VOL 23 – NO 1 **SPRING 2012**

ISSN 1188-3936 http://www.ddd.uwo.ca

Western Medicine&Dentistry
Schulich School of Medicine & Dentistry

Schulich
MEDICINE & DENTISTRY

CLINICAL BULLETIN

of the

DEVELOPMENTAL DISABILITIES DIVISION

Welcome to our community! Social Inclusion for Persons with Intellectual & Developmental Disabilities: An Essay

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The Government of Ontario, guided by the Ministry of Community and Social Services', Developmental Services Branch, has established a "social inclusion" policy (1) in 2008 to guide its provision of services for persons with intellectual and developmental disabilities across the province. Persons with such disabilities need a range of services over their lifetime as their intellectual and adaptive impairments commence early and tend to persist.

This essay reviews some historical background, considers various implications for professional care providers and offers suggestions on how implementation of the social inclusion policy thus far might be strengthened.

Entering a New Era

Ontario closed its three remaining institutions for persons with intellectual and developmental disabilities in March 2009. These closures marked the end of the institutional era of care, an interval that commenced in 1876 with the opening of an asylum for idiots (later called a hospital-school) in Orillia. The staff of early institutions enthusiastically applied new insights about teaching children with intellectual and developmental disabilities and shielded them from the neglect they otherwise experienced in local communities. In his 1964 book tracing this history, Leo Kanner (2), the American child psychiatrist best known for his 1943 description of autism, goes on to describe how unrealistic expectations and overcrowding, and later, a societal preoccupation with eugenics, led to the demise of the institutional approach. Between 1876 and 2009, Ontario had established and then closed sixteen institutions, gradually putting in their place a range of community-based alternatives for care.

Legislation formalizing a policy of social inclusion was passed in the Ontario legislature in 2008. The legislation marks the end of efforts to "deinstitutionalize" care that had commenced in 1974. It commits the province to provide a full range of community-based services. While "social inclusion" is not formally defined, use of this term in Ontario and in other jurisdictions, assumes that persons with intellectual and developmental disabilities will be integrated in local schools, healthcare services and social agencies that provide for members of the general population.

Implications for Local Care Providers

While knowledge about intellectual and developmental disabilities is equally applicable in institutional or community settings, care in the community by mainstream agencies and professionals involves a shift in the skill-sets and attitudes of local care providers. Ontario's provincial institutions employed "specialist" care providers, often training them on site. Community services and agencies employ "generalist" providers who serve mainly individuals who do not have intellectual and developmental disabilities. Unfortunately, generalist training programs provide little and sometimes no attention to intellectual and developmental disabilities. The balance of this section considers the skill-sets and attitudes needed by teachers, healthcare providers and social workers now expected to serve persons with intellectual and developmental disabilities (IDD) living in local communities.

The skill-sets relevant in serving persons with IDD can be seen as adjustments or refinements in the skill-sets involved in serving others.

The first step for a care provider is to *establish communication* with the person with IDD. Persons with IDD are variably able to use the usual modes or channels of communication. Some people may never develop functional speech, but most have less severe limitations that can be accommodated in day to day contact. Some persons with IDD are never able to communicate in writing, while others may have attained basic literacy and numeracy skills during their school years.

As a second step, most care providers then carry out some sort of *assessment* in order to plan helpful interventions. These assessments can be informal or formal; the latter including standardized psychometric testing. A new assessment procedure being utilized in Ontario as social inclusion is implemented is the Supports Intensity Scale (SIS). The SIS is employed by the staff of regional application centers where persons age eighteen or over obtain government financial support to address their various needs. In using the SIS, application centers called 'Developmental Services Ontario' (3) seek to ensure equity in the level of support provided to a population whose individual members have widely different profiles of disability.

The type of intervention provided by teachers, healthcare providers and social workers obviously reflects their particular professional competencies. Less obvious is the necessity that providers also support family members or other caregivers who are closely involved in the daily life of the person with IDD. As well, each provider must remain cognizant that many agencies and professionals can be simultaneously involved and that there are ever-present risks for poor coordination of effort and for the provision of guidance that may be confusing or contradictory for those receiving it.

Accordingly, it can be seen that in order to facilitate successful social inclusion for persons with IDD, local providers need to adjust their skills in communication, in assessment and in the coordinated delivery of various supports.

In 1998, Jean Vanier (4), the Canadian who founded the L'Arche Communities that serve persons with IDD around the world, described these persons as "among the most oppressed and excluded people in the world" (p72). This reference to oppression and exclusion is very much at variance with the goals of social inclusion. It means that attitudinal variables can be important considerations in implementing a policy of social inclusion. Like skill-sets, attitudes of care providers may need attention and adjustment.

What can be called "primal" responses (eg. fear, avoidance, rejection, etc.) may occur when a care provider encounters a person with an IDD for the first time. Such responses are a more common experience when the person with IDD presents with dysmorphic features, with unusual mannerisms, or may be someone who can be disinhibited or aggressive in social situations. Ideally first encounters should occur when caregivers are still trainees, so an instructor or mentor can create a context for positive interactions. Primal responses are usually short-lived and preventable. Assuming the trainee or the care provider is motivated, and will put in the necessary effort, good communication and a mutually satisfactory relationship can be established.

In follow-up encounters there needs to be a balance between an overprotective attitude based on pity versus a failure to empathize based on ignorance or misplaced optimism. Providers can usually rely on family members or other caregivers for advice about the right balance, and one should never be afraid to ask for their guidance. Developing and maintaining an optimal relationship with a person with IDD involves providing ample time. Indeed, failure to schedule enough time is a major hazard in successful provision for those individuals, time for them <u>and</u> time for their caregivers.

Life in the community is often stressful for persons with IDD and their caregivers. In 1972, Robert Perske (5), an American advocate, wisely noted there is "dignity in risk". Some risk is inevitable as individuals grow and mature, but obviously, overwhelming risk needs to be avoided.

In summary, the attitudes of care providers are critically important variables in promoting the optimal adjustment of persons with IDD as they are integrated in mainstream schools, healthcare agencies and social services.

Challenges in Implementing Social Inclusion

Institutions for the care of persons with IDD were originally established to reverse the deprivations they experienced in local communities and to provide education and training in protective environments. As "hospital-schools," their programs could address both medical and educational needs.

Following World War II, advocates noted that most institutions had become seriously overcrowded and unable to meet the needs of their residents. Advocates also observed that community–based schools or residential alternatives, many founded by families who had courageously pioneered innovations without government support, were preferable to these institutions. Problems in institutions and exciting developments in community care promoted deinstitutionalization and, more recently, a policy of social inclusion.

Since any policy has associated risks and benefits, we can now ask about social inclusion with this in mind. Given the basic goals of the policy, are persons with IDD welcome in our communities? Are they receiving the care and support they need in our local education, healthcare and social services agencies?

Care in the community has been evolving in Ontario over a period of approximately fifty years. Arrangements that demonstrate the contributions of various elements in a range of needed services (eg. foster homes, group homes, activity centers, and respite for caregivers) serve not only the individuals with IDD and their families. Rather, these arrangements must also reassure members of the broader community that community care is feasible, acceptable and indeed, preferable to care in traditional institutions. As deinstitutionalization commenced, restrictive zoning bylaws represented neighbourhood "resistance" to group homes, but in time these were modified appropriately as experience demonstrated that primal responses similar to those described earlier were short-lived. The major challenge being faced currently is obtaining or finding enough funding to meet the demand for residential alternatives in the community.

Many families of persons with IDD who had lived for years in institutions were very concerned, even litigious, about the impending closures and the transfer of their loved ones to community alternatives. This situation was further complicated by the views of institutional staff who had concluded that care in the community, particularly for persons with complex medical and mental health needs, was not the better option. These views were reinforced by the observations of advocates in the United Kingdom on the inadequacies of medical care in the community for people with learning disabilities (IDD) by the National Health Service. The report, **Health Care for All: report of the Independent Inquiry into access to healthcare for persons with learning disabilities** (4), by a panel of experts established to investigate these concerns and to prepare remedial actions deserves careful study here in Ontario. In the UK, and here in Ontario, it is absolutely essential that better training for healthcare providers be established to prepare "generalists" for their contemporary responsibilities. The assumption that generalist care providers could simply integrate individuals with IDD into their classrooms, and in their clinics and offices has been a serious oversight in implementing social inclusion.

Perhaps an even more significant challenge, given Jean Vanier's observations about the vulnerability of persons with IDD to neglect and abuse, is the lack of a safety net in communities across Ontario. I want to offer a suggestion for a remedy. With the new Developmental Service Ontario application centers now established across the province, we have made a good start in establishing an infrastructure to investigate concerns about neglect and abuse. With a designated protection role, similar to the child protection role of Child and Family Services agencies, application centers could represent a focal point in a safety net for adults with IDD living in local communities. The enhanced training needed by the province's generalist care providers would include reference to the importance of vigilance for neglect and abuse, as well as, how to engage the services of an application centre when either was observed.

It is interesting to speculate what the possible conclusions that scholars of the twenty second century may reach when they contrast the eras of institutional care, versus the period of social inclusion. When properly resourced, institutions of the past trained their staff to provide care, supervision and protection for their residents, albeit at the "expense" of normal patterns of family life and community living. On the other hand, social inclusion assumed that care providers with little or no training about intellectual and developmental disabilities, and the broader community itself, would welcome those with such disabilities, and somehow avoid the risk of neglect and abuse that historically follows them. At this early juncture in the implementation of social inclusion, this "welcome" may be somewhat hollow. Absence of an effective safety net creates a scenario for a recurrence of underfunding and social neglect. Social inclusion may ultimately face the same fate as the institutional care it replaced.

References

1. Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008

2. Kanner, Leo 1964
   A History of the Care and Study of the Mentally Retarded
   CT Thomas, Springfield

3. Function of the Application Entity under the Act: Section 17 (1) (a)
   Section 7(2) 2ii Effective Date: July 1, 2011
   Purpose: Application Entities shall use a provincially-consistent assessment process for Ministry-funded adult developmental services and supports to:

- improve the quality and responsiveness of Ministry-funded adult developmental services and supports**:** Using the Application Package, which comprises the Application for Developmental Services and Supports (ADSS) and the Supports Intensity Scale® (SIS®), to collect information on the support needs, priorities and circumstances of

eligible applicants, will facilitate accurate assessments and inform the development of individual support plans directed by the needs of eligible applicants;

- **reduce the burden on persons with developmental disabilities and families**: Having a standardized, valid and provincially-consistent assessment process for all Ministry-funded adult developmental services and supports will mean that applicants will not have to repeat their personal history when they apply for developmental services and support;

- **improve system fairness and sustainability**: Adopting a provincially-consistent approach to needs assessment will support equitable service decisions so that persons with developmental disabilities with similar support needs and in similar circumstances will receive similar adult developmental services and supports, no matter where they live in the province; and

- **support better planning**: Using a provincially-consistent approach to collect information on the support needs, priorities and circumstances of persons with developmental disabilities will provide valid and reliable information to inform individual service and support planning. This approach will also provide a basis for conducting accurate, comparative statistical analyses of collected data, to be used for planning at the community and provincial levels (See Policy Directive 8 – Reporting to the Ministry).

4. Vanier, Jean 1998
   Becoming Human: Jean Vanier's Massey Lectures
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5. Perske, Robert 1972
   The Dignity of Risk and the Mentally Retarded
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6. Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities. 2008
   Aldridge Press Cheswick
   Author: Sir Jonathan Michael and the Independent Inquiry into Access to Healthcare for People with Learning Disabilities
   Published date: 30 July 2008 **Copyright holder:** Crown (UK)

An independent inquiry into access to healthcare for people with learning disabilities was established under Sir Jonathan Michael's leadership in May 2007, following the publication of the Mencap report "Death by indifference," which described the experiences of six people who died whilst under the care of the NHS. The Disability Rights Commission Formal Investigation into equal treatment had also raised questions about the quality of healthcare for people with learning disabilities who were physically ill.
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf

Resources & News on the next two pages…

A new resource: ASPERGER SYNDROME IN ADULTHOOD: A COMPREHENSIVE GUIDE FOR CLINICIANS

“An outstanding addition to the literature. This volume is comprehensive in scope and is a valuable addition to the growing body of work on this topic.” **—Fred R. Volkmar, MD, Irving B. Harris Professor and Director, Child Study Center, Yale University School of Medicine; Chief of Child Psychiatry, Yale New Haven Hospital**

“*Asperger Syndrome in Adulthood* represents a very welcome addition to the current literature on what happens to individuals on the autism spectrum after they graduate from high school or college. Maintaining an evidence-based perspective, the authors address a wide range of issues, including some controversial ones, in way that is accurate, accessible, and very applicable to the promotion of quality-of-life concerns. A very useful volume.” **—Peter F. Gerhardt, EdD, Chair, Scientific Council for the Organization for Autism Research, and Director, McCarton Upper School**

Despite the dramatic proliferation of research, clinical perspectives, and first person accounts of Asperger Syndrome (AS) in the last 15 years, much of this information has focused on the application of the diagnosis to children, even though AS is present across an individual’s entire lifespan. This book is one of the only guides to AS as it manifests itself in adults. It integrates research and clinical experience to provide mental health professionals with a comprehensive discussion of AS in adulthood, covering issues of diagnosis as well as co-morbid psychiatric conditions, psychosocial issues, and various types of interventions from psychotherapy to psychopharmacology. It also discusses basic diagnostic criteria, controversies about the disorder, and possible interventions and treatments for dealing with the disorder.

Contents: 1. Introduction to Asperger Syndrome and Autism Spectrum Disorders in Adults • 2. Assessment of Asperger Syndrome in Adults • 3. Mental Health Symptoms in Adult Asperger Syndrome • 4. Neurodevelopmental, Genetic, and Medical Issues in Adult Asperger Syndrome • 5. Psychosocial Issues in Adult Asperger Syndrome • 6. Psychotherapy and Psychopharmacotherapy in Adult Asperger Syndrome • 7. Complementary Interventions and Evidence-Informed Practice in Adult Asperger Syndrome

Available on Chapters/Indigo, Caversham booksellers, Parentbooks and at The Redpath Centre, Amazon.ca and other booksellers worldwide.

Kevin Stoddart, PhD, is the Founding Director of The Redpath Centre and Adjunct Professor, Factor-Inwentash Faculty of Social Work, University of Toronto. He has worked in the fields of Autism Spectrum Disorders (ASDs), Asperger Syndrome and child and adult mental health. For the last twenty years, his clinical focus has been children, youth and adults with mild ASDs, primarily Asperger Syndrome.

Lillian Burke, PhD, is a Psychologist and Assistant Director of The Redpath Centre. Dr. Burke first specialized in Autism Spectrum Disorders (ASDs) in the 1980s, and since then, has continued to work with children and adults who have ASDs and developmental disabilities. In her private practice, her primary activity is assessment of individuals for ASDs and Asperger Syndrome.

Robert King, MD, has worked, for over two decades, with multiple interdisciplinary teams, largely in rural underserved regions of Ontario, supporting individuals with intellectual disabilities, Autism Spectrum Disorders and mental health concerns. He is currently consultant to ACT-DD, Brockville Mental Health Centre, Pathways to Independence, Kerry's Place Autism Service, and Community Living agencies in north-western Ontario.

In Memoriam: Jeanette J.A. Holden, PhD, FCCMG

Jeanette was born in Vancouver and obtained her BSc and PhD with Dr. David Suzuki in Genetics. After completing a postdoctoral fellowship (funded by the Killam Foundation) at the Biozentrum in Basel, Switzerland, with Dr. Walter Gehring, she was a visiting scientist at Cambridge University in the UK, guest scientist at the Biozentrum in Szeged, Hungary and the University of Lund in Sweden, and lecturer at UBC, before coming to Queen's University in 1978. From 1979-1986, she was the director of the Cytogenetics Service Lab at Kingston General Hospital and had academic appointments in the Departments of Biology and Pediatrics at Queen's. Since 1986, she was director of the Cytogenetics & DNA Research Lab (and the Autism Research Laboratory) at Ongwanada and professor of Psychiatry and Physiology at Queen's. Dr. Holden's main research was on the genetics of Autism Spectrum Disorders and various intellectual and behavioural disabilities, including Fragile X Syndrome and other forms of X-linked mental retardation (XLMR). Since 2001, she was Program Director of the Autism Spectrum Disorders – Canadian-American Research Consortium (ASD-CARC), carrying out interdisciplinary research dedicated to "Unraveling the Mystery of Autism Spectrum Disorders" (www.AutismResearch.com). The Team has received major research grants from the Canadian Institutes of Health Research (CIHR), the Ontario Mental Health Foundation, and the Canada Foundation for Innovation, a CIHR Interdisciplinary Health Research Team grant and a CIHR Strategic Grant for Autism Research Training, co-funded by Autism Speaks/NAAR (www.AutismTraining.ca). She worked together with Autism Ontario, Autism Society Canada and other autism organizations to develop a Virtual Community of Autism Stakeholders (www.AutismConnects.com). She served on the Board of Autism Ontario (formerly Autism Society Ontario) for many years until 2004, but continued as a member of its research committee. She was also a Board Member of Autism Society Canada. Her brother, Jim – who is autistic – and her family were her inspiration for helping other individuals and families with ASDs and other developmental disabilities. She believed that by working together, the lives of all persons with disabilities will be enriched.

In April 2007 she was diagnosed with leukemia. She fought this terrible disease with strength and resolve, and continued to be very involved with her research during her illness. On February 22nd 2012 she passed away peacefully at home with her mom holding her hands and her loved ones by her side. She is survived by her mother Anne and her brothers Jim and Brian.

We lost a dear friend, a great mentor, a brilliant educator, visionary researcher, passionate scientist and steadfast leader in the autism community. She will be deeply missed. But at the same time Jeanette leaves a strong legacy and pride amongst us to have worked with her as a team to advance her vision and enable the common goals that she inspired. Together, with your continued support, we will ensure the continuation of Jeanette's substantial legacy and collaborations through ASD-CARC (Autism Spectrum Disorders, Canadian-American Research Consortium) to honour her remarkable career, love, compassion and unending support for the global autism community. http://www.asdcarc.com/