

Dual Diagnosis and Access to Services

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Abstract

Persons with a dual diagnosis have a complex spectrum of needs, including mental health needs that are not currently met with existing first-line and intensive services. The present study looks at the areas of concern that parental caregivers have in regard to accessing services for their adult children with a dual diagnosis. A number of issues that affect the ability to meet the health needs of persons with a dual diagnosis were identified by the caregivers. Their experiences point to a need for: 1) maintenance of open communication between both health and social service providers, and the clients with a dual diagnosis and their families; and 2) improvement in the availability and accessibility of services, including emergency psychiatric services for handling crisis situations, and programs beyond school age. Greater awareness of dual diagnosis among the public at large and better support for caregivers are also needed.

Background

An estimated 85,000 persons in Ontario have a dual diagnosis (Bradley & Summers, 1999) of a developmental disability and a concurrent emotional, behavioural, or psychiatric problem/illness. Often, persons with a dual diagnosis have a complex spectrum of needs, and require services from both the developmental and mental health sectors. The "Making it Happen" document (Ontario Ministry of Health, 1999) acknowledged that some individuals have needs that cannot be adequately met with existing first-line and intensive services, and identified individuals with a dual diagnosis as a target population to consider for mental health reform. In order to improve mental health services for clients with a dual diagnosis, it is important to identify and consider the context in which barriers to accessing services exist, and the impact these barriers have on the experiences of persons with

a dual diagnosis and their families. The aim of this study is to identify areas of concerns that parental caregivers have in regard to accessing services for their adult children with a dual diagnosis.

Method

This qualitative study involved seven in-depth, one-on-one interviews with parents of adults with a dual diagnosis. Informants for the study were recruited through the Dual Diagnosis Program at the Centre for Addiction and Mental Health, and Surrey Place Centre. Each participant completed a semi-structured interview, either in person (n=1) or over the telephone (n=6). The interview covered background information on the informant's family and the family member with a dual diagnosis, experiences with the healthcare system leading up to diagnosis, experiences in follow-up care, current services and supports, and areas for improvement. The informant population consisted of 6 female caregivers and 1 male caregiver. Four of the caregivers had their children living at home at the time of the interview. The age range of the family members with a dual diagnosis was 21 to 40 years of age. Psychiatric diagnoses were depression (n=1), schizophrenia (n=2), obsessive-compulsive disorder (n=3), and multiple diagnoses (n=1).

Results and Discussion

A number of issues that affect the ability to meet the health needs of persons with a dual diagnosis were identified by caregivers. These issues were: communication with the client with a dual diagnosis and with the family, availability and accessibility of services, availability of professional assistance during a crisis situation, and caregiver support and respite services.

Communication with the client and the family

Caregivers' concerns regarding communication with service providers can be broadly divided into two main areas, namely, the lack of communication and explanation of the diagnosis to the family, and parental concerns about their children's ability to communicate their needs to service providers. Two of the caregivers indicated that clinicians did not take the time to explain their child's diagnosis to them, although other caregivers felt that the diagnosis was adequately explained.

Availability and accessibility of services

A key area of concern for the caregivers was the availability and accessibility of services. All caregivers reported challenges in accessing services. One caregiver described the process of accessing services as being "like pulling teeth." The challenges included difficulties in finding the appropriate service providers ("I found it difficult to find anybody who could help"), and long waiting times of upwards of one year for programs. Some caregivers also felt that their children's concerns were not given appropriate or adequate attention by service providers. Caregivers also reported a lack of programs available to their children beyond school age.

Availability of professional assistance during a crisis situation

Six of the seven caregivers reported crisis situations involving their children with a dual diagnosis. Two of the caregivers sought help from emergency/crisis services at these times. One of the caregivers reported that the crisis centres she contacted did not answer her calls. The other caregiver was asked to bring her child into the emergency room on her own. One caregiver who did not contact a crisis centre indicated that she believed that the services would not be timely enough to help her family during a crisis. Three of the caregivers contacted the police for help. Often, the choice for parents was between calling the police and handling the crisis with resources within the family, or with the help of neighbours and/or friends. Some parents expressed concerns that having the police involved and potentially having their child with a dual diagnosis arrested would not be in the best interests of their child.

Caregiver support and respite services

Respite services were not readily available and funding from Special Services may not cover sufficient number of hours of respite. One caregiver reported decreasing amounts of financial support despite the same level of need. Some caregivers also indicated that they experienced indifference and little help from their extended families and the community at large. The need for support for caregivers was emphasized by many of the caregivers. As one caregiver offered, the "greatest help is to help the caregiver."

Conclusions and Future Directions

This study highlights some parental concerns in the areas of communication, accessibility and availability of services, and caregiver support. Both health and social service providers need to maintain open communication with clients and their families, and to explain the diagnosis to the parents/families. The accessibility and availability of services need to be improved. Families require help in navigating the system. An agency that can act as a central source of information may be helpful in this regard. Emergency psychiatric services for handling crisis situations at home are needed. Finally, there is a need for awareness of dual diagnosis among the public at large, and better support for caregivers.

References

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