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The Clinical Profiles of Women with Intellectual Disabilities and Affective or Adjustment Disorder Utilizing Mental Health Services

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Abstract

Women with disability often express the same psychological needs as their non-disabled peers: a need for autonomy and self-determination, belonging, being in an intimate relationship, getting married, having children, or holding a job. Expression and fulfillment of these needs is at best difficult for someone with an intellectual disability and becomes even more difficult if there are other complicating factors present such as dependency, anxiety, or self-esteem issues. This report presents a review of referrals to a specialized dual diagnosis[1] program for women with mild levels of intellectual disability whose maladaptive behaviours could best be conceptualized as stemming from care providers' inadequate understanding and support of their psychological and emotional needs. The challenges of supporting women who present with complex psychological, emotional, and interpersonal needs, and the implications for staff training and staff support are discussed.

While women with an intellectual disability express the same emotional and psychological needs as their non-disabled peers, including the need for autonomy, self-determination, intimate relationships, or well paying jobs, fulfillment of these needs is very difficult and often impossible (Bradley, Lunsky, & Korrosny, 2006; Walsh, 2002; Thomas 1999). Women with mild levels of intellectual disability often use non-disabled individuals for social comparison, especially siblings, relatives, or acquaintances. The negative effect of such social comparisons as well as family and cultural expectations often result in low self-esteem (Dagnan & Sandhu, 1999; MacMahon & Jahoda, 2008). Failure to meet social expectations, particularly with regard to gender role, has been identified as a psychosocial risk factor for developing mental health problems (Lunsky & Havercamp, 2002). Other risk factors include poor social support (Lunsky & Benson, 1999) and limited coping skills (Lunsky, 2003).

1 A dual diagnosis refers to the presence of mental health needs in a person with a developmental disability. Mental health needs include diagnosed mental illness or symptoms consistent with a mental illness (Ministry of Health and Long-Term Care and Ministry of Community and Social Services, 2008). Reported prevalence of mental health issues in adults with intellectual disabilities ranges from 7 to 97% depending on the study,the diagnostic definitions and the methodology used. A recent population-based study reported 40.9% point-prevalence of mental health issues among adults with ID when including problem behaviours, and 22.4% when problem behaviours were excluded (Cooper et al., 2007).

Women with intellectual disabilities are a very vulnerable group, often with complex personal histories that put them at increased risk for mental health issues. These histories may include the experience of early separation from family of origin through institutionalization or foster care arrangement, loss of a parent to death or divorce, or, very significantly, abuse.

While both men and women with intellectual disabilities are more likely to be abused physically, emotionally, and sexually than the general population (Horner-Johnson & Drum, 2006; Nettelbeck & Wilson, 2002), women are at even greater risk for sexual victimization (Furey, 1994; Lunsky, et al. 2009; Sobsey & Doe, 1991; Walsh & Murphy, 2002). Abuse has been found to correlate with a number of psychiatric problems (Lunsky & Canrinus, 2005; Sequeira, Howlin, & Hollins, 2003) including dissociative states and post-traumatic stress disorder (Ryan, 1994), and suicidality (Walters, Barrett, Knapp, & Borden, 1995; Lunsky, 2004).

Emotional and psychological difficulties may present in individuals with intellectual disabilities in the form of challenging behaviours which typically include physical aggression, destructiveness, self-harm, and inappropriate social behaviours (Allen, & Davies, 2007; Royal College of Psychiatrists, 2001). Emergency psychiatric services may be sought, at times repeatedly, either by the person with ID themselves or their caregiver (Lunsky & Gracey, 2009).

It is generally recognized that many individuals with mild levels of intellectual disability can be adequately served by generic mental health services and should be accessing those rather than specialized dual diagnosis services. Experts in women's mental health have also proposed that, similar to women in the general population, women with mild intellectual disability who experience psychological difficulties should be served by gender-sensitive mental health services because of their distinctive needs and the role of physiological, psychological and social concomitants in mental health issues (Kohen, 2004).

The purpose of the present study was to review the clinical profiles of women with mild or high moderate level of intellectual disability and concurrent diagnosis of anxiety, mood and adjustment disorders/reactions to learn more about the reasons and circumstances for seeking services from a specialized dual diagnosis service.

Method

The study sample was drawn from the referrals to the Dual Diagnosis Program at the Centre for Addiction and Mental Health, Toronto, Canada, between 2000–2006. This specialized tertiary care program provides interdisciplinary outpatient assessments, consultations, and time limited interventions, as well as inpatient services, to adults (age 16 and above) with intellectual disabilities and mental health issues including challenging behaviours.

A review of the referrals indicated that over one third (132/355) of all the clients referred to the Dual Diagnosis Program between 2000 and 2006 were women. Fifty one (39%) of these women received extensive interdisciplinary consultation, which in some cases included an inpatient admission (29%; 15/51).

Almost half (24/51) of the women receiving extensive consultation had a mild-to-high moderate intellectual disability (ID). After excluding women diagnosed with a psychotic spectrum disorder or an autism spectrum disorder, twelve women were identified as having a mild level of intellectual disability and either a psychiatric diagnosis of depression, anxiety disorder or adjustment reaction. It is these 12 women that were the focus of this study and will be described in this paper.

The descriptive information for each woman was obtained through a chart review conducted by the first two authors. The chart review focused on obtaining demographic information, reasons for referral, clinical concerns, current circumstances and history of early significant life events.

Results

As indicated in Table 1, the women that were referred for consultation were relatively young and the majority lived in their parental home. Most were referred for consultation because of behavioural issues, particularly behaviour that was challenging to the caregivers, rather than for the treatment/management of psychiatric

symptoms. At the time of referral, half of the women expressed suicidal ideation or engaged in self harm behaviours (e.g., refusing to eat or take necessary medications, threatening to or attempting to jump in front of a car or train, cutting, overdose). In addition, one third were also presenting with medical/somatic complaints (stomach upset/pain associated with stress, neck and/or lower back pain).

A review of background information (Table 2) indicated that almost half of the women sought, or were brought by their care providers to emergency services (Emergency Room/ER) for emotional and or behavioural disturbance in the 3 months preceding the referral and some did so more than once.

One third of the women had substance use problems. Almost half, 42%, experienced recent changes with regard to their residence. The majority of the women did not attend any day programming primarily due to the lack of opportunity (58%) but in some cases because of refusal (25%). Many of the women experienced disruptive, often traumatic, events during their childhood/adolescence. Forty two percent were placed as children in institutions or foster homes and 34% experienced parental divorce. More than half of the women had a history of sexual abuse and almost half had experienced physical abuse.

The following three case vignettes will serve as an illustration of the type of specific concerns that prompted the referral for consultation as well as the clinical/diagnostic formulation and recommendations.

Case Vignettes

Case A. Mid-40s, returned to live with her parents after residing in a group home for 10 years. No day programming or peer contact as parents were restricting her social activities because of concerns about her developing intimate relationships. AA started to exhibit defiant and aggressive behaviour at home, regressed in her adaptive skills and became increasingly dependent on her mother (e.g., wanted to be washed, assisted in toileting). Her mood became depressed. Referral was made for consultation and inpatient admission to review psychiatric diagnosis and medications. The following diagnostic formulation was developed following inpatient assessment: (a) there was no psychiatric illness present, (b) she presented with issues related to dependency and autonomy as her goals for intimacy, relationships, and self-determination were being frustrated by her family. Psychotropic medications were discontinued; inpatient treat-

Table 1. Women With Mild ID and Anxiety, Depression, and Adjustment Issues (N = 12)

Average age:	32 (range: 17–46)
Residence*	
Family or own home	67% (8)
Group home	33% (4)
* *at referral 4 individuals were in a general hospital*	
Primary reason for referral	
Challenging behaviour/ aggression	75% (9)
Psychiatric Symptoms/ decompensation	25% (3)
Suicidal Ideation/Self-harm	50% (6)
Medical complaints	33% (4)

Table 2. Background variables (N = 12)

Visited ER in last 3 months	42% (5)
Current Substance Use	33% (4)
Recent changes in residence (in most cases within 3 months; in one case 8 months prior to admission)	42% (5)
Vocational/day programming	
Attending	17% (2)
Available but refusing	25% (3)
No programming	58% (7)
Early Significant Life Events	
Placement in foster care/ institution	42% (5)
Parental divorce	34% (4)
History of physical abuse	42% (5)
History of sexual abuse	58% (7)

ment focused on psychosocial interventions through Day Treatment Program. Discharge recommendations included placement in a group home residence, provision of day programming, and increasing opportunities for peer contact and skill development, including social and relationship skills as well as Adult Daily Living and Community Living skills.

Case B. Early 40s, with a history of becoming attached to staff and reacting with aggression to staff leaving. Recently moved to a self-contained basement apartment in a group home with only half a day of outside programming a week. She was spending days alone with very limited contact with staff and was noted to be envious of staff attention given to "higher" needs residents. At the time of referral, she was displaying severe disruptive and unsafe behaviours including screaming, uttering verbal threats, throwing objects, hitting/kicking others, and self-injurious behaviours. On one occasion, she had disrobed in public. Behavioural interventions which made contact with staff contingent on not displaying problem behaviours were ineffective. The diagnostic formulation stressed significant attachment issues and limited adaptive coping skills and the absence of psychiatric diagnosis. Discharge recommendations included training staff in how to interact and support her in distress, increasing day programming and social interactions, and the scheduling of positive events.

Case C. Mid-30s, recently moved to a group home with lower functioning residents after a successful year-long transitional placement out of her family home. She had lost her father as a child and had a long history of anxiety and depression. She had attended a regular community college program but failed the first year. She wanted a well paying job like her sister, and a boyfriend. She was referred for consultation because of increased dependency on staff (refusal to travel independently), refusal to attend programs, regressive behaviours, and accessing emergency services (calling 911 and going to Emergency Departments of local hospitals). She was complaining about staff and was very unhappy when her boyfriend was not allowed to stay overnight. The diagnostic formulation encompassed depression with psychotic features and focused on emotional vulnerability, poor distress tolerance, and emotional regulation skills. The discharge recommendations included psychotropic medication, staff training in developing awareness of psychological vulnerabilities, changing style of interacting, and utilizing basic Cognitive Behaviour Therapy (CBT) strategies to assist in emotional modulation/control.

Summary and Discussion

The purpose of this chart review study was to gain a better understanding of the reasons why consultation was sought from a specialized dual diagnosis program for higher functioning women with intellectual disability and emotional concerns—women who should be expected to receive services from generic mental health services. The results of this preliminary study indicate certain similarities among the twelve women identified as having the diagnosis of depression, anxiety, or adjustment reaction. In the majority of the cases, the referral was prompted by significant behavioural disturbance. Challenging behaviours included physical and verbal aggression, functional regression, non-compliance, and self-harm. These behavioural difficulties developed or intensified following a significant change in either the living arrangements (residence) or support system (such as frequent turn over of staff with resulting termination of important relationships and inconsistencies with support). In addition, frustration of important psychological needs, such as desire for intimate relationship, social contact, or self-determination, was prominent.

Prominence of challenging behaviours as the reason for referral suggests that caregivers may not have recognized the presence, or importance, of significant emotional distress until the presentation became more behavioural or externalizing in nature. Neither suicidal ideation nor self harm behaviours, although present, led to referral. This very concerning finding parallels those of other studies that reported that caregivers tended to miss depressive symptoms (Bramston, Fogarty, & Cummins, 1999; Moss, Prosser, Ibbotson, & Goldberg, 1996) or were unaware of suicidal ideation (Lunsky, 2004) in adults with intellectual disability.

A significant proportion of the women in this study had a history of trauma that included sexual and physical abuse, and early loss or separation from their family of origin. At the time of referral, one third of the women were experienc-

ing significant physical symptoms typically associated with stress and anxiety and were using substances. Many used emergency services prior to referral and four were hospitalized in acute care psychiatric units at the time of the referral. It was clear that these women were experiencing significant emotional distress and exhibited limited coping and poor distress tolerance skills. In addition, the overwhelming majority of the women was not involved in any vocational or day program activities and was likely socially isolated or had very limited social outlets.

The caregivers, in their focus on disturbing maladaptive behaviours, appeared to either miss or fail to address the underlying emotional distress and the reasons for it. Instead, their response to maladaptive behaviours often involved labeling them as "manipulative/stubborn" and imposing increased restrictions in response, thus further eroding the individual's sense of self-determination.

What are the implications of these preliminary insights for provision of services for women with mild levels of intellectual disability exhibiting emotional disturbance? First, the findings have important implications for diagnosis and treatment as they highlight the importance of shifting focus from the challenging behaviours to the underlying emotional and psychiatric difficulties and developing appropriate intervention strategies that might involve a combination of pharmacological, environmental, interpersonal and therapeutic approaches, in addition to behavioural management strategies. Given the high rates of abuse in this population, consideration should be given to the possibility that the problem behaviours relate to a history of abuse and neglect, and re-formulated as such (Peckham, 2007). Second, it is important to recognize and address caregivers/support staff needs in supporting women with mild intellectual disabilities. Specifically, this should involve developing awareness of emotional and psychological needs of women with intellectual disabilities vis-à-vis non-disabled peers/age appropriate social networks, training in adopting an interaction style that promotes teaching and developing emotional coping skills, and providing staff with access to clinical supervision to assist with resolving counter-transference issues/reactions to prevent a "system burn out" with some individuals. This is particularly important given that negative interpersonal relations are a major source of stress for people with mild intellectual disability (Hartley & MacLean, 2005). Third, it is important to recognize the significant role social networks and supports play in women's mental health and to foster the development and maintenance of such supports. And last, it is important to advocate for access to gender-sensitive generic mental health services. For many women, understanding of their behaviour as an attempt to ensure some measure of mastery, control, connectedness, and affiliation in the face of helplessness and vulnerability might offer a more helpful approach than viewing it from the perspective of their symptoms or psychopathology.

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