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Intellectual Disability and Stigma: an Ontario Perspective

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Introduction

DSM-5 has introduced the term “intellectual disability” replacing “mental retardation” to refer to individuals with significant impairments in intelligence and adaptive functioning that onset before age 18 (Paris 2013). Mental retardation now joins a number of earlier nosologic terms like oligophrenia, amentia and mental deficiency, terminology carefully documented by Leo Kanner (1964). Over time any term selected by nosologists for this population eventually assumes a stigmatic connotation that stimulates requests for an alternative. What is the nature of stigma associated with this category of mental disorder? Are there particular issues that need to be addressed apart from renaming it from time to time?

Although little has been published on stigma as experienced by persons with an intellectual disability, an investigation by Jahoda and Markova (2004) provides important insights. After defining stigma as arising “when a person differs from dominant social norms on a particular dimension, and is negatively evaluated by others”, the authors conducted in depth interviews with 18 subjects moving from a long-stay institution and 10 subjects making the transition from their family home to live more independently. All subjects believed that they had experienced stigmatized treatment and were clearly aware of stigma associated with intellectual disability. The authors concluded that “a lack of social acceptance was an area of major concern for these individuals”

This essay explores intellectual disability and stigma from an Ontario perspective in relation to clinical phenomenology, social history and neglect by mental health professionals. As will be seen, there are important societal and professional attitudes about these individuals that stigmatize them. These attitudes are amenable to change, indeed must be changed if one is committed to improvements in their quality of life across the province.

Clinical Phenomenology

Although its members share defining early-onset intellectual and adaptive impairments, the population with intellectual disability is otherwise notably heterogeneous. Some members are young, some older, some seriously impaired, although the vast majority are most mildly impaired. Some members have difficult-to-control epilepsy, but most are seizure-free. Some members are dysmorphic or physically disabled, and many have a “dual diagnosis” (i.e. a second mental disorder as described below). It is little wonder that members of the general population experience difficulties in recognizing the clinical phenomenology involved. Such difficulties predispose members of the public to misunderstand these individuals, to be indifferent to their special needs and, in some cases, to fear them. Misunderstanding, indifference and fear contribute to stigmatization. Members of the general population who are understanding, generous and empathetic are uncommon and will usually recount a personal history of unique interactions and experiences that inform their freedom from stigmatizing attitudes.

Given contemporary policy that supports social inclusion of persons with intellectual disability, it can be seen immediately that successful implementation of this policy must include advocacy to reduce stigmatization. Such advocacy includes public education campaigns and training for those who provide local community services for all citizens (e.g. teachers, vocational instructors, recreation counselors, police and judges). Instruction supportive of social inclusion needs to cover not only the complex phenomenology of intellectual disability but also the barriers represented by stigmatizing attitudes.

Social History

The social history of intellectual disability and its relationship to issues of stigma can be considered in respect to two eras, one when care in institutions was prominent, and the second involving deinstitutionalization and the promotion of social inclusion. Indeed, although many factors influenced the shift from institutional care to social inclusion, stigma associated with life in institutions that were overcrowded and poorly equipped was a most important variable.

Institutions were first established to educate and train individuals with intellectual disability whose needs were neglected in local communities. In the absence of community options for care, institutions became grossly overcrowded and, by the end of the Second World War, so difficult to manage that the need for alternatives had become obvious to all. Misunderstanding and indifference, as outlined earlier, fostered stigmatization of individuals with intellectual disability during the institutional era. These attitudes were enhanced by fear linked to eugenic considerations that characterized intellectual disability as predominantly genetic in origin and frequently associated with delinquent behaviours and promiscuity (Radford & Park 1995).

Implementation of deinstitutionalization and social inclusion has been a greater challenge than had been anticipated in the 1970's when Ontario's Ministry of Community and Social Services assumed provincial responsibility for the program (Stainton 1995). While indifference to the special needs of persons with intellectual disability has waned somewhat, there have been major difficulties in understanding these needs in terms of formulating community-based approaches to meeting them.

Additionally, fear of these individuals has dissipated as it has become obvious that genetic factors in etiology are far more complex than originally conceived and that the individuals themselves are more likely to be abused than to be abusers. Presently in Ontario there is class action litigation concerned with alleged abuse and neglect during the institutional era, and at the same time, an Ombudsman investigation of concerns expressed by families that the current needs of the intellectually disabled are being ignored, a reflection that misunderstanding, indifference and perhaps primitive fears continue to be relevant. At any rate, one can conclude that stigmatizing attitudes have survived the closure of all of Ontario's institutions and that the public education and training of community service providers suggested earlier require attention.

Neglect by Mental Health Professionals

Not only is intellectual disability identified as a mental disorder, almost 40% of persons with an intellectual disability suffer from a second mental disorder (i.e. are "dually diagnosed"). In relation to stigma, an additional mental disorder complicates the individual's adaptive problems and raises the risks of misunderstanding, indifference and fear. How has planning for persons with dual diagnosis in Ontario addressed their complex needs and the increased risks of being stigmatized? Is the professional neglect of persons with dual diagnosis itself a manifestation of stigmatization?

The Ministry of Community and Social Services has established regional referral centres where the Supports Intensity Scale is utilized to identify individual needs for residential options, day programs and "specialized and professional supports" provided by Ministry supported transfer payment agencies. The Ministry of Health and Long Term Care, responsible for mental health services, is expected to integrate persons with dual diagnosis in its "mainstream" programs. This is an unfortunate expectation given that most mental health professionals have received little, if any, training about this population. The Ministry of Community and Social Services sponsors the "Community Networks for Specialized Care" program to foster training and development activities to support inter-ministerial collaboration on behalf of persons with dual diagnosis, an almost impossible assignment given the serious deficiencies in the training of mental health professionals. Short duration workshops and seminars are simply inadequate in preparing mental health professionals to provide optimal care for persons with dual diagnosis. For example, in the United Kingdom, preparing psychiatrists to serve persons with dual diagnosis involves 3 years of specialized clinical training.

Accordingly, a third suggestion (along with public education and training for community service providers) for reducing the impact of stigma is to engage the support of Ontario's Academic Health Science Centres in establishing specialized regional treatment programs where mental health professionals can develop the clinical skills necessary to competently serve persons with dual diagnosis. The service – teaching endeavours in place in southeast London, England described by Bouras and Holt (2010) provide an excellent model for adoption in Ontario. To do less than suggested here on behalf of these "high needs" individuals is to accept that their stigmatization fosters continuing professional neglect, neglect that has been reversed in the United Kingdom as they have closed their traditional institutions and have implemented a policy of social inclusion.

Conclusion

This essay has examined aspects of intellectual disability and stigma in relation to improving the care of persons with intellectual disability and dual diagnosis in the Province of Ontario. Misunderstanding of the problems experienced by these individuals, indifference to their special needs, and neglect by mental health professionals are identified as important manifestations of stigma and suggestions are provided to minimize their impact. These include public education, training for those who deliver community services for all citizens and inclusion of intellectual disability and dual diagnosis in the curricula of mental health professional training programs.

The cognitive and adaptive impairments that define intellectual disability usually improve over time but are rarely "cured". They create a variety of adjustment problems for these individuals over their lifespan, including some that reflect stigmatic attitudes engendered in others (O'Brien 2001). Such attitudes are remediable and the suggestions brought forward here are directed at modifying their harmful effects. These remedies must be seen as important elements in a broad range of treatment and support services provided for persons with intellectual disability and dual diagnosis across the province.

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2013 UPDATE on: The Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis

In July 2013, the Ministries of Health and Long-Term Care and Community and Social Services provided recommendations derived from the effectiveness evaluation on the implementation of the Ministry of Health and Long-Term Care (MOHLTC) and Ministry of Community and Social Services (MCSS) Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis (2008).

Also, six local tools were collected as promising practices that selected local communities had put forward as being helpful in coordination and delivery of services and programs. The tools can be accessed at: http://eenet.ca/news/dual-diagnosis-local-tools/

The intention of the project was to provide an opportunity to highlight the strengths and weaknesses of the Guideline and its implementation to date, provide an overview of promising practices and develop a tool kit of promising practices for use in the field across the province.

The consultants conducting the evaluation received information from service providers across the province in both the mental health and the developmental services fields. The process was also informed by expert advice from an external advisory committee that included service providers, Local Health Integration Networks (LHINs) leads, Community Networks of Specialized Care (CNSCs), researchers, parents and MOHLTC and MCSS staff.

MOHLTC and MCSS have reviewed the report's recommendations to identify implications for both ministries and impacts on LHINs, MCSS Regional Offices, CNSCs and organizations delivering dual diagnosis services and programs. The ministries will continue collaborating and will convene an advisory committee for the development of the dual diagnosis framework that will build on the Guideline.

THE RECOMMENDATIONS

1. DEFINE THE AGENDA

Recommendation 1.1: It is recommended that all new relevant policies from MOHLTC and MCSS recognize the issues and needs of individuals with a dual diagnosis and provide meaningful strategies that are specific to that population.

Recommendation 1.2: It is recommended that an inter-ministerial framework for Dual Diagnosis services be developed that defines the expectations for systems management and service delivery strategies. This could include defining the appropriate continuum of supports from both the health and social service sectors. The framework should draw from and be supported by current policies from both ministries including Developmental Services Transformation (MCSS) and Open Minds, Healthy Minds, (MOHLTC).

2. DEFINE THE STRUCTURES

Recommendation 2.1: It is recommended that at the corporate level, an inter-ministerial standing committee be created to set policy direction and to set operational direction to the field regarding expectations and outcomes. The work of this committee would benefit from being informed on a regular basis by a standing advisory committee of external representatives from the health, mental health and developmental services sectors.

The two ministries need to determine how at a local/regional level the systems will work together to jointly support and enable cross-sectoral efforts. Making it easier to jointly fund new initiatives was identified as a concrete change that would improve service in the field.

Recommendation 2.2: It is recommended that MCSS and MOHLTC determine through the MCSS Regional Offices and the LHINs, the appropriate structures at the field level to be charged with a specific mandate for addressing dual diagnosis issues.

The basis of a viable structure exists in the CNSCs. Many of the CNSCs already have participation from the developmental, health and mental health sectors and good work has been taking place in many communities. Rather than starting again with a new structure, the CNSCs need to be strengthened so they can become a more effective vehicle for change.

Recommendation 2.3: It is recommended that at the operational level in the field, the Community Networks of Specialized Care be jointly designated and mandated by both ministries as the structure with responsibility for implementation of policy and operational strategies. This mandate should include expectations for required participation in the Network and the continuum of supports that should be available across the province. The Networks should be provided with appropriate financial and structural support to deliver on this new mandate.

Recommendation 2.4: It is recommended that progress in the field be measured by required reporting on appropriate process indicators (see above recommendation) established by the two ministries.

3. SUPPORT THE ACTIVITIES

Recommendation 3.1: It is recommended that tools that support local processes (both from the Tool Kit and from local communities) be shared with communities for use on a discretionary basis. Looking to the future, Green Light for Mental Health offers a model for the development of a toolkit that is nested in a well-defined policy context and measures progress toward predefined outcomes.

Recommendation 3.2: It is recommended that Green Light for Mental Health be considered as an effective model for the future developmental of an integrated approach to assessing progress in a well-defined policy and operational context.

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http://www.intellectualdisability.info/ **This British website is an excellent resource with many free articles that we highly recommend.**

- Ideal learning resource for medical, nursing and other healthcare students
- Everyone working in healthcare will find invaluable information on this site
- Senior editorial team have clinical and academic experience spanning the last 30 years

http://www.improvinghealthandlives.org.uk/projects/annualhealthchecks

Health Checks for People with Intellectual Disabilities: Request for Information from the Improving Health and Lives Learning Disabilities Observatory The Improving Health and

Lives Learning Disabilities Observatory is planning to update their current systematic review on the evidence relating to health checks for people with intellectual disabilities

(See **http://www.improvinghealthandlives.org.uk/projects/annualhealthchecks** or www.ihal.org.uk/gsf.php5?f=16714 to download a copy of the review).

As well … *See further information about recently published new articles and revised articles.*

"Welcoming a patient with Intellectual Disabilities into General Practice: Reasonable Adjustments in Primary Care" by Dr Ella Baines, was published in February 2013.

"Improving Hospital Experiences and Ensuring Safer Discharges" , an interview with Jim Blair, Consultant Nurse in Learning Disabilities, by Alexander Chiu, Final Year Medical Student at St George's University of London, and Dr Jason Tsang, Foundation Year 1 Doctor, was published in May 2012.

"*Primary Care and Intellectual Disability"* by Malcolm McCoubrie and Ella Baines, and "*Your next patient in A&E may have an Intellectual Disability*" by Lindsey Stevens and Carly Bush, were published in November 2011.

A revised and updated version of "*Confronting the Distortions: Mothers of Children with Down Syndrome and Prenatal Testing*" by Lisa Bridle, was published in December 2011. A revised and updated version of "*The Use of Medications for the Management of Problem Behaviours in Adults who have Intellectual [Learning] Disabilities*" by Shoumitro Deb, was published in February 2012. A revised and updated version of "*Brain Development: Neuro-Behavioral Perspectives in Developmental Disabilities*" by Jay Rao, was published in October 2012.

https://www.vch.ca/your_health/health-topics/health_services_for_community_living/

In B.C., deinstitutionalization of persons with ID occurred decades ago and people aging with intellectual disabilities have lived in various community settings for years. Health Services for Community Living (HSCL) is a unique B.C. provincial program established following the closure of large institutions to specifically address the healthcare needs of people with ID living in the community. Health Services for Community Living (HSCL) provides support to adults with developmental disabilities and their families and caregivers. Check out their website as well for resources.

HSCL will help:

Facilitate access to a range of community health services including physiotherapy, occupational therapy, nursing, nutrition and dental hygiene
Train and support family members and caregivers
Provide referrals to health care providers
Advocate for specialist care
Implement care plans for specific health concerns

http://www.fasdontario.ca/cms/resources/diagnostic-clinics And check out this FASD website for the Fetal Alcohol Spectrum Disorder Ontario Network of Expertise