

Review of Admissions of Individuals with Autism Spectrum Disorders to a Specialized Dual Diagnosis Program

Abstract

Little research has been conducted on adults with autism spectrum disorder (ASD), a co-occurring psychiatric disorder, and an intellectual disability (ID). The purpose of the current study was to review the characteristics of adults with ASD who are admitted to a specialized Dual Diagnosis Program at the Centre for Addiction and Mental Health (CAMH). The study involved an in-depth chart review of all clients in both the outpatient and inpatient services from 1999 to 2005 with diagnoses of an ASD, a mental health concern, and an ID. Our sample of clients included 20 clients who accessed only the outpatient clinic for consultation purposes and 20 who were seen as inpatients. This paper describes the characteristics of these clients and compares the outpatient and inpatient groups. Significantly more inpatient than outpatient clients received the diagnosis of Autistic Disorder as compared to other ASD diagnoses (e.g., Asperger Disorder). The three most common co-occurring diagnoses across these clients were a mood disorder (30% for both groups), an anxiety disorder (30% for consultation group and 10% for inpatient group), and schizophrenia or psychosis (15% for consultation group and 35% for inpatient group). The most common primary reasons for referral to the clinic for both groups were challenging behaviour (45% for consultation group and 30% for inpatient group) and threat/danger to others (20% for consultation group and 35% for inpatient group). Significantly more inpatient clients (45%) than consultation clients (5%) were referred by other departments at CAMH. Thirty-eight percent of the clients had their Axis 1 diagnosis changed from intake to exit. Further findings highlighting demographic and psychiatric characteristics of this population are discussed in light of better understanding this complex group.

Autism spectrum disorder¹ (ASD) is a commonly used term that encompasses three of the pervasive developmental disorders outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR): Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (Allen, 1988; American Psychiatric Association [APA], 2000; Wing, 1996; Wing & Gould, 1979). Recent research suggests that 1 in 165 to as many as 1 in 110 people have ASD

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1 ASDs are characterized by impairments in social interaction and communication, and are associated with a narrow range of repetitive interests or activities.

(Centre for Disease Control and Prevention, 2009; Fombonne, 2005; Tidmarsh & Volkmar, 2003) with an estimated 70,000 people with ASD living in Ontario (Autism Ontario, 2008). Estimates of the male: female ratio vary from 1.33 to 16 with a mean 4.3 (Fombonne, 2003).

An intellectual disability (ID) is present in about 75% of individuals with ASD (Bradley & Lofchy, 2005) and many have additional behavioural, medical, and mental health problems (APA, 2000; Howlin, 2005; Sverd, Sheth, Fuss, & Levine, 1995). The term “dual diagnosis” is often used in Ontario to describe individuals who have both an ID and mental health problems that may include very challenging behaviour in the absence of a diagnosable psychiatric illness (Griffiths, Stavrakaki, & Summers, 2002; Lohrer, Greene, Browning, & Lesser, 2002). Adults with IDs are three to four times more likely to have a mental illness as compared to other adults (Lunsky & Puddicombe, 2005). Moreover, both behavioural challenges and mental health problems commonly co-occur in ASD with 6% to 57% of patients with PDD requiring inpatient treatment (Saulnier & Volkmar, 2007; Sverd et al., 1995). Therefore, many individuals with ASD are considered as having a dual diagnosis.

In particular, individuals with ASDs, especially those with lower cognitive ability, are at increased risk for developing behavioural problems, such as aggression, and self-injurious behaviour (Horner, Carr, Strain, Todd, & Reed, 2002). This behaviour, in addition to the characteristic restricted and repetitive behaviour associated with this population, can further interfere with learning and social interaction opportunities (Perry & Condillac, 2003). An Ontario-based study found that adolescents and young adults with ASDs and IDs exhibited more difficult behaviour, such as eating disorders, sleep disorders, poor impulse control, and elimination disorders than did an ID only control group (Bradley, Summers, Wood, & Bryson, 2004). These challenges can severely impact both the individual's life (e.g., in terms of social isolation) and the day-to-day activities within the family. Moreover, the difficulty in managing this behaviour on a daily basis can lead to increases in stress levels among caregivers and can often be the major impetus for seeking support from community services. In fact, some researchers assert that behavioural problems represent the

most important reason for residential placement of individuals with ID and ASD (Perry & Black, 1997; Russell & Tanguay, 1981).

The co-occurrence of ASD and mental health concerns ranges from 4% to 58% (Howlin, 2005; Lainhart, 1999; Sverd et al., 1995). Emerging research shows that this population may experience a number of psychiatric symptoms or disorders, such as depression, anxiety, suicidal behavior, schizophrenia, and hyperactivity (Sverd et al., 1995). For instance, Ghaziuddin and his colleagues have studied the co-morbidity of depression and ASD and they found that depression was the most common psychiatric disorder, affecting 2% of a sample of children and adolescents with Autistic Disorder who were referred to a tertiary care clinic (Ghaziuddin, Tsai, & Ghaziuddin, 1992). Another study examined teenagers with ID and autism and found that they had higher rates of episodic psychiatric disorders (47%) than others with ID only (17%; Bradley & Bolton, 2006). In this study, depressive disorder was the most common co-occurring diagnosis in the autism group and the group had significantly longer depressive episodes than the matched ID group.

Despite the fact that ASD is a life-long disorder, a relatively small proportion of publications have focused on adults (Howlin, 2005). Moreover, there is very little research on adults with ASD who also have an ID and a mental health problem (Palucka & Lunsky, 2007). Ghaziuddin and Zafar (2008) reported on a clinical sample of adults who had preliminary diagnoses of ASD. Ten of the original 38 subjects had not been diagnosed accurately and did not have ASD. Of the 28 remaining for whom the diagnosis of ASD was confirmed, 21 had co-occurring psychiatric disorders, the most common of which was depression. However, although these subjects had a variety of other medical difficulties (e.g., seizure disorders), only two subjects were reported as having an ID and half of them had a diagnosis of Asperger's Disorder.

Unfortunately, a lack of awareness of how common a dual diagnosis is within this population often leads to the presence of psychiatric difficulties being missed (Sverd et al., 1995) and individuals not getting appropriate services. The relationship among ID, ASD, and behavioural and psychiatric conditions is complex

and making an accurate diagnosis and supporting these individuals can be difficult. Difficulties in the client's understanding and ability to describe and communicate the symptoms, the ability of caregivers to observe and interpret changes in a client's behaviour, and the misinterpretation of behaviour may lead to inaccurate diagnoses. Moreover, people with ID and mental health problems have complex treatment needs, are harder to rehabilitate and thus, may have longer hospital admissions than those without an ID (Kotak, Noore, Muthiah, Raffique, & Schmidt, 1995). A good understanding of this population is essential for making accurate diagnoses and providing appropriate and effective treatment and mental health supports and services (Chaplin, 2004).

To date, two Ontario-based studies have examined this population (Lunsky, Gracey, & Bradley, 2009; Palucka & Lunsky, 2007). One study documented the clinical characteristics of adult psychiatric patients with ASD and ID and how they compared to individuals with and without ID who were also using hospital based psychiatric services (Lunsky et al., 2009). The most common co-morbid psychiatric diagnosis of the ASD/ID group was psychotic disorder with no individuals in this group receiving an anxiety disorder diagnosis. The ASD/ID group was less likely to have a psychotic disorder diagnosis than those individuals in either the ID or non ID group. However, they spent more days in hospital and were recommended for a higher level of care than the others. The authors concluded that this group of individuals has high clinical needs that are not always well met.

The second study (Palucka & Lunsky, 2007) involved examining the characteristics of adults with ASD who were inpatients in a specialized Dual Diagnosis Program in a tertiary care hospital over a six-year period. They reported demographic characteristics, information on reasons for referral, co-morbid diagnoses, and length of hospitalization. Individuals with ASD constituted one third of all the inpatient admissions to the program; the majority of the clients were male (69%) and about a half were born outside Canada (46%). For 69% of them, the most common ASD diagnosis was Autistic Disorder (69%); 40% had severe ID, and the most prevalent co-morbid psychiatric diagnosis was bipolar mood disorder. Results revealed that serious physical

aggression was the most frequent reason for individuals with ASD seeking services (occurring in 77% of the cases). The remaining reasons included behaviour that was difficult to manage (15%) and risk of self-harm/suicide (8%).

The aim of the present study was to extend the Palucka and Lunsky (2007) research by including a larger sample of clients with ASDs, both individuals using the inpatient service, and others using only the outpatient services within the Dual Diagnosis Program. The main objective was to examine the demographic characteristics, referral reasons and sources, and to study the diagnostic characteristics of this population. By incorporating an outpatient group in addition to an inpatient group, a secondary goal of the study was to understand how individuals referred for the inpatient and outpatient services differ. We hypothesized that the inpatient clients would be more severe in terms of the type of ASD and the number and type of additional psychiatric diagnoses.

Method

This study involved a review of all admissions of clients with ASD to the Dual Diagnosis Program at the Centre for Addiction and Mental Health (CAMH) between October 1999 and January 2005. The Dual Diagnosis Program serves individuals with ID and mental health needs, 16 years and over in the Toronto and Peel regions. The program provides services through two interdisciplinary outpatient teams (one for each region) and an inpatient team. All teams include health care professionals with expertise in psychiatry, psychology, nursing, behaviour therapy, social work, and occupational therapy. The inpatient team, in addition, has a recreation therapist, a developmental worker, a child and youth worker and a nurse educator. The clinical services offered include outpatient assessment, consultation, time-limited treatment, in-home and crisis supports, program recommendations, and inpatient assessment and treatment. The outpatient teams triage clients to the inpatient unit; the exceptions are direct transfers from other hospitals or programs at CAMH, or legally mandated admissions. The inpatient admission is typically recommended if there are unclear diagnostic issues, complex treatment needs, a need for a review of medications (especially in

cases of significant polypharmacy), or challenging behaviour that threatens the breakdown of a community placement or is no longer manageable in the community.

Client files contain a standardized referral intake form which includes client referral source, reason for referral and demographic information. Files also contain final reports and discharge notes, which include information on diagnosis at discharge and discharge setting. Information in these forms and reports is provided by clinicians working in the program as part of standard care. Admission and discharge information of all inpatients and outpatients using our service is compiled in a database.

The first author searched the database to obtain all cases with an ASD diagnosis at admission or discharge ($N = 89$). When there were questions about client characteristics or missing information, the clinicians working with specific clients tried to retrieve the required information. The staff who updated the database was trained by psychologists (second and third authors). Information on demographics, referral reason and source, psychiatric diagnoses, and placement at discharge is presented.

Of the 89 individuals, a significant proportion ($n = 49$) received only outpatient facilitation services (brief interaction that typically involves program recommendations and assisting caregivers with links to other services) and data on them were limited. Of the remaining 40, twenty received in-depth consultation services as outpatients and 20 patients were admitted to the inpatient unit. Hence, for the purposes of this study, the 20 individuals receiving comprehensive outpatient services (OP Group) were compared to the 20 receiving inpatient services (IP Group). Twelve of the individuals in the IP Group were also included in the previous Ontario study (Palucka & Lunskey, 2007).

Results

Characteristics of Clients

The OP Group had a mean age at admission of 25.7 years with a range from 16 to 56 years and was not significantly different from the age of the IP Group that ranged from 17 to 52 years with a

mean age of 31 years. The majority of the clients were male with a ratio of males to females of 3:1 in the OP Group and about 2:1 in the IP Group.

On admission, clients came from a variety of residence types, the most common being group homes (40% for OP Group and 45% for IP Group) and their family homes (35% for both the OP and IP Groups). Other residences included independent settings, boarding homes, supportive housing, short term safe beds, and extended care facilities. No more than one client in each group came from one of these residence types.

Referral Characteristics

The most common referral sources and reasons for referral are presented in Table 1. The OP Group was most often referred by Developmental Services (35%) and by family and friends (20%). The IP Group was also frequently referred by Developmental Services (25%), but was more frequently referred by other departments of CAMH than the OP Group (45% vs. 5%; $\chi^2(1, n = 20) = 8.53, p < 0.01$). This is likely because other parts of the hospital would transfer their inpatients with ASD from more general units to the Dual Diagnosis Program because of the expertise and resources available on the unit. Few individuals in either group were referred from mental health institutions outside CAMH (5% and 10% for the OP and IP groups respectively). Other referral sources included family doctors, community mental health clinics, case managers, residential facilities, and medical hospitals.

The primary reason for referral for both groups was challenging behaviour (45% for the OP Group and 30% for the IP Group), which included behaviour that was difficult to manage, but was not threatening to others. Although the OP Group was referred for clarification of a psychiatric diagnosis more often (20%) than the IP Group (5%) and more individuals in the IP Group were referred because of forensic involvement (20% vs. 5%), these differences were not significant (across all referral reasons, p -values ranged from .151 to .327 for Chi-square tests). Most clients (85%) were referred for more than one reason. When all referral reasons for all clients were collapsed across groups, the two most common reasons for referral were challenging behaviour (58%) and threat/danger to others (46%).

Table 1. Referral Characteristics

Referral Characteristic	OP Group (%)	IP Group (%)
Referral Source		
Developmental Services	35	25
Family/friend	20	5
CAMH	5	45
Mental Health Institution	5	10
Other	35	15
Primary Reason for Referral		
Challenging behaviour	45	30
Threat/danger to others	20	35
Clarification of psychiatric diagnosis	20	5
Criminal Justice Involvement	5	20
Other	10	10

Discharge Information

A change in residence from admission to discharge was uncommon among the OP clients ($n = 2$), although eight IP clients did not return to their original residence after discharge.

The ASD and psychiatric diagnosis (DSM-IV Axis 1 diagnoses) of the clients are presented in Table 2. These diagnoses represent the diagnoses at the time of discharge from the service (as diagnosed by a psychologist and/or psychiatrist). Autistic Disorder was the most common ASD discharge diagnosis overall, although it was far more common in the IP Group than in the OP Group (75% vs. 30% respectively; $\chi^2(1, n = 20) = 8.12, p < 0.01$). At discharge, outpatient clients were more likely to have a less severe form of ASD (35% with PDD-NOS and 15% with "ASD") compared to the IP Group (10%; $\chi^2(1, n = 20) = 7.62, p < 0.01$).

All other Axis I diagnoses were grouped into eight categories as displayed in Table 2. The most common diagnosis overall was a Mood Disorder, occurring in 30% of both groups. Anxiety Disorders were more common in the OP Group (30%), whereas Schizophrenia and other psychotic disorders were more common among the inpatients (35%). Within the OP Group, seven individuals (35%) did not have any psychiatric diagnosis in addition to ASD; similarly in the IP Group six clients (30%) had no other diagnosis. Statistically, no Axis 1 diagnosis other than Autistic Disorder was signifi-

cantly more common in one group compared to the other (p -values ranged from .151 to .327 for Chi-square tests).

Within the Dual Diagnosis Program, diagnostic assessment for autism included a thorough review of all records available including past psychiatric admissions, school records, psychological assessments, obtaining developmental history when possible, direct observation, and psychometric assessment (which could include the Autism Diagnostic Observation Schedule [Lord, Rutter, DiLavore, & Lisi, 1999], the Autism Diagnostic Interview - Revised [Rutter, Le Couteur, & Lord, 2003], the Gilliam Autism Rating Scale [Gilliam, 1995], and the Childhood Autism Rating Scale [Schopler, Reichler, & Renner, 1988], depending on the case). This assessment was conducted by the inpatient or outpatient psychologist. Psychiatric diagnosis was based on a comprehensive review of a client's history, interviews with the patient and care-givers, direct observation, psychological assessment, as well as a good understanding of how the ASD contributed to the presenting concerns. Psychiatric screening tools (e.g., Reiss Screen for Maladaptive Behaviors; Reiss, 1988) and behavioural scales (e.g., Aberrant Behavior Checklist; Aman, Singh, Stewart, & Field, 1985) were also administered, typically to the care-giver within or outside of hospital.

Fifteen individuals, seven OP clients (35%) and eight (40%) IP clients, had changes in their mental health diagnosis from admission to dis-

Table 2. Diagnostic Characteristics

Diagnosis	OP Group (%)	IP Group (%)
ASD Diagnoses		
Autistic Disorder	30	75
PDD NOS	35	10
Asperger Disorder	20	15
ASD or Autistic Features	15	0
Psychiatric Diagnoses^a		
Mood Disorder ^b	30	30
Anxiety Disorder ^c	30	10
Schizophrenia/Psychotic Disorder ^d	15	35
Behaviour Disorder ^e	15	0
Adjustment Disorder	5	0
Learning Disorder	5	0
Substance-Related Disorder ^f	5	0
None	35	30

^a Psychiatric diagnoses are not mutually exclusive, thus percentages may not total to 100.

^b Mood Disorder includes Mood Disorder NOS, Dysthymic Disorder, Depressive Disorder NOS, Bipolar 1 Manic Episode, and Bipolar Disorder NOS.

^c Anxiety Disorder includes Anxiety Disorder NOS, Panic Disorder, Obsessive Compulsive Disorder, and Post Traumatic Stress Disorder.

^d Schizophrenia/Psychotic Disorder includes Schizophrenia, Schizoaffective Disorder, Psychosis NOS, and Substance-Induced Psychotic Disorder.

^e Behaviour Disorder includes Conduct Disorder and ADHD.

^f Substance-Related Disorder includes polysubstance dependence.

charge. For 70% of these cases, the diagnosis of ASD became more specific. For example, some individuals had an NOS diagnosis clarified by having it completely removed or changed to a more specific diagnosis (e.g., Autistic Disorder). Moreover, the mean number of diagnoses for one individual on intake and exit for the IP Group changed from 1.9 to 1.65 (there was no change for the OP Group). Other changes in diagnosis from entry to discharge include: removing the diagnosis of Schizophrenia/Psychotic Disorder from four of nine clients and removing the diagnosis of Obsessive Compulsive Disorder from three of four clients. Interestingly, one OP client was admitted with an anxiety disorder and no ASD, but was discharged with Autistic Disorder and no anxiety disorder. These changes in diagnosis may reflect the challenge of diagnosing psychiatric disorders in individuals with a dual diagnosis and the tendency to reconceptualize the symptoms as being attributable to the ASD and not the additional psychiatric disorder.

Discussion

Individuals with ASD comprised about a quarter (27%) of all clients who were admitted to the Dual Diagnosis Program from its opening in the fall of 1999 to the beginning of 2005. The OP and IP Groups were quite similar demographically in terms of age, and male/female ratio. Clients were residing mostly in group homes and their family homes on admittance to the dual diagnosis program. Most clients were referred by Developmental Sector Services and because of challenging behaviour. These results highlight the need to offer more support and/or training to people in the community who are working with adults with ASDs and other psychiatric or behavioural concerns. Moreover, the prevalence of challenging behaviour in this population (which in some cases can even lead to involvement in the criminal justice system) emphasizes the specific need for earlier intervention for problem behaviour with these clients when they are children and adolescents. In addition, training families and staff to manage this behaviour should be a major focus in the ID/ASD field.

Palucka and Lunsky (2007) reported that 69% of their IP group had Autistic Disorder and 15% had Asperger Disorder; these data are similar to our IP Group results. However, the frequency of Autistic Disorder, Asperger Disorder, and PDD-NOS was more evenly distributed for the OP Group. Moreover, as expected, Autistic Disorder was more common among the IP Group, which makes sense given that Autistic Disorder is often viewed as more severe than Asperger Disorder or PDD-NOS. Of the co-morbid psychiatric diagnoses, the most prevalent was a bipolar mood disorder in the previous study (Palucka & Lunsky, 2007). This review reported mood disorders as the most common secondary diagnosis, although one third had no psychiatric diagnosis besides the ASD (vs. 23% in the previous study). There were no differences in the occurrence of other diagnoses between groups, which is somewhat surprising as one may think that the more severe the diagnosis (e.g., a psychotic disorder versus a learning disorder), the more likely an individual would need inpatient services. Yet, these insignificant results may be due to the limitations of the study, such as the small sample size.

There were some changes in diagnoses from admission to discharge, suggesting that it is challenging to diagnose clients with ASD and ID. For example, difficulties in determining which ASD diagnosis to give, and differentially diagnosing OCD, schizophrenia, and anxiety were evident among our clients. The diagnosis of schizophrenia or other psychotic disorders is particularly difficult in individuals with significant language delays or communication limitations who cannot report effectively or reliably their subjective experience. There is also an overlap between the negative symptoms/deficit states of schizophrenia and core symptoms of ASD, which adds to diagnostic challenges (Konstantareas & Hewitt, 2001; O'Dwyer, 2000; Petty, Ornitz, Michelman, & Zimmerman, 1984). In addition, psychotic-like, disorganized, and bizarre behaviors can be seen in response to stressful life events (O'Dwyer, 2000).

Therefore, for these clients to function optimally, it is necessary that the first step is accurate assessment and diagnosis. Systematic approaches and practice guidelines have been developed to assist in diagnosing co-morbid disorders in persons with ID generally (Royal College of Psychiatrists, 2001; Bradley & Hollins, 2006; Deb, Matthews, Holt, & Bouras,

2001), and in individuals with ASD specifically (Bolton & Rutter, 1994). Clearly, this is challenging in this population and thus, thorough assessments and in-depth consultation (including consultation from specialized dual diagnosis services in complex cases), are necessary when making decisions about these clients.

Limitations

There were many limitations to this study, including sample size and lack of data for certain variables. A larger sample would allow for more in-depth analyses in comparing the OP and IP Groups, which would give us a better understanding of the characteristics of individuals who need more support. In addition, with more data available for the clients who only accessed the Dual Diagnosis Program for facilitation services, we would be able to describe the population that is in need of less intensive dual diagnosis services. There are also many more questions about this population that are as important as the ones addressed in this study that we were not able to examine due to limited data. For example, it would be interesting to look at what types of medication these clients are taking, the types of intervention received during inpatient admission, inpatient length of stay, and which services these clients access in the community after being seen at the dual diagnosis program. Family variables, such as involvement in the clients' lives, coping skills, and stress levels are also variables that may affect the functioning of these individuals. Our data were not complete enough to look at these variables, although we recommend and hope that future studies focus on these variables with this population.

Clinically, this study made available some information on common characteristics of a group of people with ASDs who sought services from a specialized mental health service for individuals with dual diagnoses, which will ideally guide clinicians in their work. A better understanding of people with ASDs who are referred to a dual diagnosis program will inform research and clinical practice. In particular, understanding common reasons for referral and the prevalence of co-morbid psychiatric concerns will help lead to well informed treatment recommendations. This study has demonstrated that adults with ASD and ID are sometimes diagnosed incorrectly, possibly due to diagnostic overshadowing, which should alert

clinicians to the importance of exploring and changing or confirming previous diagnoses. This study has contributed to the growing body of literature about individuals with psychiatric concerns and ASDs. As the research literature in this field progresses, the identification of subgroups of patients within this population with particular characteristics may be possible, leading to a clearer understanding of the etiology of these disorders (Sverd et al., 1995). The presence of an ASD complicates assessment and treatment, and the management of psychiatric disturbances may require medical management and highly structured cognitively and socially oriented interventions. Understanding this population better will lead to an appreciation of realistic treatment goals, which may avoid treatment failure and re-admissions, and consequently, the demoralization of patients, family, and educators of individuals with ASDs and dual diagnoses (Sverd et al., 1995).

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