

Knowledge Notes
Developmental Disabilities Co-occurring with Mental Illness
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January 2013

Objective

To provide a snapshot of current knowledge related to developmental disabilities co-occurring with mental illness.

Background

The co-occurrence of mental illness in persons with developmental disabilities (PDD), also known as developmental disabilities (DD), as intellectual disabilities (ID) or more pejoratively as mental retardation (MR), is not well understood. According to the National Association for the Dually Diagnosed NADD (n.d.), **dual diagnosis** is a term applied to the co-occurrence of the symptoms of both PDD and mental illness. It is important to note that the term dual diagnosis is not used exclusively to identify the co-occurrence of PDD and mental illness. The overarching term dual diagnosis or co-morbidity is a generic term referring to the co-occurrence of disorders suffered by an individual (Telias, 2001). An alternate example of a dual diagnosis refers to the co-occurrence of substance abuse disorders and mental illness.

Individuals identified as PDD experience difficulty functioning and adapting. Functionality is evaluated by an IQ score of 70 or below and adaptability by skill mastery in areas such as eating, dressing, communicating, socializing, and assuming responsibility (American Psychiatric Association, 2000). PDD can be mild, moderate, or severe. Two key issues facing the dually diagnosed and those who care for them include a high prevalence of mental illness and a perceived lack of services.

Key Issues*1. High Prevalence of Mental Illness*

Adults with intellectual disabilities can experience mental illness at a prevalence rate of 40.9%, 3 to 4 times greater than the general population (Cooper, Smiley, Morrison, Williamson & Allan, 2007). When admitted to psychiatric units, their problems can be more severe and they can receive more interventions than individuals without developmental disabilities (Chaplin, 2011). They may spend more days in hospital (Bouras, Martin, Leese, Vanstraelen, Holt et al, 2004; Morgan et al, 2008; Saeed, Ouellette-Kuntz, Stuart & Burge, 2003). The majority are likely to be subjected to chemical restraint (Webber, McVilly & Chan, 2011).

In Canada estimates suggest that 380,000 Canadians (Yu & Atkinson 1993, republished in 2006) and between 6,000 and 13,000 Albertans live with a dual diagnosis (Hughson, 2009). About forty-two percent of all hospitalizations among PDD Canadians occurred for psychiatric conditions (Lunsky & Balogh, 2010). Canadians with PDD are at fifteen times higher risk of

receiving a psychiatric admission of schizophrenia (Balogh, Brownell, Ouellette-Kuntz et al. 2010) and this risk is also 3 to 4 times greater than the general population (Morgan, Leonard, Bourke & Jablensky, 2008). Further, PDD Canadians are at 4 to 5 times higher risk of experiencing dementia and at nearly 3 times higher risk of being depressed than non PDD individuals (Shooshtari, Martens, Burchill, et al. 2011). Fourteen percent of PDD participants in an Australian study had an incapacitating anxiety disorder (White, Chant, Edwards, Townsend, Waghorn, 2005). The high prevalence rate of developmental disabilities co-occurring with mental illness is further influenced by traumatic events, challenging behaviors and assessment issues.

Traumatic events Adults whose intellectual disability is mild or moderate, rather than severe, may not have greater prevalence rates than the general population (Whittaker & Read, 2006). However, traumatic events can also play an important role in their psychopathology. In one study, 75% of participants with mild to moderate intellectual disabilities had all experienced at least 1 traumatic event during their life span, predisposing them to significantly increased odds of a mental disorder (Martorell et al, 2009).

Challenging behaviors Challenging behaviors, although not listed as DSM-IV-TR psychiatric diagnosis, have consistently been identified as a reason for admission to hospital (Cooper et al 2007; Cooper, Smiley, Allan, Jackson, Finlayson et al, 2009; Cooper, Smiley, Jackson, Finlayson, Allan et al, 2009; Whittaker & Read, 2006). Challenging or problem behaviors such as aggression, self-injury, and destructive, disruptive, or non-compliant behaviors often precipitate hospitalization (Lowe, Allen, Jones, Brophy, Moore & James, 2007). However, while challenging behaviors coexist in some people with intellectual disability, disturbances in psychiatric functioning are not believed to underpin the majority of these behaviors (Allen & Davies, 2007).

Assessment issues Assessing mental illness among persons with intellectual disabilities is not straightforward. Limited training is available to professionals (Quintero & Flick, 2010). In turn, mental illness may go undetected in PDD. Many diagnostic criteria include self reports of thoughts, feelings, physiologic states, past events and reactions to these events. This requires a level of language discrimination and memory skills that may not be present in adults with intellectual disabilities (Bouras & Holt, 2007). Diagnostic overshadowing, or ignoring mental health problems because the symptoms are judged to be “just” part of the developmental disability, can occur (Reiss & Szyszko, 1983). The social isolation often accompanying PDD can leave individuals with distorted perceptions of whether what they are experiencing is ‘normal’ (Silka & Hauser, 1997). Hospital emergency department staff reported a lack of knowledge related to intellectual disabilities (Lunsky, Gracey, & Gelfand, 2008) and paid carers need training in the early detection and warning signs of mental ill health (Smiley, Cooper, Finlayson, Jackson, Allan et al, 2007). Canadian online resources such as the text: *Introduction to the Mental Health Needs of Persons with Developmental Disabilities* (Griffiths, Stavrakaki & Summers, 2002), and the guidelines: *Planning Guidelines for Mental Health and Addiction Services for Children, Youth and Adults with Developmental Disability* (BC Ministry of Health, 2007 March) begin to offer important direction.

2. *Perceived Service Gaps*

Deficiencies In a national survey examining the range of mental health services available to individuals with a dual diagnosis and perceived service gaps across Canada, respondents identified that generic mental health providers were poorly equipped to meet the needs of these individuals, that waitlists for specialized services were typically 4 months or longer and less than half of the respondents reported that expertise or specialized services existed in inpatient treatment or emergency room facilities (Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007). Aggression/challenging behavior was identified as the main reason for admission to and barrier to discharge from hospital (Lunsky & Puddicombe, 2005, December). An inability to access appropriate mental health services in a timely manner leads to crises resulting in hospital emergency room visits, warranting intervention to correct the deficiencies at both the clinical and systems levels (Lunsky, Gracey, & Gelfand, 2008).

Beyond medication Researchers continue to question the efficacy of psychotropic medication treatments for individuals with intellectual deficits who present with challenging behaviors (Antonacci, Manuel & Davis; Benson & Brooks, 2008; Tyrer et al, 2008) and yet, as many as half of the adults in this population have been prescribed psychotropic medication (Lunsky, Emery, & Benson, 2002). They may not believe they have either choice or involvement in their medication regime (Crossley & Withers, 2009). Services that include but are not limited to prescribing medication are needed.

Conclusions

In summary, the co-occurrence of developmental disability and mental illness is termed dual diagnosis. Persons with developmental disabilities experience a high prevalence of mental illness, particularly schizophrenia, dementia, depression, and incapacitating anxiety; as many as 75% of them can be expected to suffer a traumatic event during their lifetime. Challenging behaviors, including aggression and self-injury rather than DSM diagnostic criteria, often precipitate their admissions to psychiatric units. Assessment is complex; professionals may have limited training and treatment may seem focused on psychotropic medications, leaving dually diagnosed individuals and those who care for them with the perception that existing services are deficient.

Recommendations to remediate these deficits are not clear cut. Given the high prevalence of hospital admissions among this group, health professionals can expect to encounter individuals dually diagnosed with PDD and mental illness. Increased funding for research and increased training for health professionals will begin to help. Educational opportunities where family members and paid carers can learn about managing mental illness and strategies they can implement to deescalate challenging behaviors will also begin to help. Creating these opportunities is both a challenge and opportunity to support and advocate for these vulnerable individuals.

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