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No Simple Solutions for Complex Needs

DEBORAH ELLIOTT

Department of Psychiatry

Queen's University

Kingston, Ontario

Réussir la réforme du système de santé mentale et de la toxicomanie signifie créer un système qui réponde aux besoins des cas les plus complexes et les plus difficiles à traiter: les personnes qui ont un double diagnostic et des désordres concomitants. Les personnes dont la condition relève de la psychiatrie, et qui souffrent, en outre, d'une déficience intellectuelle ou de toxicomanie, sont celles dont les besoins sont les moins satisfaits. Une réforme réussie doit incorporer de nouveaux modèles de paiement pour les professionnels qui soignent les cas les plus complexes, de nouvelles méthodologies dirigées vers des stratégies comportementales et non pharmacologiques, un plan d'action qui vise les désordres liés au syndrome d'alcoolisme foetal et autres incapacités évitables, et des alternatives à l'incarcération pour les personnes dont les besoins sont complexes.

Getting it right on mental illness and addictions reform means creating a system that meets the needs of the most complex and difficult to treat cases: persons with dual diagnosis and concurrent disorders. People with a psychiatric condition plus an intellectual disability or addiction suffer the greatest unmet need. Successful reform must incorporate new payment models for professionals who serve those with the most complex needs, new methodologies targeted at behavioural and non-pharmacological strategies, an action plan to address fetal alcohol spectrum disorders and other preventable disabilities, and alternatives to incarceration for persons with complex needs.

INTRODUCTION

This paper will look at some of the issues raised in the interim report of the Standing Senate Committee on Social Affairs, Science and Technology on mental health, mental illness, and addiction related to concurrent disorders and dual diagnosis. Individuals with a concurrent disorder have a psychiatric condition and an addiction. Dual disorders or dual diagnoses are terms that describe an individual who has an intellectual disability (ID) and a psychiatric disorder. Although this paper will focus on those individuals who have both an ID and a psychiatric disorder, many of the issues discussed apply to other vulnerable populations who have difficulty receiving adequate care and treatment in the current service-delivery system. If the Senate committee recommends a system of care that meets the needs of the *most complex* cases, that system would also meet the needs of those with less complex needs.

BACKGROUND

Intellectual disability or mental retardation has been defined more by social policy than biology. There are three criteria needed in order to make a diagnosis: (i) sub-average intellectual functioning on an IQ test; (ii) concurrent deficits or impairments in present adaptive functioning in at least two areas such as communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety; and (iii) onset of the disability before the age of 18 years (*Quick Reference to the Diagnostic Criteria from DSM-IV-TR* 2000, 52). The prevalence of children and adults with intellectual disabilities is estimated to be between 1 and 3 percent of the population depending on the study and definitions used (Bradley, Thompson and Bryson 2002; Ouellette-Kuntz and Paquette 2001; Health and Welfare Canada 1988). Thirty percent is the accepted conservative prevalence rate for psychiatric disorders in individuals with ID (Canadian Mental Health Association, Ontario Division 1998).

Although some programs may have to be specialized, many individuals with ID would benefit from accessing generic mental health services. Intellectual disability should not be an exclusion criterion for any service. Individuals with ID also have an increased risk of physical and psychiatric illnesses (Ouellette-Kuntz forthcoming). They also have higher incidence of undiagnosed physical and psychiatric illnesses; therefore it is likely that the unmet need is far greater than currently documented. Stigma and discrimination directly contribute to this disparity; individuals with IDs experience the stigma from an early age and the stigma related to their mental illness is in addition to what they are already experiencing. They are doubly stigmatized.

Policies that increase private funding are likely to further marginalize vulnerable populations unless money is specifically targeted for certain populations. There must be accountability in the system to minimize mandate drift. There is unlikely to be one funding strategy that addresses the concerns of all the diverse interest groups. The answers are as varied and as complex as the individuals who need care. The economic arguments made for helping, for example, the depressed male worker, back into the competitive workforce are not as straightforwardly applied to persons who, by definition, are unable to engage in competitive employment. As the nature of the workforce changes, influenced by the new knowledge-based economy, individuals with lower levels of intelligence are likely to be even more disadvantaged than previously. Those individuals with IDs and mental health concerns will be further marginalized if outcome measures rely on a return-to-work paradigm.

ISSUES OF FAIRNESS AND EQUITY

The European Association for Mental Health in Mental Retardation, in the Declaration of Rome 2003, indicated that there is a significant human rights issue if people with intellectual disabilities are denied the best available mental health care

(Seidel 2004). This is the basis for the recent court challenges by parents of children with autism. If the Senate committee recommends a system of care that meets the needs of the most complex cases, that system would likely meet the needs of those with less complex needs. If the members of the committee focus on solutions that deal with less complex issues, the system is unlikely to meet the needs of those who are most in need of care. This would be unacceptable if physical care were the focus of discussion. For instance, most psychiatrists working with patients who have a dual disorder or a serious and persistent mental illness agree that private practice and fee-for-service methods of funding do not optimize patient outcomes; yet the standard of payment for psychiatric care is still based on the psychoanalytic hour. The work of the psychiatrist is most efficient when there is also payment for telephone interventions, consultations with case managers and families, and other forms of indirect care. Community-based, multidisciplinary teams that provide an integrated treatment plan are most effective in maintaining the mental health of individuals with complex needs. Policymakers should recommend funding an equitable system that reflects the values of the majority of Canadians. An equitable system would actively encourage mental health professionals to use the skills and training they have learned in our publicly funded educational institutions and to use those skills to treat individuals with the greatest complexity of needs.

CONTROVERSIAL ISSUES

Research with vulnerable populations is controversial. Asylums, forced sterilizations, and other policies related to eugenics are still painful issues for many individuals and their families. There are many ethical concerns and no easy answers. The important issue here is that research with this population involves extra effort to ensure that proper consents are given by informed substitute decision-makers and this extra work and expense may deter researchers from exploring topics related to mental

disorders and persons with IDs. There needs to be a great deal of debate about how the results of genetic research will be used before family members and organizations will consider supporting it (Wildeman and Downie 2001). Although many cases of ID have a genetic cause, it is unlikely that research dollars will be sufficient to find a cure for those genetic abnormalities. The government has a role to play in this sensitive area.

Families need to be assured that knowledge will be acquired ethically and used to improve the lives of their loved ones. Vulnerable populations are excluded from much research, including drug trials. Because there is little pharmacological research done with this population we lack evidence on which to base clinical decisions. Many individuals with IDs who exhibit challenging behaviours receive psychotropic medication for which there is minimal evidence as to best practices. A national action plan could direct the Institute of Neurosciences, Mental Health and Addiction to develop a strategy to address the injustice related to those groups normally excluded from research and medication trials. Best practices for the integrated use of pharmacotherapy and non-pharmacological interventions could be established. Federal dollars are needed for this research, as it is unlikely that it would be a priority for the pharmaceutical industry.

FETAL ALCOHOL SPECTRUM DISORDER

Fetal alcohol spectrum disorder (FASD) is the most common *preventable* form of ID. In one Canadian study, although only 50 percent of those with FASD met the strict criteria for ID and therefore qualified for disabilities services, 92 percent had a secondary mental health disability (Clarke *et al.* 2004). If the federal government were to maintain a sustained effort directed toward fetal alcohol spectrum disorder in all of its aspects, from prevention to developing educational strategies, social-skills training programs, and employment opportunities for those affected, the impact on disability and mental health

issues would be tangible. Lessons could also be learned and some could be generalized to other preventable forms of mental retardation, such as early childhood trauma, infectious diseases, poor nutrition, and environmental toxins. The new Public Health Agency of Canada under the leadership of Dr. David Butler-Jones should take on this task.

FORENSIC ISSUES

The percentage of people with IDs in both psychiatric hospitals (Lunsky *et al.* 2003; Burge *et al.* 2002; Saeed 2003) and the prison system (O'Brien 2002) is increasing. The Senate committee could recommend that money be spent to look at the legal issues related to persons with IDs. Issues involving competency, court diversion programs, mental health legislation as it relates to capacity to care for oneself, the roles of the Public Guardian and Trustee, and a reporting mechanism for abuse situations involving vulnerable adults could be systematically explored. The federal government could provide helpful legal advice to the provinces. One goal could be to reduce the number of federal prisoners who have a dual diagnosis and to find alternatives that would address their complex needs. If the federal government could demonstrate success, other jurisdictions would follow its example.

RECOMMENDATIONS

- Examine systems of care that address the complex needs and it will likely inform systems that meet the needs of those with less complex needs.
- Recommend payment models for professionals that reward the work that is needed to serve those with complex needs.
- Direct the Institute for Neurosciences, Mental Health and Addiction to explore research priorities for individuals with complex needs and

to develop research methodologies to assess best practices in pharmacotherapy for challenging behaviours. The research should look at behavioural and non-pharmacological strategies. The development of integrated best practices will increase collaboration among caregivers.

- Ask the Canadian Public Health Agency to develop and implement an action plan to address the complex issues related to fetal alcohol spectrum disorders.
- Set goals and establish programs to reduce the number of federal inmates who have intellectual disabilities and help the provinces to develop alternatives to incarceration for this patient population.

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