personal and social development, a low level of community presence, few meaningful interpersonal social relationships and little association with people without mental retardation. (21,23, 24). Those in group homes have lower self-determination than those in parental homes (20).

Challenging behaviours were reported improved in some (19, 22, 25) partly improved in some (21) and not improved in others (26).

Several studies report that health care access (19, 24,) including to family physicians, psychiatrists, psychologists (26) and other medical specialists as well as dentists (27) is a greater concern for those who have moved into the community than before. Poor access is compounded by physician shortages and inadequate training of graduating physicians. The role of nurse specialists is discussed below.

The nature of the common health issues is well described with constipation, seizure disorders, dental hygiene, cerebral palsy, scoliosis, contractions, aspiration risk, skin conditions, and dysphagia identified (28) and sensory impairment, chronic hepatitis B, and health maintenance programs noted (29). Although most studies show little difference in medication use before and after deinstitutionalization, better familiarity with medications such as anticonvulsants, psychotropics, and laxatives may facilitate the safer reduction of their dosages,

Bio-scientific approaches (so far a relatively small component of deinstitutionalization assessment) have been mostly descriptive of clinical needs and ranges of treatment modalities, before and after movement into the community setting. Most medication reviews are not rigorous by standards of modern evidence, such as randomized control trials or even cohort comparisons. Very recently, a randomized control trial is underway out of Britain on psychotropic medication for aggressive challenging behaviour, under the direction of Dr. Peter Taylor, and has included an Australian clinical site team led by Dr. David Harley in Brisbane.

One study looking at readmission rates to institutional settings reported an 8.4 % readmission rate to the institution for reasons of physical aggression or physical deterioration.(26) Two studies of large populations in New Jersey (30) and the UK (31) report much higher than average (tenfold and double, respectively) acute care hospital admission rates for those moved into the community than would have been expected had the patients not been deinstitutionalized.

Of particular concern are studies by Strauss et al (32,33,34,35,36) and Read (37), who from California and the U.K., respectively, have shown higher mortality rates in the community compared with the expected mortality had the resituated individuals remained in institutions. Reasons put forward include health insurance gaps, insufficient access to adequately trained providers, and poor care coordination. An example in the California study was a finding of deaths due to bowel perforation occurring six times during the study period with five of the occurrences in the community. The mortality rate was greatest in the highest functioning group of resituated individuals.

Studies which address the costs of deinstitutionalization express concern about government money saved by shutting down institutions not moving to the community to provide services. Most expectations are that appropriate transfer of services into the community will not be cost saving. One study suggests an overall increase of 25% in funding as necessary (25). A UK report reflecting on England, Wales and Northern Ireland in 1993 suggested anticipated costs of 39,200 pounds capital expenditure and 26,000 pounds per year per individual to maintain the needed services. (38).

In terms of the reorganization of services, recommendations emphasize: the need for more intergovernmental management cooperation, expecting a major burden to fall on middle managers, (39, 40); a need for more specialized skills in providers to deal with more complex patients; avoiding staff shortages; avoiding loss of experienced staff; and encouraging innovative models of care coordination.

Radford and Park in their historical review of Developmental Disabilities in Ontario summarize that overall, benefits seem to have outweighed difficulties, but noted that some studies reported little real participation in the wider community and continuing high degrees of marginalization. “Developmental disability is still too closely associated with poverty, affordable housing seems increasingly elusive, downloading and funding cutbacks threaten access to health care and social services, and for some the specter of homelessness looms large.” (41)

Nursing care in the community is essential to meet health targets for persons with developmental disability. The nature of the most suitable training for such nurses is controversial. In Australia, specially trained Mental Retardation Nurses were phased out in the 1990’s as their training emphasis on biomedical health was deemed inappropriate for the evolving “developmentally-based model” of care delivery. (42) Evaluations of “disability” community nurses working collaboratively with family doctors, in Canada, Australia and England demonstrate potential improvements in continuity, health screening and early identification of problems, medication management, and family support. (43, 44, 45, 46). Nursing education is changing with increased clinical specialty nursing, nurse practitioner programs, and in Australia a return to the acute care health centre (the tertiary sector) as the main training site.

Other health professionals have emerged such as Developmental Social Workers, Patient Support Workers and others. For them, several months to two years of training in community colleges emphasizes social health and community resources but offers minimal learning about physical health needs and assessments. Such first line providers cannot be expected to provide and be accountable for sorting out common signs and symptoms which indicate health problems when dealing with complex dually-diagnosed patients with mental illness and/or challenging behaviours, or those with medical issues of cerebral palsy, seizures, constipation, gastro-esophageal reflux disorders, and other compounding medical problems.

Michael Heffernan, a general practitioner and medical educator, practices psychotherapy and counseling in Melbourne. Michael and his wife, Nola, who has worked as a medical office manager, have two sons. The older is a general practitioner and manages the largest general practice clinic in Melbourne. The younger is a musician and part time courier who deals with a developmental disability with his family's support. Michael can be considered a very sophisticated health care system user and given his practice and academic experience, his views of Victoria's and Australia's programs are worth careful consideration. Acknowledging that his personal family experiences may influence his objectivity as a commentator, they do provide an in-depth viewpoint which adds the credibility that can only come from "walking the walk".

Michael reviewed the summary briefs of the Australian report "Out of Hospital, Out of Mind", 2003, a report to the Mental Health Council of Australia of mental health policy reforms which champion deinstitutionalization. The report concludes that one of its most chronically disadvantaged groups continues to be ignored.

Following are Michael's comments. The report "is in accord with my practical experience." "I believe the report shows that the move to deinstitutionalized care of the mentally disabled in Australia is a relative failure." The report indicates that failure is not one of policy but of implementation. It argues for increased resource allocation. "I think an alternative interpretation of the data is worth examining, namely that the deinstitutionalized model of care implemented is a failure. Further, that both models of care - as practiced - institutional and de-institutional are relative failures."

He proposes objective measures to evaluate either model: exacerbations, relapses, or recurrences of the primary diagnosis; incidence of co-morbid conditions; incidence of physical ill-health; compliance with medication; incidence of hospitalization for mental illness; incidence of self-harm; incidence of suicide; nutritional status; living conditions; abuse-emotional, physical and sexual; and quality of life. "Allowing for selection bias and low numbers, the community-based model does badly, even very badly, on these criteria." He acknowledges no personal experience of institutional care.

"Both models can be made to work (judged by common performance criteria and with input of enough capital). The institutional model is the more efficient/practical/manageable /reliable/controllable. The nature of what constitutes an institution might also be refined. A beginning would be to define the structure of both the present models, the assumptions underlying them, their performance criteria and 'business plan'. This might expose some important limiting factors that have been overlooked."

"I hear Australian politicians saying: 'We have given huge amounts of money to the deinstitutional experiment.' I think they are also saying: 'Why hasn't it worked? Don't ask us for more money. Fix it.' My practical experience with the system causes me to be very cautious about any proposition as simple as 'give us more money and we will make the theory work.' I think it is time to reassess the theory."

Educational Programs

Undergraduate Medical Education

There is a wide range of curricular commitment to developmental disability across medical schools. At the “Working Conference for Supporting Persons with Dual Diagnosis in Southwestern Ontario” in May of 1998, Dr. Thomas Cheetham reported on the status of the five Ontario medical schools’ undergraduate curricula. His review showed that of four schools offering lectures, one had one hour and two had two hours each about developmental delay. Of small group teaching, two schools provided two hours; one had an hour in its pediatric clerkship; one offered an elective experience; and one indicated that in pre-clerkship, PBL cases or project work might have some element of developmental delay. In clerkships, one school reported that all clerks had a two hour seminar and one clerk every three weeks did a rotation through the Child Development Centre; one school noted that all clerks received two to three hours experience with children but no specific focus on adults with developmental disability; one school reported that a few hour experience might happen depending on the clerkship schedules; one school indicated that experience with developmental disabilities depended on the clinical teachers’ practice experience; and another school reported that any experience would depend on the students’ exposure to particular clinical settings where developmental disabilities were treated. When asked for the number of faculty with training in developmental disability, one school reported at least fourteen (ten in Psychology and four in Pediatrics); one school reported ten (three geneticists, two pediatricians, one each in Psychiatry, Family Medicine and Neurology, and two unspecified others); one reported six; one reported three; and one was not able to determine the number.

A review of Australia’s ten medical schools in 1999 by Lennox and Diggins demonstrated a wide disparity in learning experiences offered about intellectual disability. Half were felt to have significant curriculum gaps. An enabling influence was that a school had academic appointments in disciplines emphasizing intellectual disability. Changing to problem-based formats was considered a potential risk to sustaining adequate emphasis. (47, 48).

During my present study, two particular medical curricula showed significant inclusions of developmental disability. Monash medical school has a five year curriculum. In year I, there are a lecture and three tutorials about intellectual disability during an introductory course on history, attitudes, services and language of Medicine; two patient-centred-learning cases (one week each) on a child born with Down Syndrome and an Adolescent with Spina Bifida; and there is an expectation during a rural practice experience for students to identify access and availability of resources to families with a disabled child. In year II, two of eight cases presented by students in an integration-theme semester for endocrinology, cardiovascular medicine and gastroenterology, include

a section on developmental disability. In year IV, two cases presented by students in an integration-theme semester on Women's and Childrens' Health and General Practice/Psychiatry includes a case of a young woman with an intellectual disability and a case of a child born with spina bifida. Also in year IV is a two hour workshop on understanding the impact of developmental disability on a family and a skills session (three hours) on communication with people with developmental disability; a one hour lecture and two 2 hour tutorials in which tutors with intellectual disabilities work with small groups of students; a three hour session that clarifies definitions of developmental disability, cerebral palsy, autism, etc.; and a two hour tutorial which has students work through cases of persons with developmental disability and mental illness. In year V, two students at a time may spend a six week selective in the Centre for Developmental Disabilities.

Much of this included content resulted from the enthusiastic intervention of Dr. Jane Tracy who attended as many curriculum planning meetings as she could where she assertively volunteered for any possible course preparation into which she could meet the needs of that particular course component by using developmental disabilities as the clinical case example. She demonstrates clearly the importance of having a "champion" or "advocate" on one's faculty for particular course content. Dr. Tracy has edited a CD about the Monash curriculum on developmental disability that will be available soon for other medical schools to employ.(49)

At the University of Manitoba, there is no one individual championing developmental disabilities in the curriculum. Nor is there a coordinated curriculum 'program' on developmental or intellectual disability. There is, however, some identifiable content, for which Developmental Pediatricians contribute the most. Because the Manitoba undergraduate medical program has a computer-accessible retrieval capacity, one can enter key words and determine if and where various topics are included. This search can then lead to the recovery of educational objectives and course descriptions and lecture notes. Associate Dean Bryan Magwood and Curriculum Coordinator Pat McCullough entered as key words the following: developmental disability, developmental, newborn, dysmorphic syndrome, Down syndrome, Fetal Alcohol Syndrome, trisomy, Autism, Mental Retardation, Fragile X syndrome, genetic abnormalities. This revealed some twenty-three hours of Developmental Disabilities content in a four year curriculum. (see Table 1).

The hope of the Undergraduate Dean is for some curricular device to bring these various units into an integrated component around the whole of persons with developmental disabilities, as a disadvantaged population.

I did note that there is very little mention of Fetal Alcohol Syndrome (a significant problem in Manitoba and one for which the faculty has substantial expertise).

Table 1

**University of Manitoba, Undergraduate Medical Curriculum
Regarding Developmental Disabilities (2005)**

TOPIC (<i>elaboration</i>)	FORMAT	TIME	TAUGHT BY
Medical Genetics-Developmental (<i>Pattern formation, genotype drug sensitivity, pharmacogenetics</i>)	Lecture	1 hr	Pediatrics
Stages of Human Development (<i>Erikson</i>)	Lecture	1 hr	Clinical Health Psych
Newborn Screening (<i>genetically determined variability in biochemical and inborn errors of metabolism, neonatal screening, PKU, SIDs</i>)	Lecture	1 hr	Pediatrics
Global Perspectives on Public health (<i>child development effects of recent tsunamis, HIV</i>)	Lecture/Disc	2hrs	Comm Health Science
Clinical Dysmorphology and Cytogenetics (<i>clinical evaluation, risk of transmission, FAS, Down, Cleft Lip & Palate</i>)	Tutorial	1 hr	Pediatrics
Infancy: The First Year (<i>developmental milestones</i>)	Lecture/Disc	1 hr	Pediatrics
Preschool Development (<i>developmental milestones</i>)	Lecture/Disc	1 hr	Pediatrics
Learning and Behavioural Problems (<i>pervasive developmental disorders, attention deficit hyperactivity disorder, conduct disorder and oppositional defiant disorder</i>)	Lecture/Disc	1 hr	Ped. Psychiatry

(Note: Disc=Discussion)

Table 1, cont'd

Learning and Communication Disorders (<i>diagnostic criteria for Autism, Aspergers, etc</i>)	Lecture/Disc	1 hr	Ped Psychiatry
Developmental Delay: Mental Retardation (<i>Etiological Classification</i>)	Lecture/Disc	1 hr	Pediatrics
Basal Ganglia, Function and Disease (<i>movement disorders, neuroleptics, Parkinsonism</i>)	Lecture	1 hr	Physiology
Developmental Disabilities, motor impairment (<i>associated impairments</i>)	Lecture	1 hr	Pediatrics
Development in Children with Blindness	Assigned Study	1 hr	Pediatrics
Approach to Developmental Problems	Tutorial	1 hr	Pediatrics
Genetics counseling, Couple and Family (<i>five themes, WHO guidelines, breaking news</i>)	Assigned Study	1 hr	Pediatrics
Sexual Development and Differentiation (<i>hormones and sexual differentiation, investigation of ambiguous genitalia, anatomy of congenital adrenal hyperplasia</i>)	Lecture	1 hr	Pediatrics
Neuromuscular and Spinal Cord Pathology (<i>pathophysiology of CNS and PNS</i>)	Lecture	1 hr	Pathology
Genetics in Neurology (<i>Huntington, Spinocerebellar ataxia, mitochondrial disorders, Alzheimers</i>)	Lecture	1 hr	
Well Newborn History and Physical Examination	Clinical Skills	2 hr	Pediatrics

These two medical schools, one Australian and one Canadian, have curricula which apply twenty to thirty hours of curriculum time to Developmental Disabilities. They exemplify two quite different ways of presenting subject matter and experiential opportunities to students. They are among the leaders in commitment to Developmental Disabilities of the thirty-five schools in the two countries.

Other schools demonstrate commitment. Besides didactic presentations, Queen's (Ontario) students attend a day at the Rideau Regional Centre (scheduled to close in five years). Alternatively, students visit the Ongwanada Resource Centre, where they interact (as they do at Monash) with "simulated patients" (persons with developmental disability acting in the role of others facing the kinds of problems faced by themselves and their peers with disabilities).

University of Melbourne, influenced by Drs. Jane Tracy and Donna Henderson of the Centre for Developmental Disability Health Victoria, offers an antenatal PBL case on Down Syndrome and a 2 hour seminar on the impact of a diagnosis of developmental disability in year II; a PBL case on a child with Fragile X syndrome and a symposium with parents of children with disabilities in years V-VI; a 3 hour seminar about persons with developmental disabilities in a course on Rehabilitation, Aged care, Psychiatry of Old age and Palliative care; and a General Practice case work-up of a patient with cerebral palsy that includes a video and workbook. Year I clinical experiences may include Developmental Disabilities and Year III-IV students may take their research study at the Centre for Developmental Disability Health Victoria.

There is little in undergraduate medical education that relates to problems of adults with developmental disabilities and their families, the emphasis being on children.

Developmental Pediatrics and some Psychiatric Divisions of Developmental Disability have established as academic disciplines. The Netherlands has a recognized medical specialty in Developmental Disabilities. There is a unique clinic in Brisbane where a physician (general internist), Dr. Robyn Williams operates the Specialist Healthcare for Adults with Intellectual Disability (SHAID) clinic, at the Mater and Princess Alexandra Hospitals.

The expectation in both Australia and Canada has been, as deinstitutionalization has continued and as more persons with developmental disability are living into adulthood, that family doctors will assume the primary medical care responsibility for them. But family doctors, not having been involved in planning for deinstitutionalization have been poorly prepared and are only partly willing to assume such clinical responsibility. Those who have accepted such responsibility are generally considered to be doing a good job. This is an obvious academic challenge for Family Medicine, as well as for Psychiatry and relevant subspecialties such as Neurology, Orthopedics, Rehabilitation Medicine, Gastroenterology, Otorhinolaryngology, Ophthalmology and Geriatrics, among others.

Postgraduate (Residency) Education

Postgraduate educational programs (residencies) in Family Medicine have not, in general, responded to the need for better training in Developmental Disabilities. A review of U.S. Family Practice Residencies in 1997 (50) had a response rate of 71% and reported that 32% had didactic teaching, 42% had residential care experience and 24% had clinic experience with patients with Developmental Disabilities. Commonest topics in the didactic programs were delayed development in infants and seizure management. Least taught were issues of comprehensive management, family issues, behavioral problems and long-term planning. The authors noted little enthusiasm among residency directors about the need for such teaching and there was a low value placed on comprehensive management, improving access to care and long-term planning. Two years later, a similar review noted only 60% of U.S. Family Practice residencies had specific instruction about mental retardation, and suggested the lack of training had serious risk implications for quality of care. It recommended that residents' attitudes must be addressed and relevant literature must be explored outside of Family Practice journals (51).

There have been no equivalent Canadian or Australian surveys of Family Medicine residencies. At the University of Western Ontario there were four 1.5 hour seminars in the residency program that have recently been reduced. At Queen's there is one three hour seminar and residents have particular learning objectives when attending group homes. At Manitoba there is no explicitly identified residency component on Developmental Disabilities. Australian General Practice training programs similarly vary. Most experience for residents/trainees' is hit and miss, depending on whether or not in their clinical practice exposure they encounter individuals as patients who have intellectual disabilities and whether or not their supervising mentor at the time of such encounters has current knowledge on developmental disabilities to impart.

Queen's Department of Family Medicine has had a third year post-residency or fellowship year position available for several years which has been filled irregularly. Monash and University of Sydney have Master's level postgraduate distance education courses on Developmental Disability which are poorly subscribed and under consideration for discontinuation because without applicants it is difficult to justify the considerable effort required to sustain the currency of the course material.

Psychiatry postgraduate programs provide content variably, on Developmental Disability usually dependent on whether the department has a designated Division of Developmental Disabilities. Dr. Jenny Torr's elective program in Melbourne is well subscribed by Psychiatry residents interested in developmental disabilities. The United Kingdom Psychiatry programs have a six month component in Learning Disabilities as part of their core curriculum.

A survey in 2001 of the sixteen Psychiatric Training Programs in Canada revealed inadequate training opportunities in many of the programs, particularly with regard to adolescents and adults. While some didactic experiences were usual, supervised clinical opportunities, of which many were optional, were rare. Mandatory experiences were found where at least one psychiatrist specialized in the area and had an academic departmental affiliation, and were more likely in provinces that had a declared need for improved services.(52) In 2002, a survey of psychiatry residents indicated their training in intellectual disabilities could have been enhanced at both undergraduate and residency levels. (53)

In 1999, a review of Canadian Schools of Social Work reported that few courses offered even a minimum level of coverage of issues pertaining to developmental disabilities and no Canadian program offered specific courses in Developmental Disabilities (54).

Basic Nursing education does not have core requirements in Developmental Disabilities. (55). In Australia, nursing education is returning to tertiary care sites because clinical learning experiences in acute care regional settings has been found insufficient. This shift is unlikely to improve content in Developmental Disabilities. Special Learning Disability Nursing programs in Australia were discontinued several years ago. Postgraduate training in Nursing in Ontario is not established for Developmental Disabilities as a nursing specialty. Much of the emphasis on Learning Disability Nursing in the U.K. is presented as Professional Development programs for Practice Nurses. (56)

Continuing Professional Development

Continuing Medical Education or Continuing Professional Development (the newer term) directed to update practicing physicians rarely offers programs that include presentations or discussions on developmental disability. The Centre for Developmental Disability Health Victoria recently presented a program which was well received by a small number of General Practitioners. "Caring for People with Developmental Disabilities, What the GP Needs to Know" was a comprehensive program prepared by Drs. Henderson and Tracy which included; defining a developmental disability; early recognition and diagnosis; the ways patients present; referral indications and resources; an update on new knowledge and common syndromes; and, what to expect in adolescence. More usually, a small component of a wider program may be related to Developmental Disabilities. For example, at the recent Annual Medical Forum of the College of Family Physicians of Canada, a presentation and discussion group on Fetal Alcohol Syndrome was one of over 100 different clinical topics offered to Family Physicians over a three day meeting.

A recent report of the IASSID (International Association of Scientific Study in Intellectual Disability) to the WHO (World Health Organization), " Aging and

Intellectual Disability, Improving Longevity and Promoting Healthy Aging” noted a lack of training on intellectual disability itself among primary health care providers and a lack of training on health issues relative to older persons with intellectual disability. It recommended “Nations should ensure that there are sufficiently educated and trained medical and health personnel to provide appropriate preventive and treatment-oriented health and social services” (57).

What is the Minimum?

In 1999, the Ontario Ministries of Health and Community and Social Services struck a Task Force on Instruction in Developmental Disabilities for Medical Undergraduates, chaired by Emmanuel Persad, the chair of the Department of Psychiatry at the University of Western Ontario. The resulting report suggested that standards and guidelines for teaching were required, that there ought to be a core curriculum for each medical school and that exposure to developmental disabilities for medical students should be improved. “We have concluded that medical school departments, such as Family Medicine, Pediatrics, Psychiatry and Neurology, are and need to be involved in this effort. Currently in Ontario, pediatricians, developmental pediatricians, clinical geneticists, pediatric neurologists, often have more involvement with developmentally disabled children, while family doctors and psychiatrists have more involvement with adults. Adolescents drift somewhere in between with little or no transition planning,”

The Task Force outlined a proposed curriculum package that advocated relevant knowledge be provided through lectures, seminars, and assigned reading (Down Syndrome and Autistic disorders as prototype disorders were considered the minimum exposure) and that direct hands-on contact with children and adults and care givers is needed to ensure development of requisite skills and attitudes. It also recommended including questions on the Medical Council of Canada exams that assess the students’ learning. Core readings were suggested in: Attitudes and Ethical Issues, Medical Assessment and Care of Persons with Developmental Disabilities; Published Health Care Guidelines for Specific Diagnostic Entities Associated with Mental Retardation; Dual Diagnosis; Scientific Progress; and Problem Based Learning Examples.(58)

The authors of the 2001 review of Psychiatry training programs in Canada recommended that the Royal College of Physicians and Surgeons of Canada, the Medical Council of Canada and provincial licensing authorities should recognize the specialist needs of person with intellectual disabilities in their accreditation, certification and licensing guidelines. (52) The Royal College of Physicians and Surgeons in Canada has just approved Developmental Pediatrics as a subspecialty in its own right (requiring formal accreditation though no exam).

In October, 2003, I presented to the 12th Annual Conference on Developmental Disabilities of the St. Amant Centre my view of what the minimum programs in undergraduate, postgraduate medical programs should include.

At the undergraduate level, students should experience a review of the prevalence of developmental disabilities, the interviewing and examining skills required and two or three specific syndrome examples. There should also be an integration of these basic clinical topics with relevant basic science information.

Approximately 25-30 hours of curriculum time for student learning would be committed. It is to be expected and encouraged that different medical schools' curricula would deal with this in keeping with their pedagogical (andrological) styles. As each develops new ideas, resources, and teaching techniques, they can be shared and emulated where appropriate.

For Family Medicine residencies, in addition to the above, there should be a review of the most recent health maintenance targets for persons with developmental disabilities as developed by Beange, Lennox and Parmenter (59) and endorsed by WHO; the presentation of examples of "health watch guidelines" for common syndromes; consideration and discussion of family issues; and reviews of the present resources and support agencies available in the present health and social systems.

Practising physicians need, first of all, to be involved in planning changes in the health care system, such as those incurred by deinstitutionalization, and their involvement as primary medical care providers should include opportunities for updating clinical skills and learning new information about developmental disabilities.

It needs to be emphasized that the health care system organization and resources available must be sufficient and accessible to support good clinical practice by recognizing the service needs of practitioners, , including medical, nursing, other health professional and technical support staff that will sustain the participation of an experienced multidisciplinary workforce and establishing career pathways for health professional providers., The educational system cannot be sustained if the service system is built on insufficient and irregularly provided resources. And the reverse is true. A strong, updated service system cannot be sustained if the educational system is built on insufficient and irregularly provided resources.

Regulatory Requirements, Accreditation

In Canada, the Liason Committee for Medical Education's undergraduate medical guidelines and Family practice training requirements of the College of Family Physicians of Canada do not specify expectations of learning about developmental disabilities. What content is present in their programs is dependent primarily on local "champions" pushing the agenda forward in their local curricula.

Clinical Psychology regulations in Canada have no curricula requirements for developmental disabilities. Some programs offer elective opportunities. Developing programs in Autism treatment are more likely in the future to offer advanced learning experiences in Developmental Disabilities as supervising psychologists are required.

Research

What questions about Developmental Disabilities need answering? What research methodologies are most suitable to apply? Who will conduct the research? For those with Developmental Disabilities who are the focus of the research, how will their privacy and well-being be maintained when research requires their consent and participation? What funding is available to conduct the research? How are research findings translated effectively into providing care that improves the quality of life for people with Developmental Disabilities?

There are as many questions to be answered as there are situations of clinical care, gaps in knowledge about basic science, and social behaviours that involve people with Developmental Disabilities and their families and support workers. Three years ago I consulted several colleagues and two research consortia involved in considering the priorities for research. The topics are listed here to simply serve as examples considered important to pursue. Basic Science topics included: elucidating the biochemical and neuro-chemical mechanisms leading to developmental disability; understanding proteomics as they lead to potential therapeutic interventions; defining specific mutations, their protein products and functions; genetic factors in congenital malformations of the central nervous system; gene identification in autistic disorders; elucidating genetic and environmental risk factors for non-disjunction in Down Syndrome; and mechanisms of the effects of Fetal Alcohol Syndrome, and gene-environment interactions. Clinical Science topics included: molecular screening of populations for carriers of the common genetic disorders; environmental and occupational influences on the risk of chronic disease in adults; nutritional deficiencies' role in developmental disabilities; better detection of women at risk before they become pregnant; the effectiveness of screening for hearing, vision, behavioural and

neuromuscular problems; best ways of counseling and supporting women at risk; early psychosocial development effects on reproductive and childrearing capacity; neuro-imaging and its potential in assessing developmental disability; preferred behavioural modification techniques in reducing disability amongst FAS children; and effectiveness of early intervention programs. Social Science topics included: attitudes of public and professionals towards developmental disabilities; improving public attitudes; developing meaningful education, employment and housing programs; the effects of “labeling”; cultural differences in acknowledging and managing persons with developmental disabilities; and the ethics of consent, including those unable to give direct consent for participating in research.

Research methodologies are also complex. They include: traditional group designs measuring the relative impact of the process on outcomes; studies seeking to determine predictor variables for success outcomes; life-history interviewing and examining community attitudes towards community residences. These come from the 2004 text by Emerson et al and introduce a series of discussions on research techniques. (14).

Who should be doing the research? A simplistic answer is basic scientists, clinical scientists and social scientists, trained and experienced in research. A more comprehensive answer considers the increasingly obvious need for research collaborations of these three integrated directly with service providers and involving in participatory ways those persons with Developmental Disabilities and their families who are the focus of the research. There is a relative dearth of the clinical scientist cohort presently available who encompass the interest, capacity and resources to commit the necessary time and effort. They require particularly evidence of career pathways in the health professional academic worlds that will support their involvement. They also require an increase in their numbers so that a reasonable proportion of them can commit the time necessary to do the research.

The ethical issues of consent and concerns about “labeling” are perhaps the major obstacles confronting the furtherance of significant research activity to further elucidate Developmental Disabilities. These obstacles are seen at the highest international levels of discussion between the advocates for the Developmentally Disabled (led by Inclusion International) and the International Association for the Scientific Study of Intellectual Disabilities (IASSID). Those who zealously defend “normalization” have not been able to accept the scientist’s need for “classification”. There persists a failure to integrate the culture of advocacy with the culture of scientific analysis. I observed directly during discussions at a research committee meeting attended by representatives of a community agency the declaration that the agency’s participation in the research initiative depended on their control of the research agenda. There sometimes seems to be a stubborn resistance to acknowledge the contributions of either group by its opposite. Perhaps the research questions are being presented in the wrong syntax, the methods proposed are not

sufficiently promoting participation by the subjects of the studies or we may simply have two solitudes that are irreconcilable. This is the major challenge facing the leadership of these groups of advocates and researchers and all groups involved ought to face the challenge with respect and determination to do better.

Funding for appropriate research is more available than ever before. While less monies and resources exist in Canada and Australia than are proportionately available in the United States, which received such a boost from the Kennedy family's personal interest, there have been significant increases in the ranges of opportunities in the new institute structure of the Canadian Institutes for Health Research structures. Of the thirteen institutes, all have potential relevance to the population of persons with Developmental Disabilities. For example, even the Institutes of Cancer Research and of Circulatory and Respiratory Health have relevance through the high propensity for those with Down Syndrome to have leukemia and congenital heart disease. Other institutes such as the Institute of Genetics or the Institute of Health Services and Policy Research have more obvious applicability to the vulnerable population of the Developmentally Disabled.

Monies available in the Social Science and Humanities Research Council (SSHRC) are less than in either the Canadian Institutes for Health Research (CIHR) or the Natural Science and Engineering Research Council (NSERC). This disparity may reflect the cost of doing the business of research in social science and the humanities compared with biomedical and natural science research. But, as ethical imperatives escalate and increasing standards of evidence affect social and humanities research, the monies available for research into the social and humane aspects of Developmental Disability studies may be found insufficient.

The translational challenge of getting new knowledge into the field is shared by all health research enterprises and in the case of Developmental Disabilities is primarily hampered by the shortage of clinical providers with research capacity, especially in primary medical care, and secondarily by the silos of bureaucratic and academic organization.

Recent Developments

Ontario has announced its intent to close the last three remaining institutions for developmental disability by 2009. In spring of 2005 was outlined a basic strategy with an initial price tag of \$41 million and a further \$70 million promised. The plan defines four networks of specialized care, three years funding to help recruit and retain professionals, and the building of 390 homes of which 90 will be for individuals with high needs due to mental health issues and challenging behaviours. However, the plan ignored (except for a small fellowship fund) the need for academic strengthening in the universities and colleges, and paid no attention to health professional or staffing remuneration to meet the need for increased community service requirements.

Resistance to institutional closure has come from present residents and their families, staff and unions, and municipal governments who depend on the institutions for accommodation and care, employment and economic stability. Researchers fail to find convincing evidence to support the efficacy of deinstitutionalization.

A telephone survey out of Queen's University conducted two months after the announcement indicated that Southeastern Ontarians did not support the proposed Rideau Centre closure. (60). A submission by the Ontario Public Service Employees Union in March, 2005, promoted the idea of establishing the present three institutional sites as "Centres of Excellence" and argued against the closure of the three Ontario institutions on the basis of poor outcomes elsewhere and lack of community preparedness.(61) Government officials have been recently quieted by a threatened class action suit to be heard in its preliminary bid on August 27. Progress on deinstitutionalization has been slowed down.

Media pick-up of the controversies is exemplified by Margaret Wentz's column in the *Globe and Mail*, Jan. 11, 2005 and a rebuttal from British Columbia. Referring to the proposed Rideau Centre closure, Wentz writes "They (families of current residents) have learned that the disability lobby groups—the ones that want every single institution to be shuttered, in the name of progress and human rights—are far more powerful than they are. What began as an enlightened social policy has turned into entrenched dogma. And that dogma has turned terribly cruel." Responding in a letter to the editor, Pat Mirenda, of the University of British Columbia writes, "the fears expressed by the parents she quoted are very common to families in this situation, but that does not mean they will come to pass". She continues, "In British Columbia, where all citizens—including those with the most severe disabilities—have lived in the community for almost a decade since the closing of provincial facilities like the Rideau Centre, many parents expressed the same concerns...." "Now, those same parents would almost unanimously agree that community living provides their children with better, richer lives than they were ever able to access in an institution."

Manitoba politicians announced in the Spring of 2005 a \$40 million plan to rebuild the Developmental Centre at Portage la Prairie to the surprise of government bureaucrats, academics and professionals, and advocacy groups. The provincial Association for Community Living quickly published an alternative and slightly less expensive plan for community based re-situation of the approximately 600 residents.(62) A scandal involving a private community multi-site residential facility resulted in government shut-down and transfer of the program to a directly government budgeted facility. This has darkened the context (and may have rushed the announcement) of the proposed upgrading of the Portage facility.

New South Wales government decisions recently reduced substantially the resources for families and facilities in the community for persons with developmental disabilities. The cuts to the Adult training Learning and Support program in 2004 reduced the amount of financial support to participate in special activity programs from \$19,000 to \$13,500 per individual.

Summary

To date, the outcomes of deinstitutionalization in the scope of this review are not convincingly successes or failures. Quality of life is reported improved in many ways but not for choice of living companion, community social integration, vocational gains, and appropriate access to primary medical care and professional specialty services. Health status improvements are not proportionately greater than for the population at large. Studies of medication use, in general, show no substantial reductions after deinstitutionalization.

For some common, particular conditions such as dental caries, gastro-esophageal reflux, and challenging behaviour, appropriate management is not being applied in a timely manner. And, scientific rigor by today's standards is not being applied to the biomedical studies in this disadvantaged population. Preventive care and health maintenance, for which recommended guides now exist, is only irregularly applied. Ethical issues of consent in decisions for care and participation in research remain unresolved.

The academic preparation of health professionals is lacking in many universities and community colleges and, where evident, is mostly reflective of teacher and researcher champions. It has no authority in curriculum standards or accreditation requirements. Developmental pediatricians fairly universally and psychiatrists, less consistently, have been providing the academic and service leadership. But, for people with developmental disabilities who survive into adulthood (which are more and more), and for those who do not have DSM diagnose-able psychiatric conditions (about 70%), the professional academies are failing to respond to the need.

Medical undergraduate curricula, with a few exceptions, are failing to graduate doctors with a sufficient, basic education in developmental disabilities. Developmental Pediatrics seems to have taken hold, but postgraduate programs in Family Medicine and Psychiatry require national standards for Developmental Disabilities content in their core curricula. Other specialties such as Ophthalmology, Neurology, Orthopedics, Otorhinolaryngology, Physiatry, General Internal Medicine and Dermatology ought to review their curricula for adequate inclusion of Developmental Disability components.

Dental schools, Nursing Schools, Rehabilitation Schools, Social Work Schools do not appear any better. In community colleges, courses in Developmental Social Work are preparing the likely largest group of frontline service workers for the future, but have not fully adjusted curricula to deal with health issues and community based settings (group homes, semi-independent residences) instead of major institutional settings.

On the service side, difficult and delayed access to these same clinical disciplines reflects this lack of educational content and organized clinical learning opportunities in their training. Academic disciplinary boundaries impede collaborative programming and resource sharing. The present shortages of particular kinds of health professionals add to the problem of access.

Career pathways for service professionals and academics in Developmental Disability remain poorly defined and inadequately supported.

Research monies are more available than a decade ago for biomedical research and for social and applied studies and studies in the humanities, although the proportion of funds for research in social sciences and humanities remains a distinct minority of research funds available. Particularly with Canada's new CIHR restructuring there are opportunities in applied and multidisciplinary research. However, there are not many collaborations or even enough Developmental Disability scholars to effectively compete for some of these funds.

Meanwhile, with the increasing prevalence of Autism, Fetal Alcohol Syndrome, HIV - AIDs, larger numbers of extremely premature live births with their increased risk of developmental disability and the continued devastation of children in developing countries and natural disaster areas, the total pool of persons with developmental disabilities is increasing. Early recognition technologies and the choices of pregnancy avoidance and pregnancy terminations work to reduce the pool but the balance is towards an increased population requiring services.

Some politicians announce major new initiatives that are not supported by or even known to key stakeholders, who include their own ministry officials, their constituents with disabilities and their families, and the health professionals who are expected to provide the services and educate the students and practitioners of the future. Other politicians engage their officials, consult available expertise and involve the users of services as they forge ahead with well considered policies and programs, often (and usually quietly) against prevailing opinions. Ministry departments resist sharing of resources and avoid invitations to collaborate across programs when relinquishing control is expected.

There are achievements upon which to build a better future for this heterogeneous and growing number of children and adults. For example, treatment of Autism is showing advances towards successful outcomes. (Manitoba's program seems tighter in terms of criteria for application and in preparation of professional carers, but presently a three year age limit on support is being challenged by parents who are seeing improvement in their affected children that needs to be sustained. This is under review now.) There is not much argument, while treatment programs are expensive for a few years, that the long term benefits of success for the individual's independence and self-sufficiency and society's relief of a life-long financial burden, the treatment is cost effective over time. Getting politicians to commit today's dollars for the long term benefit is the challenge. Another significant advance is that seizure management is improved with more effective medications and surgical innovations for previously hopeless situations. Gastro-esophageal reflux disorder is another area of improved treatment. Advances in genetics are making prevention and early identification of specific disorders more achievable. And there are exemplary academic programs which can serve as models for schools at undergraduate and postgraduate levels.

Recommendations

- I. To achieve goals of community integration, optimal health, coordinated and cost-effective service provision to persons with developmental disabilities, Provincial or State governments must **introduce collaborative ministry programs that are focused in their implementation and are administered and funded independently of individual ministry controls**. Ministries of Health, Community and Social Services, Higher Education (Colleges and Universities), Education, Children and Families, Housing, Justice, Ageing or whatever other division of authorities may be delineated in a particular government will not succeed collectively if they continue to try to serve such a complex set of needs with a mixed package of philosophies, commitments and resources controlled by ministry fiefdoms, nor can they expect the frontline providers to struggle with coordinating disparate service delivery systems for each client and family. The tasks of collaborating and resource-sharing is for senior cabinet and treasury board leaders to accept.

Several years ago I attended a public meeting at which a provincial minister was asked when she thought her ministry (education) and the ministry of health would be working effectively as collaborators. Her answer was that it was not likely to happen and if we needed to arrange cross ministry resources we would be more likely successful if we worked it out at the individual client level with local agencies..

More recently, discussions with another ministry's staff at the mid to senior level and in a different jurisdiction,, I asked why it was so difficult to get a joint program of health

and social support systems off the ground. The answer was straightforward, “we cannot get our masters to share resources if they have to give up control of their budgets”.

The Ontario Ministry of Health and Long- Term Care Bulletin No. 1 on Local Health Integration Networks describes problems of integrating networks as coordinators of service delivery (rather than providers of clinical services). “Despite many successful individual efforts at integration, healthcare providers still operate in an extremely complex environment, dominated by sector-specific silos. Consider that Ontario’s healthcare system is comprised of.....”, listing 2071 function delivery units such as 600 community support service agencies, 581 long term care facilities, 353 mental health agencies, 155 hospitals, among others. It goes on “Today, the individual Ontarian must navigate a system that has numerous unaligned programs and services, as well as conflicting and overlapping boundaries.”(<www.health.gov.on.ca/transformation/lhin>)

Manitoba’s Ministry of Family and Community Affairs has initiated an Applied Behavioural Analysis (ABA) program for 58 eligible children enrolled for up to a three year program (costing \$58,000 per student year). For those going on to the public school system a further amount of up to \$41,000 per year may be provided for home tutoring, consultant services and instructional assistants. These are offered by the ministries of Family and Children’s Services, Health, and Education in a collaborative program that deserves acknowledgement for inter-ministerial cooperation. To date, assessments show that 40% move into the regular school stream, 40% show notable improvement, and 20% show little or no substantial improvement. The government has committed to a five year evaluation of the program’s first fifty students (budgeted for \$300,000). This commitment to evaluation is also highly commendable.

A senior bureaucrat in a ministry of social and community services said to me “Why should we be paying doctors?” My reply was simple. “Your ministry has accepted the mandate to provide necessary services to this population. They need medical services for which the doctors must be paid. If you think that’s the job of the health ministry then its up to your ministry to bring it up with them.”

- **II. Politicians** determining the direction and dispersal of government resources **ought to engage users and providers of services as well as their own ministry officials in discussions and planning.** Such engagement should happen early in the process and not be a last minute afterthought or politically expedient invitation.

The Manitoba government’s recent announcement to reconstruct the province’s Development Centre at Portage la Prairie was a political one based on little or no involvement of ministry bureaucrats, no involvement of the advocacy groups for persons with developmental disabilities, no input from academic or service professionals, no consultation with other provider agencies, academic professionals or researchers. Given

the surprise commitment of nearly \$40 million, it caught most stakeholders off guard. It is no wonder that Community Living Manitoba reacted with a counter proposal for a more community- oriented proposal and the media picked up the issue enthusiastically. One experienced health professional, who attends clients in the centre, offered the opinion that the present clients would have their needs met less well if the institution were closed and they had to seek care in the community from generic sources. That same professional was preparing to make a public statement to that effect. So the discussions and possible compromise solutions will be fought out in the media rather than in a collegial, constructive and informed manner.

In spite of substantial academic and professional input into discussions, the announcement of the Ontario proposal for resituating over 1000 persons with developmental disabilities from three institutions into the community made no reference to the involvement of academic health science centres nor to the needs of the medical workforce. While the input was ignored, at least there was input. Why ignored? Likely because the lead ministry would not assume responsibility for engaging the other ministries in the implementation, or attempted to do so without achieving sufficient commitment to include their participation in the announcement. There is good evidence that the Ministry of Community and Social Services and the Ministry of Health and Long Term Care are working together on the plan, however. Both have indicated support and participation in a forthcoming (November) colloquium on Primary Care for Adults with Developmental Disabilities at Surrey Place in Toronto.

- **III. The academies** (Universities, Colleges and their accrediting bodies) **must be clear in their curricular guidelines** for health and social professional programs **about including learning experiences and curriculum content that reflects on the disadvantaged populations of society**, exemplified by people with developmental disabilities and their families. (Other disadvantaged populations include the permanently disabled, Aboriginals, homeless, refugees, the unemployed and impoverished, the frail elderly, and the chronically mentally ill). Academic faculties and departments **should review their separate and collaborative commitments to learning components about developmental disabilities** and strengthen any weaknesses.

There are no accreditation requirements for medical undergraduate curricula to include content on “developmental disability”. The Liaison Committee on Medical Education (accrediting medical undergraduate programs) has guidelines that avoid specific content expectations. Similarly the College of Family Physicians (accreditor for Family Medicine residency) and the Royal College of Physicians and Surgeons of Canada (accreditor for medical specialty residencies) do not specifically require “developmental disability” content. Nor do the guidelines of the American Psychology Association who accredit clinical psychology programs. Similarly for the American Dental Association for Dentistry programs. Other university professional programs are not accredited by a formal national process.

The College of Family Physicians of Canada (CFPC) does organize its accreditation according to the “Four Principles of Family Medicine” one of which is “Family Medicine is community based” and another “The family physician is a resource to the community”. Similarly the Royal College of Physicians and Surgeons of Canada has invoked the specialist’s “CanMeds Roles” into accreditation requirements so that all specialty programs are expected to include the doctor’s roles as expert, advocate, manager, scholar, collaborator, communicator and professional. These expectations, if realized, are more likely to graduate physicians better prepared to respond to the needs of disadvantaged populations of patients such as those with developmental disability. But, the content requirement is not explicit.

A recent initiative by the Association of Faculties of Medicine in Canada called “The Social Accountability of Medical Schools” makes reference to medical schools’ mandate to respond to the needs of the disadvantaged. Certainly, the population of people with developmental disabilities comes under this descriptor and so there is an opportunity to promote developmental disabilities as a very good example for medical schools to adopt.

This limited review of undergraduate curricula in Australia and Canada has indicated to me how very important it is to have people on faculty with a special interest in developmental disabilities, “champions”, to ensure a place in the curriculum’s lectures, small groups and clinical learning experiences. Also, the development of learning materials and strategies that can be shared from one school to another will further assist in making Monash-like programs universal.

The University of Manitoba has approved a PhD program in Psychology with a special stream in ABA (unique in Canada). ABA tutors may achieve a certificate from a U of M program involving two courses in Behaviour Modification and two supervised practica.

- **IV. Health professional organizations should** review their disciplinary responsiveness to the complex needs of persons with developmental disabilities and their families and **ensure that undergraduate, postgraduate and continuing professional development programs profile the appropriate provision of services to this disadvantaged population.** They should similarly profile the special needs of this vulnerable population in remuneration negotiations and other discussions with government. Health professional organizations and support staff unions **ought to review remunerative & employment and benefit packages for all stakeholders and ensure that those serving the population with developmental disabilities and their families are treated fairly** in comparison with equivalent formulae applied to the general workforce.

Special attention to the service gap as persons with developmental disabilities leave the care of developmental pediatricians and enter adulthood should be a priority in these considerations.

The largest provincial chapter, the Ontario College of Family Physicians of Canada recently listed “disadvantaged” populations. The list included aboriginals, frail elderly, chronic mentally ill and others, but not “developmentally disabled”. The Ontario Medical Association and Doctors Nova Scotia have negotiated with government a premium on office fee visits for the elderly because they take longer to see and are more complex. This has not happened for people with developmental disabilities.

Most developmental disability workers who work in group homes or in the community work at minimum wage or slightly better. They can see little opportunity for advancement and so the staff turn over is frequent, Nurses working in the community setting are employed for less than their colleagues in hospitals or institutional settings.

Institutional shutdowns result in loss of expert professional staff with years of experience working with people with developmental disabilities: nurses, psychologists, physiotherapists, occupational therapist, sex therapists, chaplains, wheel chair and prosthetic technicians, play therapists, and others. There is no plan for re-engaging these employees in community settings. The counter proposal to the Manitoba plan prepared by Community Living Manitoba paid special attention to the rehiring of experienced staff for newly developed positions in the community. The Centres of Excellence proposal by OPSEU in Ontario similarly would sustain expertise in the proposed system. But there are no government plans to preserve expertise. Special developmental nursing training programs in Australia have been discontinued.

The plan for “normalization” expects deinstitutionalized individuals to find their resources for health and social supports from the same “generic” pool of providers available to the population at large. That means health professionals with limited experience and little or no educational preparation will be expected to add to their practice lists. And, they are in short supply.

- **V. Health Authorities** in their management of the provision of services to their regions **ought to give priority attention to the disadvantaged populations** who find accessing care more problematic and lack sophisticated lobbying resources.

Some acute care facilities in academic health science centres have developed outreach programs for disadvantaged populations in their community. Others have little to offer other than their emergency rooms. Emergency medicine is not what is needed nor is it suitably structured to meet the needs of persons with developmental disabilities. Most childrens’ hospitals have clinics for child development. Few general hospitals have clinics for adults with developmental disabilities. Some psychiatric clinics serve the specific needs of those with developmental disabilities, especially if the Psychiatry Department has a Division of Developmental Disabilities, but most do not.

Some subspecialty departments are not prepared or resourced to provide services that are needed for people with developmental disabilities. Ophthalmology services to the Rideau Centre are provided in the form of a consultant visit quarterly, but it is not the same ophthalmologist from visit to visit. Because of a shortage of neurologists at Queen's in Kingston, neurology services have been irregular at the Rideau Centre. Patients requiring EEG's go to Kingston now or to Ottawa if they require anaesthesia to have their EEG. In Brisbane, a young man with gastro-esophageal regurgitation symptoms waited six years to get an oesophagoscopy...he was found to have Burkitts' esophagitis, a pre-malignant condition..

Dental services at the Portage la Prairie Developmental Centre are provided by an academically based Dentist from Winnipeg two days a week because no local dentist will see the clients there and no other academic dentists are willing to commit to regular attendance. Dental students attend one or two sessions.

- **VI. Advocates** for persons with developmental disabilities, health and social **professionals**, researchers and **scholars and political leaders ought to work harder to understand each other's culture and viewpoint** in order to achieve the optimal outcomes of health, community integration and quality of life for persons with developmental disabilities and their families. There is no future in sustaining dogmatic, idealistic and turf-protective attitudes. Advocate organizations for persons with developmental disabilities and their families ought to put their primary effort into coordinating their activities rather than competing for attention and resources.

Sitting on a research committee for an institution serving persons with developmental disabilities, I heard a senior representative of a regional advocacy agency advise that its support depended on the researchers doing research that they, the agency, would proscribe. He then pointed out that there had never been any research done by medical or nursing professionals that had improved the health of persons with developmental disabilities.

Inclusion International and the International Association for the Scientific Study of Intellectual Disability (IASSID), respectively the world's largest advocacy organization and the world's largest scientific association focusing on developmental (intellectual) disability, have significant disagreement about what research and what research methods are appropriate in studying Developmental Disabilities. That biomedical research requires the categorization and grouping of individuals is difficult to accept by those who stress individualization and normalization. Issues of consent, restraint, "the medical model" (which few agree has one definition), early recognition and pregnancy prevention and intervention all boil into the mix of controversies. Several years ago I met with the then presidents of each organization. Both expressed dismay at the estrangement, but recent discussions with one of them suggests not much has improved in their relationship.

*Also disturbing are the discussions well exemplified in the *Wente Globe and Mail* article and her rebuttal by a UBC faculty member over deinstitutionalization. (see page 35). As one researcher colleague noted “.perhaps the closing of all institutions is not positive to all long-term clients at all.” “those who really have lived at the institutions for very long times and are deeply rooted there, should be allowed to continue” “...perhaps grandfathering some of the older clients in their current institutions might be more sensitive to them. The expectations of uprooting one-and-all ‘for their own good’ to community homes, etc may be welcome by some, not so by others.”.*

If the energies put into sustaining these arguments were re-channeled to efforts at understanding, compromise and collaboration, much more could be accomplished.

- VII. Progress can be made towards improving outcomes for those with developmental disabilities and their families by sustaining **spending commitments equivalent to the level preceding the institutional cut-backs of expert staff** which have been substantial during the last phase of client discharges to community settings over the past five to ten years. (For Ontario the benchmark for appropriate expert staff complements should be based on employment patterns in the year 2000) . Amongst **what is required** will be: analysis of **efficient operations**, (e.g. reducing duplicate services, facilitating multi-skilling, determining the total pot of money presently available), **maintaining currency** in educating professionals and staff , employing effective **modern technological methods**, **rewarding providers** of essential services appropriately, promoting appropriate use of available **research monies**, **encouraging academic programs** to review their responsibilities in educating students about developmental disabilities, establishing **attractive career paths** for academic, professional leaders and skilled support staff.

Generally, governments deny that the driver of deinstitutionalization is to save money. On the other hand, reviews of funding show that monies saved by closing institutions are not redirected to improving community programs.

At Rideau Regional Centre there were fourteen Physical Therapy and Occupational Therapy staff five years ago. There are now seven of which some are part time. The only speech pathologist and the only sex counselor positions have been declared vacant.

These experts should have been transferred to community settings but are simply lost to the overall resource pool. The 178 former residents of the last significant exodus were of higher function and generally healthier than the present population. The social worker case managers on staff then contributed substantially to the discharge letters. The last social worker position was discontinued nearly two years ago. Approximately 430 clients remain of which 240 require wheel chairs full or part time. When RRC is fully

closed, others with expertise, such as the technical expert who provides wheel chairs customized to individual needs and other physical aids, will be lost to the system. These kinds of experts could be engaged in community colleges as teachers and coordinators of community technical resource centres for the newly situated population.

Some reports suggest that deinstitutionalization cannot be properly accomplished without at least a 25 % increase in financial commitment. Previous U.K. figures suggested for each person deinstitutionalized there is a capital cost of 39,200 pounds and an ongoing yearly cost of 26,000 pounds. Seven years ago Scotland was making the greatest per capita financial commitment to persons with developmental disability.

Because services, support, education and health care come from so many government pots it is difficult to get a total comprehensive cost estimate. It is noted that developmental disabilities create more health care costs than do dementia and schizophrenia combined. A figure of just over 8% of the total health care expenditure on persons with developmental disabilities has been suggested.

Recently with new managements for Autism, there have been reports of effective management (Applied Behavioural Analysis or ABA and Intensive Behavioural Intervention or IBI) returning children to the mainstream of schooling and full vocational potential. In Manitoba, it is noted that \$58,000 per student year for three years is the starting place and the government has funded a three year evaluation of its program to determine the overall efficacy. The most expensive treatment for any general category of developmental disability may result in the best long term investment for governments to risk.

Ontario recently added an academic chair in Autism to two existing chairs in Developmental Disability held in departments of Psychiatry at the University of Toronto and Queen's University. The directors of three leading centres for developmental disability in Australia at Melbourne, Brisbane and Sydney are substantially supported by government healthcare/academic funding. But six years ago funding was nearly halved in Melbourne when two units (University of Melbourne and Monash University) were made one. As a result, two leading expert family physicians with interests in developmental disability moved away...one to another aspect of medicine entirely and the other to another state. There is little security in academic positions in developmental disability.

- VIII. Increased **financial commitments** by government should be based **proportionately on demonstrated increases in the population of developmentally disabled** (which are happening) with **special considerations for additional monies given to new and proven treatments** whereby delayed long term benefit can be realized with the likely expectation of also being cost-effective.

There is anticipated a continued increase in the population of persons with developmental disabilities. Autism, Fetal Alcohol Syndrome, HIV-AIDS, developmental delays complicating extreme prematurity, international starvation and natural disasters, have been added to the pool. An increased population will require increased resources. If present expenditures for institutional maintenance and operations are redirected in full, it is not likely that increases in spending will require additional increases on a per capita basis.

Autism is the current example of an expensive success which offers long term financial savings but more importantly a potential for long term normal quality of life. Genetic developments offer other opportunities to avoid pregnancy in high risk situations, and to intervene before conception or in utero and avoid or reduce disability. We can anticipate other advances.

- IX. As primary care models change, their planners and implementers ought to fully consider the **improved access to services for persons with developmental disabilities and their families and other disadvantaged populations as a major component of innovative programs.**

All provinces are considering and implementing new primary care delivery systems. The concept of generic care ought to include the special needs of particular disadvantaged populations and not fall into a one kind of service for all. Fee premiums to family doctors for the elderly, as recently initiated in Ontario, should be extended to developmentally disabled persons and their families to acknowledge the highly complex presentations of illness and the increased time required to assess and manage them. In Australia, the recently introduced "care plan" program by which General Practitioners may apply for collaborative supports with other health professionals for complex care individuals, while a promising innovation, has had only limited success, apparently because of the detailed application process and to some degree a lack of awareness by busy GP's.

The Ontario primary care programs of family health networks, family health groups, comprehensive groups ought to emphasize access and service to disadvantaged populations as premium considerations. Shared-care models for family physicians to collaborate with consulting specialists also offer potential advantages in the care of person with developmental disabilities. Sessional appointments of family physicians with special interests and skills as community and regional coordinators are also worth considering.

Provinces/states approaching the last round of significant deinstitutionalization have an opportunity to offer to participating physicians an electronic medical record system that could be a model for full practice implementation over time. At the same time such an EMR system could be the basis for a knowledge and resource network for developmental disabilities to immediately improve the capacity of primary care providers to serve the needs of individuals with developmental disabilities and their families.

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61. Ontario Public Service Employees Union (2005) Centres of Excellence, Serving People with Developmental Disabilities.
62. Community Living, Manitoba (2005) Manitoba Developmental Centre Redevelopment; A Community-Sponsored Alternative Proposal.

**APPENDIX I. Literature and the Arts with respect to Developmental Disabilities:
Books**

“Forever Baby” by Mary Burbidge is a personal story by an Australian general practitioner about her developmentally disabled daughter and their family. Hi-Mark Press Pty. Ltd., Williamstown, 1997, ISBN 0-330-36009-4.

“Expecting Adam” by Martha Beck is the story of two Harvard academics whose second child has Down Syndrome. A poignant and funny tale of their dealing with attitudinal barriers in a high powered centre of academic excellence, more than somewhat lacking in its ability to respond to the challenge of perceived imperfection in its midst. Berkley Books, New York, 1999, ISBN 0-425-17448-4.

“Corker” by Wendy Lill is a play profiling a developmentally disabled young man who alters the values and function of a politically and business-oriented couple and their family and friends. Several references to the social and political world’s ineffectiveness in providing appropriate resources in a Canadian (Halifax) setting expose the reality of today’s experience of a lone, disabled, adult struggling to make a life. The play has enjoyed a successful Maritime run and was profiled in the Blythe Festival in Ontario. Talonbooks, Burnaby, 1998, ISBN 0-88922-394-7.

“Rottweiler” by Ruth Rendell is a mystery thriller in which a major character is developmentally disabled, living on his own but dependent on an aunt whose life is ultimately forever affected by her guilt-laden loyalty to her nephew. Amazon. 2000.

“Metamorphosis; The Fibre Art of Judith Scott” by John M. MacGregor is the photographic and written story of a 55 year old woman with Down Syndrome, who though unable to speak has emerged as a recognized fabric sculptor with unique bundling of threads and yarn around a mysterious core, often appropriated from other’s belongings. 1999, Creative Growth Art Center, ISBN 0-9673160-0-6.

“The Journey to Here; 25 stories for 25 years” by Alexandra Rabins and C. David Reader, is a photographic essay for the V.S.A. (Very Special Arts) program’s twenty-fifth anniversary. Twenty-five American artists are profiled, each with a significant disability. 1999, Disability Today Publishing Group. Inc., Grimsby, ON, ISBN 0-9680667-8-X.

“Tru Confessions” by Janet Tashjian is a children’s novel about a young girl’s life with her brother who has a developmental disability. Scholastic Inc., New York. 1997. ISBN 0-590-96047-4.

“Images of Autism”, The Medical Humanities Art Program at the University of Manitoba encompasses the works of twenty-three first year medical students who explore the experiences of persons with Autism and their families. 2002. A web-site, www.vision.ca/mhap and a catalogue (on file at the Neil J. Maclean Library, University of Manitoba) profile the presentations.

APPENDIX I: (ii) Literature and Arts with respect to Developmental Disabilities: Movies/Videos

“My Left Foot”, 1990. A child with cerebral palsy, unable to speak, born into a poor Irish family, evolves into a recognized author of novels and poetry. The movie, directed by Jim Sheridan, won two Academy awards for best actor (Daniel Day Lewis) and best supporting actress (Brenda Fricker).

“Pauline & Paulette”, 1989. The care-taker sister of a mentally challenged woman dies suddenly and the disabled sibling, Pauline, is thrust upon another sister, Paulette, who runs a lingerie shop and is not prepared to keep her. Pauline is sent on to a third sister in the big city, Brussels, who also has her own life complications including a boyfriend. The movie, directed by Lieven Debrauwer, was recognized at the Academy Awards, the Cannes Film Festival, and the Toronto Film Festival.

“Jewel”, 2001. The sixth child of a solidly married couple has Down Syndrome, and as she approaches adulthood, the mother finds it hard to let go. Farrah Fawcett acts as the mother. Good sensitivity but some technical errors. 2001, Director Paul Shapiro.

“Metamorphosis: The Fiber Art of Judith Scott”. Video. 2000. Creative Growth Art Center. Accompanies book above by same title. (10 ½ minutes).

“Out of Mind”, 2005 Australian Broadcasting Corporation, documentary on deinstitutionalization with interviews by Matthew Carney. Focus is on those with Mental Illness and homelessness. <www.abc.net.au/4corners/content/2005/s1463798.htm>

“Il Duce Canadese”:, 2005 CBC movie of Italian Canadians in Montreal during WW II, in which one of the main characters who is developmentally disabled emulates the actions and dress of Benito Mussolini and in so doing contributes to his and his family’s difficulties (including internment) with government authorities.