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Developmental Disabilities Division

**Managing the Challenge of “Challenging Behaviour”  
for Persons with Intellectual Disabilities**



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**Introduction**

When the cognitive and adaptive impairments that define intellectual disabilities are accompanied by problem behaviours, formulating care plans can be quite difficult and complex.

In the United Kingdom in the mid 1980's, as former residents of institutions were being resettled in local communities, “challenging behaviour” was introduced as an operational concept in reference to those with a severe level of intellectual disability and problem behaviours (Emerson, E., Toogood, A., Mansell, J., Barrett, S., Bell, C., Cummings, R., & McCool, C., 1987). The term reflected the special efforts required to provide a “normal” and “accessible” life in the community while also minimizing any risks of harm associated with the problem behaviours. It also demonstrated the professional dedication of a small group of psychologists and academics who had pioneered the

resettlement of individuals with “high needs” who many had concluded would require lifelong care in institutional settings.

This paper considers the origin and evolution of “challenging behaviour”, including the application of the term in formulating care plans in contemporary practice. A concluding section reviews some implications of these developments for the provision of services for persons with intellectual disabilities and problem behaviours in Ontario now that all of the province’s institutions are closed.

## History

Eric Emerson, a psychologist from the University of Canterbury (Emerson, E., 1990) presented information on 29 individuals being resettled from the Darenth Park Hospital, to the Eighth Congress of the International Association for the Scientific Study of Mental Deficiency in 1988 in Dublin. These individuals had severe intellectual impairments and problem behaviours. Emerson’s paper provided a functional definition of “challenging behaviour”, without reference to traditional diagnostic nosologies:

“Behaviour of such intensity, frequency, or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to or use of ordinary community facilities.”

So defined, these individuals were said to occur with the prevalence of 1:100,000 of the population. Each exhibited an average of 2.6 problem behaviours with violence to others (69%), violence to the material environments (48%) and self-injury (41%) being the most frequent. Problem behaviours usually occurred during “demand conditions” (i.e. following the occurrence of staff disapproval, task demands, structured activities and segregation); none of these behaviours were identified as being “attention seeking.” Care plans ensured locally provided service, with many individuals living alone or with one or two others. Costs of care ranged from £27,000 to £105,000 per client.

At the same time, as reported in a later account describing services for people with intellectual disability and offending behaviour (Chaplin, E., & Xenitidis, K., 2010), a “Mental Impairment and Evaluation Service” (MIETS) was established in 1987 also as part of the resettlement effort linked to the closure of the Darenth Park Hospital. It would appear that Emerson and his colleagues focused their efforts on individuals with severe intellectual impairments and problem behaviours, while the MIETS Unit concerned itself with “mild mental handicaps and behavioural and psychiatric problems” (Chaplin, E., et al., 2010). The role of the MIETS Unit, based in a psychiatric hospital serving the region, involved responding to the clinical issues brought forward by local caregivers, including:

- Clarification of diagnosis
- Describing the functions and determinants of behaviour
- Risk assessment and management
- Medication rationalization
- Development of optimal placement profiles

The Unit is described as “low security” and was therefore equipped to manage those clients who were referred for issues regarding conflict with the law, and included fire setters and sexual offenders.

Later observations of interest from the southeast London area were recorded by Bouras, N. & Drummond, C., (1992). They investigated problem behaviours and psychiatric disorders in 318 adults referred to an ambulatory clinic serving a general population of 320,000. Most of the referrals (54.4%) had mild intellectual impairment, 28.6% moderate and 17.0% had a severe intellectual impairment. Problem behaviours were observed in 167 individuals (52.5%), with aggression towards others being the most prevalent. Problem behaviours and a DSM-III-R diagnosable psychiatric disorder coexisted in 66 (20.8%) referrals. Outpatient followup was provided for 187 (58.8%) individuals, 35 (11%) were admitted to a psychiatric unit, 22 (7%) were referred to a general medical hospital and other services, such as referral to day programming, were made for the remaining 74 individuals.

Another perspective is provided in a survey of 234 individuals with “challenging behaviour” described by Moss, S., Emerson, C., Kiernan, C., Turner, S., Hatlon, C., & Alborz, A., (2000). In this study the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PASS-ADD) Checklist was utilized to screen for four categories of psychiatric disorder. The prevalence of anxiety, depression or psychosis was “high” (26.7%) in individuals with challenging behaviour and “very high” (43.7%) in the group with “more demanding” levels of challenging behaviour. Intellectual level was not measured but there was a strong association between level of challenging behaviour and impairment in language. The authors observed “there is a clear potential for reducing challenging behaviour through the identification and treatment of unrecognized psychiatric problems”.

This brief historical review of “challenging behaviour” since the mid 1980's allows us to conclude;

- Problem behaviours occur at all levels of intellectual impairment and are not confined to those with a severe level of intellectual disability,
- Problem behaviours may be associated with significant medical or environmental problems,
- Problem behaviours, although often occurring in isolation, may also be symptomatic of/or magnify the severity of underlying psychiatric disorders, and
- Problem behaviours are more prevalent in those with speech and language communication difficulties.

### **Preparing Care Plans**

Knowledge about challenging behaviour and its management continues to accumulate in the twenty-first century. This section reviews selected observations from the more recent professional literature and the authors' experiences as practitioners in assessing

and preparing care plans for individuals with intellectual disabilities and problem behaviours. These care plans aim to guide the efforts of caregivers and professionals in promoting the individual with disability's quality of life while simultaneously minimizing risks associated with problem behaviours.

More recent investigations clearly illustrate that "challenging behaviours" are associated with factors beyond those identified as behavioural targets for intervention in past studies. Those endeavouring to prepare care plans that can accommodate the broad range of factors that predispose to or trigger problem behaviours need to be familiar with behavioural phenotypes (Gothelf, D., 2007), health problems (Kwok, H., & Cheung, W.H., 2007), communication impairments (McClintock, K., Hall, S., & Oliver, C., 2003), stressful life events (Owen, D.M., Hastings, R.P., Noone, S.J., Chinn, J., Harman, K., Roberts, J., & Taylor, K., 2004), as well as the mental health issues that have been the focus of attention previously.

While co-morbidity of psychiatric disorders continues to be important, a broader interdisciplinary perspective or assessment is necessary for care plan success. This is illustrated in a systematic review of functional behavioural assessments, pointing out that such assessments should be included in a comprehensive multi-method approach involving personal/social history, medical history and physical examination, evaluation of current medication efficacy and possible side effects or interaction effects, and psychiatric evaluation (Tassé, M., 2006). As can be seen, the challenge involved in "challenging behaviour" has gradually moved on from identifying the impact of problem behaviours to understanding why such behaviours occur and how professionals can collaborate in managing them.

In the balance of this section, attention is given to issues of importance in development and preparation of care plans for individuals with intellectual disabilities and problem behaviours. A range of healthcare professionals are involved in conducting assessments, in the preparation of diagnostic formulations and care plans, and in providing interventions and caregiver support as care plans are implemented.

It is critically important that interdisciplinary assessments and conceptualizations are completed at the outset to ensure that the full range of biopsychosocial factors, now known to be relevant contributors to problem behaviours, are considered. Health, mental health and rehabilitation professionals each have relevant skills in assessment and case formulation to guide comprehensive care planning.

Although professional debate continues about the relationship between problem behaviours and mental health disorders or dual diagnosis, the approach adopted in 2001 by the Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities (DC-LD) provides a practical resolution to both assessment and intervention planning. Utilizing DC-LD as a conceptual framework not only provides clinicians with diagnostic criteria that can be reliably applied in individuals with intellectual impairment, but also accommodates recent insights about categorizing problem behaviours. In its Axis III hierarchical structure DC-LD provides opportunities to

identify problem behaviours comorbid with other disorders (e.g. personality disorders, autism spectrum disorders etc.), with medical illnesses, or isolated in its own level. Criteria for problem behaviours include reference to significant severity, pervasiveness and serious impact on the life of the disabled person or others. Additionally, the DC-LD manual provides a useful appendix describing common “behavioural phenotypes” and a listing that cross-references DSM-IV categories and codes.

To address a need for a comprehensive approach to “challenging behaviour” the authors have adopted a “threshold” conceptualization of problem behaviours to encourage and ensure interprofessional collaboration in the preparation and implementation of care plans. According to this conceptualization, episodes of problem behaviour occur when the individual’s “threshold” for manifesting such behaviours is overcome, or conversely, when biomedical, psychosocial or environmental interventions raise the threshold for exhibiting behaviours, episodes of problem behaviour will be minimized. The “threshold” concept encourages members of various professional disciplines to reorder their profession-specific terminology into a common language that can be easily grasped by others, including the individual’s care givers who will have significant roles in implementing the care plan.

This review of recently published information on why problem behaviours occur and how different professionals can collaborate in developing care plans allow us to conclude:

- Problem behaviours can arise from a broad range of genetic, developmental, health, mental health and social experiential factors,
- Problem behaviours occur in episodes when the individual’s threshold to exhibit behaviourally is exceeded, and
- Problem behaviours can be prevented or minimized through utilization of various multi-modal biomedical or psychosocial and environmental interventions that raise the individual’s behavioural threshold.

A final consideration regarding “challenging behaviour” and contemporary approaches to care planning: From an historical perspective, while “challenging behaviour” had an important role in distinguishing and promoting community care for persons with severe intellectual impairment and problem behaviours, it now appears that other approaches to identification (e.g. interdisciplinary multi-factorial assessment profiles, individualized multi modal interventions) have superseded this role. In fact, within the authors’ practices we have adopted the term “problem behaviour” and no longer find “challenging behaviour” as having any applicable relevance.

### **Implications for Ontario**

Ontario’s service planners and providers have much to learn from experiences reported from other jurisdictions over the past twenty-five years. This section reviews a more recent report on the management of “behavioural crises” in Ontario, and another that

describes the province's specialized inpatient units, to illustrate how some insights developed elsewhere can be adopted.

Weiss, J., & Lunsky, Y. (2010) reviewed the experiences of forty mothers of individuals with mild intellectual disabilities and "behavioural crises" focusing on the availability of services to assist during crisis situations. "Behavioural crises" often prompted visits to hospital emergency rooms for episodes that included aggression to self (30%) or others (70%), threats of suicide (14%) and damage to property (13%). Many of the adults (81%) were receiving mental health services at the time of crises, but these were rated as not effective in most instances (94%). A key factor appears to be the lack of training in intellectual disabilities received by professionals and the staff of mainstream agencies. Crises become inevitable when there is a poor match between help needed and existing support levels. What can be learned about this scenario from the UK experience? The answer is provided in the program description of the Mental Health in Learning Disabilities (MHiLD) service prepared by Chaplin et al. (2008). This service operates in four south-east London boroughs and provides:

- Specialized community-based mental health services: (to support and complement mainstream health and mental health services),
- Specialized inpatient services: (2 beds for each borough in a regional psychiatric hospital to provide care for those whose needs cannot be addressed in local hospital inpatient units), and
- Staff training and development: (training for caregivers and healthcare providers; and studies to promote innovations in care).

"Behavioural crises" can be seen as a signal that "proactive" support services, like those available in the MHiLD program are not being provided in Ontario, and only unsatisfactory "reactive" responses are available in hospital emergency clinics.

Further, the history and program characteristics of five specialized inpatient mental health units in Ontario, Canada were described by Morris in 2005. This review noted several shortcomings in relation to the effective management of individuals with intellectual disabilities and problem behaviours:

- The number of beds in each unit bore no relation to the population within its catchment area,
- Undue reliance on the presence of a DSM Axis I diagnosis of psychiatric illness in admission criteria,
- Lengths of inpatient stay of months or years, and
- Inconsistent attempts to integrate developmental and behavioural expertise in traditional treatment programs.

Apart from lessons inherent in the MHiLD service description already considered, what can Ontario learn from other jurisdictions? Specialized inpatient care must include a "habilitative mental health care" approach as clearly articulated in "Practice Guides" suggested by Gardner, W.I., & Hunter, R.H., (2003). These authors note, "Adequate

services require attention to treatment of both the acute and recurring symptoms of a psychiatric disorder (usually through medication) and the additional personal vulnerabilities (through use of psychological, including behavioural, assessment and intervention strategies) that underlie behavioural dysfunction.”

It also seems plausible that length of stay issues can be addressed by enhancing the skills of direct support staff providing community residential care in positive behavioural supports approaches as outlined by McLean, B., Dench, C., Grey, I., Shanahan, S., Fitzsimmons, E., Hendler, J. & Corrigan, M., (2005) and McLean, B., Grey, I., & McCracken, M., (2007) in their efforts in Roscommon County in Ireland. Assuming that improvements gained in specialized inpatient units can be maintained in community settings, lengths of stay will be appropriately reduced.

This section has observed that insights generated in other jurisdictions can inform improved management of individuals with intellectual disabilities and problem behaviours in Ontario:

- “Behavioural crises” are inevitable when an area lacks a specialized service with relevant community supports, inpatient and outpatient staff training opportunities, and
- Inappropriately long lengths of stay in inpatient units reflect a failure to provide “habilitative mental health care” and a dearth of community residential alternatives with staff skilled in positive behavioural support approaches.

### **Summary and Conclusion**

In the mid 1980's when individuals residing in institutions were being resettled in local communities, psychologists in the London area applied the term “challenging behaviour” to those with severe intellectual impairment and problem behaviours. Meanwhile, psychiatric hospitals developed specialized inpatient units and community based clinics to manage those with problem behaviours and comorbid mental disorders. Over time further investigation revealed that problem behaviours in persons with any level of intellectual impairment and arise from a broad range of genetic, developmental, environmental, health and mental health factors. Hence, the preparation of suitable care plans is based on comprehensive interdisciplinary assessment and treatment processes, involving interventions that can be community-based, inpatient or both.

Ontario's three remaining institutions for persons with developmental disabilities were closed in 2009. In order to provide quality of life and minimize the risks of harm associated with problem behaviours, the province's developmental services and mental health care providers need to adopt insights from other jurisdictions with a longer experience in serving these “high needs” individuals in local communities. It is now obvious that each region needs a specialized program with ambulatory, inpatient and staff training components to support and enhance mainstream providers in caring for those whose intellectual and developmental disabilities are complicated by problem

behaviours. Earlier opinions that suggested problem behaviours were caused by institutional environments and would spontaneously resolve in the community or that mainstream providers could simply integrate these individuals in their practices are not sustainable. Without enlightened leadership in implementing new directions, there are significant risks of harm for those individuals with disabilities, their caregivers and the broader public.

Given that persons with intellectual disabilities and problem behaviours need both developmental and mental health services, an added challenge is inter-ministerial coordination of leadership by Ontario's Ministry of Child and Youth Services, Ministry of Community and Social Services and the Ministry of Health and Long Term Care.

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## RECENT NEWS & NOTES

### NEWS FROM QUEEN'S UNIVERSITY, KINGSTON, CANADA By Dr. Ian Casson

Queen's University's Faculty of Health Sciences has a history of activity in research and medical education in Developmental Disabilities. A recent development is the appointment of **Dr. Liz Grier** by the Department of Family Medicine to the position of Developmental Disabilities Director. Dr. Grier is a family physician who is a graduate of the department's Enhanced Skills (third year) Program in Family Medicine Developmental Disabilities (DD Program). She is also the Chair of the College of Family Physicians of Canada's Developmental Disabilities Special Interest Program. Dr. Grier's appointment is part of the Department of Family Medicine's goals of developing excellence in the care of persons with DD with others at Queen's who have expertise and achievements in this work, including members of the Department of Psychiatry's Division of Developmental Disabilities, which is currently led by Dr. **Jessica Jones** (Psychology & Psychiatry) and includes the other authors of the paper above, **Bruce McCreary** (Psychiatry) and Ms. **Meg McQueen** (Occupational Therapy).

Queen's Family Medicine residents and medical students have been productive in the area also. **Dr. Ullanda Niel**, the most recent graduate of the third year DD Program was working on a program with the area Community Network of Specialized Care in piloting health passports for communication of health information about patients in the local Emergency Department. Dr. Niel is now in practice in a community health centre in Scarborough, Ontario, and part of her work is developing programs for health care of persons with DD there.

**Amanda Lepp**, a Queen's medical student, was involved this past summer in planning a program to introduce in comprehensive health reviews ("annual physicals") for patients with Developmental Disabilities of Queen's Family Health Team, the family practice of the Department of Family Medicine. The program has components for both clinical care of patients and for education of the family medicine residents and it also involves interprofessional care. Ms. Lepp's summer studentship was funded by the Stuart A. Robb Fund, an endowment at Queen's University to support research in Developmental Disabilities by medical students and residents.

**Nationally:** Some encouraging news on the national front was the adoption by the General Council of the **Canadian Medical Association (CMA)** at its annual meeting in Yellowknife this past August 2012 of the motion "DM5-41: The CMA will develop a strategy to improve the transition of pediatric patients with complex and chronic illness into adult care." The motion was adopted unanimously. The issue of transition of care for children with developmental disability into adult-based primary and specialty care was motivated in good part to the challenges of providing effective health care for young adults with DD.

### **The Ontario Chapter of the National Association for Dual Diagnosis:**

NADD Ontario welcomes the proposed Select Committee on Dual Diagnosis announced by MPP Christine Elliott on September 20, 2012. Dual Diagnosis (developmental disability with mental illness and/or challenging behavior) affects 40% of the population with intellectual and developmental disabilities, or at least 48,000 Ontarians. Dual diagnosis is a complex issue, involving and affecting families, and many service sectors including, hospitals, justice, and community housing and support services. Also in September of this year, the CBC Radio's '**The Current**' profiled some of these challenges in a documentary entitled, *Dual Diagnosis: The Long Way Home* (broadcast on September 20, 2012).

*"He was 20 years old, a young man frustrated by his own limitations in a world where few understood how to help him. As part of our project, Line in the Sand, the Current's producer, Howard Goldenthal, brings us a documentary about the dilemmas facing those with Dual Diagnosis, people with developmental and psychiatric disabilities."*

NADD Ontario looks forward to continuing to work with the Ontario Government and

partners to ensure individuals with a developmental disabilities and/or dual diagnosis can live successfully in the community.

To leave an opinion on the issue of dual diagnosis, go to

<http://www.cbc.ca/thecurrent/episode/2012/09/20/dual-diagnosis-the-long-way-home/>

A free article available from the British Medical Journal

Spotlight: **Palliative Care Beyond Cancer**

**Recognising and managing key transitions in end of life care**

There are care concepts in this article applicable to a broad range of patients.

BMJ 2010; 341 doi: 10.1136/bmj.c4863 (Published 16 September 2010)

Cite this as: BMJ 2010;341:c4863

<http://www.bmj.com/content/341/bmj.c4863>

## Dual Diagnosis

The September issue of Journal of Intellectual Disability Research includes **five articles concerning interventions for people with intellectual disability and mental health diagnoses.**

See the table of contents and abstracts no cost, full text access at a fee.

<http://onlinelibrary.wiley.com/doi/10.1111/jir.2012.56.issue-9/issuetoc>

Original Article

**Dual Diagnosis Public Policy in a Federal System: The Canadian Experience**

Heather Gough<sup>1</sup>, Susan Morris<sup>2</sup>,\*Article first published online: 10 SEP 2012

<http://onlinelibrary.wiley.com/doi/10.1111/j.1741-1130.2012.00347.x/abstract>

DOI: 10.1111/j.1741-1130.2012.00347.x

Journal of Policy and Practice in Intellectual Disabilities

Volume 9, Issue 3, pages 166–174, September 2012

**Keywords:**Canada;dual diagnosis;intellectual disability;mental health;policy

**Free article available**

<http://www.nejm.org/doi/full/10.1056/NEJMoa1200395>

*“We analyzed the genomes of 2312 children known to carry a copy-number variant associated with intellectual disability and congenital abnormalities, using array comparative genomic hybridization.”*

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Clinical Study

## **A Comparison of Medical and Psychobehavioral Emergency Department Visits Made by Adults with Intellectual Disabilities**

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