

How Can I Help? Responding Effectively To The Mental Health Care Needs Of Individuals With Intellectual Disability

J Simpson

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Abstract

The reported overall prevalence of psychiatric disorders in persons with intellectual disability ("mental retardation") is about twice that of the general population. In spite of the inordinately high prevalence, persons with intellectual disability remain under-treated by the mental health care community. In this article, the author reviews the related literature to discuss why persons with intellectual disability have frequently been excluded from mental health care practices. In addition, conditions that produce vulnerability to mental health disturbances are explored, and methods for assessing the presence of disturbances are identified. Finally, treatment options are described, and considerations necessary to better ensure the accessibility of mental health care services to persons with intellectual disability are presented.

INTRODUCTION

Reports of the overall prevalence of psychiatric disorders in persons with intellectual disability have varied wildly in the literature, with Holden and Neff (2000) describing a variance from 14 to 67 percent. While more information about the epidemiology of psychiatric disorders in persons with intellectual disability is clearly required, evidence indicates that overall prevalence is higher than for persons in the general population (Glick & Zigler, 1995; Luckasson et al., 1992; Matson & Barrett, 1982; Reiss, 1990). A prevalence range of 20 – 35 % has consistently been reported in non-institutionalized persons with intellectual disability. This compares with a range of 15 – 19% in the general population (Parsons, May, & Menolascino, 1984).

In addition to experiencing an immoderately high occurrence of psychiatric disorders, it has been demonstrated that persons with intellectual disability confront the same large variety of disorders as individuals who do not have intellectual impairment (Glick & Zigler, 1995; Walsh & Shenouda, 1999). The degree of disability, however, may affect the manner with which psychiatric disorders are displayed (Walters et al., 1995). Glick and Zigler, for example, found that persons with intellectual disability and a coexistent psychosis are more likely to experience hallucinations without delusions, than are individuals of "normal" intelligence with a psychosis and extant

hallucinations. These findings suggest that lower developmental functioning is responsible for the absence of delusions in some persons with intellectual disability.

For individuals with a convergent intellectual disability and psychiatric disorder, outcome measures show a decline in previous habilitative functioning. This is represented by first time out-of-home placement; re-institutionalization; readmission to some other supervised residential setting; loss of employment or reduced employment prospects; and reduced opportunities for social and leisure integration into regular community settings (Luckasson et al., 1992).

In spite of the high overall prevalence of psychiatric disorders in the population of persons with intellectual disability, and the unfortunate consequences that commonly accrue to those with a concomitant psychiatric disorder, persons with intellectual disability remain under-treated by the large community of mental health service- providers. As an illustration, Walters et al. (1995) found that children and adolescents with mild intellectual disability (having intermittent support needs) expressed suicidal ideation and demonstrated suicidal behaviour to an extent similar to that found in the general population of children and adolescents, but their rate of exposure to mental health services was substantially lower than that experienced in the general population.

Explanations for the relatively low rate of involvement with the mental health service system have focused on a number of misconceptions that are still held about persons with intellectual disability. One misconception is that intellectual disability provides a “buffer” against psychiatric disorders or other mental health problems, so that a person with intellectual disability is in some way protected from or inoculated against such disorders or problems. Another prominent misconception is that anticipated mental health disturbances are simply expressions of intellectual disability. Reiss et al. (1982) referred to this as “diagnostic overshadowing”. This misattribution reinforces the apocryphal belief that apparent mental health disturbances are intractable and not responsive to psychiatric interventions, inducing service providers to exclude persons with intellectual disability from the mental health care matrix.

While it is speculated that an inadequate understanding of intellectual disability contributes to failures in reporting and treating persons with a possible psychiatric disorder and intellectual disability, concern about the stigmatizing effects of a dual diagnosis also appears to prevent initiation of therapeutic processes. In this case, there may be reluctance to apply a psychiatric diagnosis to someone who already endures the debilitating stigma embedded in the label “mentally retarded”. For others, the historic application of the medical model of intervention to control, confine and sedate persons with intellectual disability has likely caused some caution (Hauser, 1997).

VULNERABILITY OF PERSONS WITH INTELLECTUAL DISABILITY TO PSYCHIATRIC DISORDERS

There is no inherent biological predisposition to psychiatric disorders because of intellectual disability, though there are events and conditions that produce central nervous system damage or other biological alterations that can produce intellectual disability and an additional DSM-IV diagnosis in the same person. An example exists in individuals with coexistent diagnoses of Mental Retardation and Pervasive Developmental Disorder. Similarly, intellectual disability and mental health or behavioural disturbances can be associated with specific genotypes, so that Prader-Willi syndrome may produce intellectual disability and compulsive behaviours in the same person (Dimitropoulos et al., 2001). A comparable example exists in individuals who have Smith-Magenis syndrome, with resulting intellectual

disability and Attention Deficit Disorder (Finucane, Dirrigl, and Simon, 2001). Generally, though, vulnerability appears to be a function of stress and insufficient coping skills (Rush & Frances, 2000).

Rush and Frances (2000) reported stressors that often confront persons with intellectual disability and can lead to mental health disturbances are:

- Transitional experiences (change of residence or workplace, achievement of developmental landmarks like puberty and adulthood),
- Interpersonal loss or rejection (of a parent, friend, caregiver, job),
- Environmental stress (overcrowding, noise, disorganization, lack of stimulation, lack of privacy, school and work stress),
- Parenting or social support problems (abuse, neglect, hostility, lack of support),
- Illness or other disabilities (serious acute illness, chronic illness, sensory deficits, difficulty with ambulation, seizures),
- Stigmatization (teasing, taunting, exclusion, being bullied or exploited), and
- Frustration (due to inability to communicate needs and wishes, or lack of choice and decision-making opportunities) (p.168).

Lunskey and Havercamp (1999) explained that persons with intellectual disability may experience an increased risk for psychopathology in the absence of adequate social support. When support is minimal or absent, individuals with disability lack assistance to solve personal and interpersonal problems. This is conspicuous in some persons with intellectual disability and depression, where low levels of social support have been observed.

Negative social interactions have also been associated with depression in persons with intellectual disability. This is a particular concern because persons with intellectual disability are considered more likely to experience negative interactions than are members of the general population. This may be the case, in part, because individuals with intellectual disability often lack sufficient freedom to minimize interactions with those who cause them stress. In

other instances, persons with intellectual disability may have difficulty expressing their desire to be left alone, or difficulty having their expressed desire honoured by others.

In his book *Becoming Human*, Jean Vanier (1998) stated that “I have come to the conclusion that those with intellectual disabilities are among the most oppressed and excluded people in the world” (p.72). Robert Edgerton (1967), using the language of his time, wrote that “persons cannot both believe that they are mentally retarded and still maintain their self-esteem” (p.207). These, then, are the broad social and psychological conditions that predispose an inordinate number of people with intellectual disability to experience pain and loneliness, and depression and desperation.

Though the application of progressive ideologies such as normalization and inclusive education have improved the quality of life of many persons with intellectual disability, investigators have still found that persons with intellectual disability in community settings often lack real connectedness to their communities, and are not uncommonly lonely and socially isolated (Lord & Pedlar, 1991; Schalock & Lilley, 1986). Schwartz (1994) claimed that there are persons with intellectual disability who live their entire lives without a single friend, surrounded only by paid care-providers, who in community settings, are more likely than not to leave their jobs after a year's time. Such can be the imposed consequences of living with intellectual disability consequences that can incite the symptomatic expression of unmet mental health needs.

ASSESSMENT OF PSYCHIATRIC DISORDERS IN PERSONS WITH INTELLECTUAL DISABILITY

Assessing for the presence of psychiatric disorders in persons with intellectual disability can be difficult, and can produce controvertible results, particularly in those with severe disability. Rush and Frances (2000) indicated that it is not possible to confidently make specific DSM-IV diagnoses in persons with severe intellectual disability, with any degree of reliability, except for Pervasive Developmental Disorder. Pary (1994) agreed that there are problems in diagnosing psychotic disorders in individuals with an IQ below 50, and that diagnoses of Schizophrenia and Schizoaffective Disorder are always questionable. The reliance of psychiatric diagnoses on first hand reports of subjective symptoms and the inability of persons with severe intellectual disability to report symptoms create difficulty in properly diagnosing in this population. Luckasson et al. (1992) emphasized the

importance of utilizing multiple sources of information to diagnose mental health disturbances in persons with intellectual disability. Adjunct informants, along with client, family and staff interviews, behaviour observations in typical environments, formal diagnostic instruments, and medical and biological evaluations, including medication and side effects evaluations, increase the likelihood of accurate assessments.

Though there currently are formal diagnostic instruments designed to assess the presence of psychiatric disturbances in persons with intellectual disability, scale development is still in its infancy (Swiezy et al., 1995). Commonly used instruments are the Psychopathology Instrument for Mentally Retarded Adults (PIMRA), Reiss Screen, Aberrant Behaviour Checklist, Emotional Disorder Rating Scale, Hamilton Depression Scale, and the Diagnostic Assessment for the Severely Handicapped (DASH).

Predictably, complete assessments include descriptions of the circumstances in each person's multiple environments that may produce stress and provoke psychiatric disorders or behaviour problems. While clearly not exclusive to persons with intellectual disability, particular stressors may be more inclined to occur and cause problems because of absent or reduced coping skills.

TREATMENT IMPLICATIONS

In some cases, mental health disturbances may be prevented, resolved or palliated when the individual, family members, and direct care-providers are trained to detect, eliminate or cope with stressors (Holden & Neff, 2000). For example, the deleterious physical and social conditions that are sometimes assigned to persons with intellectual disability can be examined and altered, so that overcrowding is eliminated, or excessive noise is reduced, or choice is provided. Additionally, levels of social support can be intensified when stressors are encountered or anticipated. Furthermore, when equipped with coping strategies, persons with disability may be provided with the means to respond to stressors in an effective manner.

Lunsky and Havercamp (1999) suggested teaching cognitive-behavioural techniques to instill communication and assertiveness skills, so persons with intellectual disability are better prepared to request support and avoid stressful social situations. In order for this approach to be successful, it is important for caregivers and family to be receptive and honour such requests. This includes

willingness to alter personal styles of interaction that may provoke distress in the person with disability.

While there has been a perception that persons with intellectual disability are not responsive to conventional “talking therapies”, individual, family, and group therapies have been used with success to treat persons with intellectual disability and a co-existing mental health disturbance. Group therapy, for instance, has been helpful in teaching social skills such as anger management. Accepted sexual abuse treatments have also been effectively implemented with children and adult victims who have intellectual disability (Mansell, Sobsey, & Moskal, 1998). The key, as it likely is for individuals without disability, is that the therapist must present information in an understandable and meaningful manner.

Rush and Frances (2000) surveyed 48 experts on the psychosocial treatment of persons with intellectual disability and co-existent psychiatric or behaviour problems. They found that environmental management, applied behaviour analysis, and client and family education (teaching about psychosocial problems and management) were the most highly recommended forms of intervention. These approaches were recommended for adults, children, and adolescents, across the complete range of intellectual disability and psychiatric or behavioural disturbances. Other approaches were considered to have substantial value for persons with certain levels of intellectual functioning, experiencing particular psychiatric problems. For instance, cognitive-behavioural therapy and classical behavioural therapy (e.g. systematic desensitization) were considered to be helpful for persons with mild or moderate intellectual disability and anxiety.

Views on the use of psychotropic medications to treat persons with intellectual disability are invariably evaluated against a dark and imperious historical backdrop. The improper use of medications to subdue or mitigate the behaviour of individuals in large, congregate, and offensive conditions has been described in the literature. For example, Wolfensberger, in a synopsis prepared by O'Brien (1994), maintained that psychotropic medications have often been used in substandard environments to suppress the behaviour of socially devalued people for the convenience of staff members. Gardner (cited in Thomas, 1994) found that an excessive number of participants in his review of persons with dual diagnoses in institutional settings, received pharmacotherapy as their major form of treatment for

psychological symptoms. He also found that in a significant number of cases, participants did not have a diagnosis that justified the use of pharmacological intervention as the primary or sole form of therapy.

Rush and Frances (2000) emphasized that psychotropic medication prescription should be a product of a well-conceived psychiatric diagnosis, or, in the absence of a clear diagnosis, a specific behavioural-pharmacological hypothesis. The diagnosis or hypothesis, with resulting pharmacotherapy, must follow a thorough assessment process, and efforts to intervene in the least intrusive and most positive manner possible. Rush and Frances explained, however, that there are occasions when medication may represent the least intrusive and most positive option, and that medication is appropriate at the onset, for persons with intellectual disability and psychotic, bipolar, and major depressive disorders.

In the event that pharmacotherapy is established, direct-care staff members should be educated about the effects and side effects of prescribed medications, so that specific objective observations can be recorded and reported (Thomas, 1994). It is important to keep in mind, however, that drug therapy is not an exclusive form of treatment.

Cameron et al (2000-01) indicated that psychiatric hospitalization may be required for some individuals with urgent mental health care needs. They stressed, however, that criteria for hospitalization should not be developed during the actual crisis, but should be established by habilitation team members in consultation with the family, long before such intervention is required. Writing about residential treatment centres for persons with intellectual disability, Cameron et al. suggested that the following factors might contribute to a decision to seek psychiatric hospitalization for a client with major depression:

- Precipitous or significant loss of body weight,
- Medical nonadherence (e.g., refusal to accept medications),
- Excessive necessity for physical or mechanical restraint,
- Disproportionate use of staff resources in order to protect the individual from harming themselves or others, and
- The inability to protect the individual from

harming themselves or others (p.8).

In their description of indications for psychiatric hospitalization, Rush and Frances (2000) listed: risk of suicide; risk of self-injury or harm to others; and, existence of acute psychotic symptoms. What needs elaboration in this context, though, are perspectives on “risk” and “acute psychotic symptoms”, to develop an understanding sufficient to permit decisions that are in the best interests of the person in distress.

With a growing body of research invested in understanding the genetic causes of intellectual disability and their characteristic and behavioural phenotypes, etiology-based consideration may gain momentum as treatment responses for some persons with intellectual disability are identified. For example, because findings appear to indicate that children with Down syndrome generally demonstrate greater visual processing skills than auditory processing skills, interventions that permit individuals with Down's to use these greater skills can be facilitative. Similarly, because persons with Williams syndrome are often observed to be sensitive and sociable, group-based therapies may be effective, perhaps more than for persons with Fragile X syndrome, who are often observed to experience anxiety in social situations (Hodapp & Dykens, 2001).

While the explication of characteristic and behavioural phenotypes is a promising area of ongoing research, a potential danger is that some treatment providers may apply an intervention formula to all members of a particular category (i.e., related disorder) of disability, without recognizing individual variations. Though knowledge of the commonly-expressed characteristics found in persons with a particular disorder can be an important adjunct to service provision and intervention, it should not substitute for knowledge about each individual who has the disorder.

CONCLUSIONS

There is broad agreement that mental health disturbances occur at an overall rate that is noticeably higher for persons with intellectual disability than for other persons in the general population. High prevalence appears to be largely a function of exposure to stressful conditions, in combination with comparatively few, effective coping strategies. It remains evident, however, that for a complexity of reasons, individuals who have intellectual disability and a psychiatric disorder, or other mental health disturbance, are less likely to

receive treatment from mental health service providers than are other members of the general population.

If accurate identification and appropriate treatment of psychiatric disorders and other mental health disturbances in the population of persons with intellectual disability are to occur, it appears that at least the following conditions must be met by members of the total service provision community (intellectual disability and mental health services):

- Acknowledgment that persons with intellectual disability also experience psychiatric disorders and other mental health disturbances,
- Awareness of conditions that place individuals at risk for the development of mental health disturbances, and in particular, those that may be potentiated because of intellectual disability,
- Knowledge of variations in the manner with which individuals may express mental health disturbances within their unique circumstances, when they also have some degree of intellectual disability,
- Willingness to include persons with intellectual disability in therapeutic processes, and
- Understanding of humane treatment approaches that can be applied to ameliorate mental health disturbances and address the individual's spectrum of needs, in the least restrictive and most positive manner possible.

It is worth re-emphasizing that appropriate treatment involves a comprehensive approach that goes beyond the simple administration of medications or the therapeutic application of certain principles of behaviour. Appropriate treatment includes education for the individual, family members, and direct care-providers about mental health disturbances and approaches to helping, and it includes access to consultation and support services as required. An appropriate, comprehensive treatment approach is also attentive to each individual's range of psychosocial needs, and is suffused with concern for the dignity of that individual (Cameron et al., 2000-01). This kind of approach recognizes the healing value of human relationships, and the importance of the individual, family, and direct care-provider in achieving desired outcomes.

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Author Information

John H Simpson, R.Psych.N., M.Ed.

Assistant Professor, School of Health Studies, Brandon University