

ISSN 1188-3936

<http://www.ddd.uwo.ca>**CLINICAL BULLETIN***of the***DEVELOPMENTAL DISABILITIES DIVISION****Triple Diagnosis – three strikes and you’re out!
The challenge of being homeless for adults with a dual diagnosis**

Donna C. Lougheed MD MSc FRCPC

Medical Head, Dual Diagnosis Consultation Outreach Team

Royal Ottawa Health Care Centre, Ottawa, ON

donna.lougheed@rohcg.on.ca**Introduction**

At our recent videoconferenced interprovincial Dual Diagnosis Community of Practice rounds, I presented ‘Triple Diagnosis,’ which looked at the plight of adult women who have a dual diagnosis (mental illness and intellectual disability) and who are also homeless, hence the term. This presentation focused on the challenges identifying and helping this group of hard-to-serve people. At the University of Ottawa, I introduce this topic to first year psychiatry residents as part of the hard-to-serve rotation I offer. In this article, I will attempt to answer the following questions: “Why is this type of person hard to serve?” and “What can we do to help him or her?”

How did I become concerned about this group? **First**, I realized through my work as a psychiatrist in shelters that there are several routes to homelessness and complex reasons as to why people remain homeless despite services being offered to them. **Second**, on analysis of our Ottawa Dual Diagnosis clinic data, I realized we were seeing a disproportionally small number of adults with mild levels of intellectual and/or developmental disability (ID), and yet the research indicates that adults with ID should have at least the

same frequency of mental illness as the population without ID. [As an aside, analyzing data from one's own clinical work can challenge us to think about why something is occurring and allow us to explore further, an example of 'better living through statistics.'] **Third**, we are starting to understand that adults with dual diagnosis are found in other mental health treatment settings, such as Assertive Community Treatment Teams. I suspect many are seen through the regular mental health system, but perhaps their mild ID is under-recognized. According to my forensic psychiatry colleagues, adults with ID are disproportionately represented in jails and prisons. Also, I have started to suspect that there are more adults with developmental delay than we realize who are homeless and in the shelter system.

Interesting questions arise when examining the issue of adults with ID living in shelters, such as do they have a mental illness? If so, does living in a shelter cause this mental illness or have they become homeless and in a shelter because of a mental illness? And of course, does ID cause and perpetuate homelessness? From a systems and service provision perspective, another question arises - if the homelessness problem is caused by or associated with mental illness, which Ontario governmental ministry should provide services – the Ministry of Community and Social Services (MCSS) or the Ministry of Health and Long-Term Care (MOHLTC)?”

Triple Diagnosis (3TD): Is it a real problem?

I believe 'Triple Diagnosis (3TD)' is a real problem. One of my colleagues, a staff psychiatrist in a psychiatric emergency service in a local hospital refers to the challenges of the 'Borderline Squared' patient, i.e., patients with intellectual challenges and the concerns of adults with Borderline Personality Disorder (unstable affect, splitting, self-harm issues), *and* with the additional challenge of intellectual delay. I am not sure all these patients have borderline cognitive delay (in fact I suspect they may be mildly delayed or even mild-moderately delayed) but certainly they are presenting with regressed behaviour. The accurate assessment of intellectual disability is very challenging in the Emergency Room (ER) for the average psychiatrist or mental health professional, especially in patients who present with regressed behaviour due to the stresses of the mental illness and the challenging social situation in which they find themselves. Once admitted to hospital, these people are very hard to discharge back into the community because they need increased day-to-day support rather than in-patient hospitalization, and yet the appropriate services aren't easily available in the community. However, the hospitals can sometimes provide accurate cognitive assessments through their psychology staff which can guide functional planning.

Looking for solutions to the problems of the adult with 3TD, it is important to understand the permanent and unchanging functional limitations produced by the cognitive levels we describe as borderline, mild and moderate delay. In addition, we need to reflect on where adults with dual diagnosis needs are being served. This includes people with an 'invisible disability' who do not on first approach appear to have significant ID; those with mild, mild-to-moderate, and even some individuals with moderate levels of ID who have been hidden

behind the 'cloak of competency'. This 'cloak' gives these individuals the appearance of being able to manage challenges of everyday life despite their cognitive delay owing to disproportionately good verbal and social skills. It is important to look at these various levels of ID from the concept of functional ability, including cognitive problem-solving skills. We do not expect adults with ID to progress but rather to stay at the same problem-solving level all their adult life. However, the professional needs to remember that the pain of organic etiology or extreme emotional stress can cause temporary regression to more immature behavior and problem-solving.

Challenges in obtaining evidence-based data

We benefit from learning about the challenges facing people in shelters and successful ways to help them through both clinical observation and consensus discussion by expert professionals. However, in medicine we like to talk about 'evidence-based' conclusions. That 'evidence' comes from good caliber research. This type of research is fairly difficult and expensive to do for the general patient population, especially in places like shelters (as opposed to university-run clinics). However, the situation is made worse when the group we want to study includes adults with ID. These individuals may not read well enough to understand consent forms. They may be leery to sign a consent form, to complete a questionnaire they don't understand, or may refuse to talk to the researcher. If the examiner believes the person is not competent to consent to be in the study, no effort may be made to contact a substitute consent giver. Indeed, many standard research protocols exclude the participation of an individual who is deemed incapable to consent.

Routes to homelessness

There are several routes to homelessness reported by homeless individuals and professionals who study this area, including the traditionally identified ones such as lack of affordable housing, lack of jobs, extreme life stressors, mental illness, and substance abuse. For the specific population of 'hard-to-serve' adults, an additional and important factor is lack of adequate, supportive psychiatric care for marginally functioning individuals. The closure of long-term psychiatric hospitals over the years has been associated with an increase in the number of people in shelters for the homeless. Interestingly, the shelters in Ottawa are all sponsored by religious groups rather than by either the Ministry of Health or the Ministry of Community and Social Services directly. Part of this has to do with a change in society's understanding of its need to look after the less fortunate. It also reflects a lack of understanding or insight into the symptoms of mental illness, often reflected as the disbelief by the individual that he or she has a mental illness.

The lack of support and particular needs of the adult with mild to moderate ID results in a second specific route to homelessness. The individual with ID who is able to present as socially compliant can have a good and conventional life, with family and professional support. The adult with a more irritable, challenging personality (for instance, those with Fetal Alcohol Spectrum Disorder), who cannot learn from his or her mistakes, is penalized for having a mental illness which can result in certain challenging symptoms leading to loss

of housing and the resultant drift into the shelter system. These individuals may also have difficulty maintaining a working relationship with health care professionals.

Cognitive impairment by itself is a risk factor for homelessness. It is characterized by immature judgment and inability to learn (sometimes looked at as decreased executive function, and recognized as impairments to decision making skills when compared to children of the equivalent mental age but different chronological age). We see this poor judgment reflected in the comments made by some of our Psychiatric Outreach Team and Dual Diagnosis Consultation Outreach Team (DDCOT) clients who are homeless: *'I don't need your help (services)', 'I don't have any problems', 'you can't tell me what to do', 'but this is my home', 'I guess I'll go stay in the 7-11 all night', 'I don't care if I go to jail – the staff there are nice to me'*. Much can be read into these protestations which can guide the experienced clinician, advocate, and program planner.

Understanding who are in our shelters

Dr Susan Farrell, a psychologist with a strong interest both in service provision issues and in individuals with severe and chronic mental illness, developed the first profile of persons staying in the shelter system over a decade ago in Ontario (Farrell et al., 1999). Her researchers found more men than women staying in the shelters; those surveyed had an average age of 38; 12% reported they had stopped school at Grade 8 or less. Sixty percent self-reported they had a mental illness. Their average length of stay in the shelter was 235 days, with 42% staying less than 1 month, and 15% more than a year.

Dr Farrell also looked specifically at women in Ottawa shelters: 85% had been born in Canada and 27% self-identified as First Nation. One quarter had not completed Grade 9. Their average length of stay ranged from 1 to 790 days, and over half (54%) had stayed in shelters previously. Thirty-three percent reported current or past problems with alcohol, and 42% reported previous or current use of street drugs (marijuana or cocaine). The women reported homelessness owing to recent arrival to the city (13%), eviction (11%), transient lifestyle (9%), unsafe accommodation or fire (9%), spousal abuse (8%), and discharge from psychiatric treatment (7%).

Dr Farrell continues her work with challenging populations as Clinical Director of our new Community Mental Health Program at the Royal Ottawa Health Care Centre (ROHCC) and working with our hard-to-serve patients.

Who is served by DDCOT?

Referral to our Dual Diagnosis Consultation Team (DDCOT) in the Champlain Local Health Integration Network is biased towards individuals known to have an ID and who have signs and symptoms of a mental illness (but not necessary a diagnosed mental illness). These are the people who have a family doctor (or another physician who provides regular care), and have significant mental health needs or behaviour problems that cause the individual, and sometimes more importantly those who care for them, significant concerns. In 2007, Susan Farrell and I looked at data from 5 years of DDCOT referrals. Of the 544 people who had

been referred to our specialty clinic, 60% were men and 40% women, 76% were from urban centres, and 24% from rural areas as we serve a large geographical area which includes a significant rural component. The patients ranged in age from 16 to 84 years, with the median age of 40. We made the following clusters of Axis 1 diagnoses: mood disorders - 42%, anxiety disorders - 16%, psychoses - 12% (Lougheed & Farrell, 2007, unpublished).

The data by itself is interesting, but when we looked at the developmental level of the patients (based on the impression of the psychiatrist with dual diagnosis experience or on IQ test results if available), we noted that the distribution was not what we would predict based on a normal population distribution. We found that 27% of this group were mildly delayed, 36% moderately, 22% severely, and 8% profoundly delayed. Statistically, we would have expected a much larger number of mildly delayed individuals, and a much smaller number of severe and profoundly delayed individuals.

Reviewing this data, I wondered where the majority of patients with mild ID and mental illness were being treated. We know that mental illness exists in this population (Fletcher et al, 2007) and their symptoms cause them and people who care for them distress. Are they accessing help? Does their intellectual impairment cause some sort of problem that makes it hard for them to get help, or do their symptoms mask their ID?

From my work over the years with many people in the shelters, I began to wonder if mild ID in combination with mental illness might result in a situation that would make it hard for individuals to access and benefit from standard services that might help them. I wondered where they were and what challenges they were facing. I went back to the DDCOT data base to determine if we had any referred individuals who were or had been in shelters. My goal was to look at their characteristics compared to other DDCOT clients and other people in shelters.

Triple diagnosis – who are they?

While there are many men who are staying in shelters with concomitant mental illness and ID, I chose to look at women owing to some of their special needs. Here are case examples of three women (with characteristics changed for purpose of privacy) with a triple diagnosis.

1.

Ms AB is a 50 year old single woman staying in a women's shelter. Her father is elderly, and her mother died many years ago. She was described as chronically irritable, angry, and non-compliant. She denies substance abuse, and staff confirm this. She was cared for in an institution for five years as a child. IQ results varied from 60 to 72 points. Her only child was apprehended by CAS when very young. She has a history of poor medication compliance despite having a seizure disorder. She has known CT head abnormalities (atrophy). She has been in jail frequently over the years for theft and assault, and has had over 50 hospitalizations. Ms AB was encouraged to move to a domiciliary hostel setting from the shelter; however, within a few months, she was asked to leave due to inappropriate attachment to staff.

2.

Ms CD is a 35 year old woman with limited French and no English. Her first language is an African dialect. Her mild level of ID is due to measles encephalitis as a child. She lived in a war zone and then a refugee camp before coming to Canada. She has a history of extreme conflict with her family, including assault of a 12 year old child. She had been dropped off at a shelter by police. While staying in the shelter she was found washing her clothes in the Ottawa River. She was described as flirtatious with men. Her only child is attending university. Some of this information was identified after she had a brief hospitalization.

3.

Ms EF, aged 45, is separated, and doesn't know where her abusive husband resides. She was placed in a rural domiciliary hostel after living in a women's shelter. Ms EF is described as complaining, passive, and somatizing. She is at risk of losing her current housing owing to incontinence of urine seen as purposeful, as well as stealing, hitting others, and calling 911 saying she is afraid she is dying. She has lost placements in the past due to similar behaviour. She stopped the use of alcohol and marijuana 2 years ago. She has past diagnoses of depression and schizophrenia at age 20. CT head reveals ventricular dilatation.

These women demonstrate the challenges that we and they face, and yet they share many of the characteristics of other adults in the shelters.

Challenges and opportunities:

Recognizing this group of hard-to-serve individuals with dual diagnosis who are staying in homeless shelters can help us develop service plans that meet their particular needs. We suspect that women with ID share some of the characteristics of the adult women not screened for ID in shelters surveyed by Farrell (1999), including life in foster homes, group homes, or residential schools - 52%; event(s) where something happened to them that they thought about for years afterwards - 85%; parents that used alcohol or drugs, causing problems in the family - 61%; and physical abuse by someone close to them – 76%.

Those of us working in this field are concerned that we don't have accurate statistics on how many people in shelters have ID. These statistics would help us plan and better distribute services or advocate for new services. In an attempt to obtain helpful statistics, Burge (2010) surveyed Assertive Community Treatment Teams in Ontario to determine how many of the patients had ID. The results given by these 67 teams ranged from 5.2% to 19%, with the average just under 10%.

Recently, Burra and her colleagues reviewed 22 studies of homeless adults over 18 years of age which looked at global cognitive deficits using the Mini-Mental State Examination (MMSE), and found between 4% to 7% of clients had cognitive deficits. However, Burra concluded that the prevalence may be underestimated for a number of reasons. In addition, they did not specify whether these deficits were owing to ID or some other reason such as head injury after adolescence.

Understanding the implications of ID and cognitive impairment on everyday life:

A main concern for the professionals who work with adults with ID is that other mental health professionals often don't understand the concept of functional implications of the various levels of ID, especially for those individuals with borderline, mild, and moderate ID who may have the previously-mentioned 'cloak of competence.' This lack of expertise and familiarity may result in false assumptions about clients' abilities to follow directions, read instructions, manage money, and assess trustworthiness in others. When individuals also have a mental illness, whether schizophrenia or adjustment disorder with anxiety, they may regress to a more immature level of functioning which then compounds the problem of recognizing and understanding functional strengths and deficits. These clients may start to avoid the professional because of fear of being criticized for not following directions (as may have happened to them in school).

Low cognitive ability may cause problems for the individual with calculating (estimating or even anticipating) risk. Hence, 'friends' are poorly chosen, and past behavior is not seen as a predictor of future behaviour (for example, the acquaintance who has previously stolen or assaulted them is likely to do it again). They may find it hard to predict that a certain action they are about to undertake is dangerous, such as sleeping outside in the winter, at the side of road or in a parking lot. Financial skills can be very poor, credit not understood, basic budgeting impossible, bank machines seen as 'free money machines,' and not as gatekeepers to bank accounts. They may find it hard to learn from mistakes, since cause and effect are not temporally related, or they may be taken in by magical thinking. They may use (in other words, have developed) a prickly or rude personality as a way to avoid being taken advantage of or harmed by others. This inability to trust authority figures because of negative experiences with Children's Aid Services, school teachers and principals, police and transit authorities, and security guards in malls means they may not be willing to trust the health care workers who approach them in order to help them.

Women who are homeless may be particularly vulnerable owing to women's more significant affiliation needs (the desire to have friends, feel wanted or be part of a group). This may make them particularly vulnerable to abuse by others, especially men. Serial sexual relationships, financial abuse, and prostitution can be some of the negative consequences, even without concurrent substance use.

We note a lack of consistency and understanding about issues related to 'capacity to consent' to care in agencies supporting adults who are homeless, as well as adults who have ID. This is true also for capacity to manage financial affairs. I believe a number of adults are abused and neglected, in effect, by the system that does not recognize these deficits, and so does not properly protect these victims.

What is needed?

The developmental sector in our area appears to have been overwhelmed by the needs of more people entering the community as a result of closures of Rideau Regional Hospital and the Dual Diagnosis Unit at Brockville Mental Health Centre of the Royal Ottawa Health

Care Group. These closures resulted in over 250 adults needing placement in the community. Well-meaning developmental sector agencies assumed the task of supporting these discharged people, but this seems to have left little to no resources for the people who were marginally supported before, or supported mostly by their families in the past.

There will be new adults entering an already taxed system every year, as children leave the child/school system or the health and social services systems between ages 18 to 21. Some of these adults will need constant supervision, particularly those with severe and profound delays who will not enter the homeless system as their cognitive deficits are easily identified. Those with mild to moderate delay will need appropriate daytime activities and supports to help them avoid mental illness precipitated or worsened by stress, substance abuse issues, and conflict with authorities that may result in homelessness. The discharge of individuals from residential care settings, where experienced professionals were available to provide preventive and emergency care, has taxed our hospitals (both emergency departments and inpatient units), local family physicians, and social service agencies. The fact that the agencies are busy with these discharged patients means fewer services are available to maintain adults with mild or moderate ID in the community, whether they live in their parents' homes, in semi-independent or independent living. Consequently, when these patients are taken to emergency departments, there are few if any social services available to prevent the trip to homelessness and the shelters.

My colleagues tell me that many physicians are unwilling to serve adults with ID and health needs for several reasons. It can be a challenge to ensure that the medical history is reliable when it is only given by the unescorted patient. The individual may agree with every question or statement by the doctor in order to be pleasant and liked. Compliance with appointments may be irregular. It may be a challenge to tease out the symptoms of mental illness from the characteristics of the ID, a phenomenon known as 'diagnostic overshadowing' (Lougheed, 2006).

There is general agreement among professionals working with this underserved population that more and better follow-up of adults with dual diagnosis is needed (Lougheed & Farrell, 2007, McCreary, 2005). Follow-up service can help prevent the path to homelessness – and 3TD.

Follow-up services should include services that understand and support the social, affiliation and medical needs of adults with mild and moderate ID who are living independently or semi-independently. Preventive and recovery oriented efforts should also include programs that offer structure and predictable, enjoyable routine in daily life to increase confidence and ability in day living skills. *[As an aside, I suspect that jail is enjoyed by some adults with ID because of this predictability of routine, and meals and recreation are all provided, activities which can be challenging for the marginally housed or homeless adult with ID].*

Appropriate supports and housing can prevent and minimize legal involvement for these individuals. Court diversion for individuals with mental illness is a start, but I would also

suggest programs which support financial issues, personal safety, and social involvement with meaningful and developmentally appropriate activities for adults with ID.

In addition, there should be support designed for individuals with weak financial skills to help them learn very basic budgeting, the risks of credit, and tips to discourage borrowing or lending. Also, support could include community financial advisors. There should also be easier community access to financial capacity assessment as at this time an individual must be hospitalized for a physician to declare him or her financially incapable. The alternative is for people to agree to a financial capacity assessment for which they have to pay. The person who is receiving \$600 a month from ODSP (or \$125 comfort allowance while staying in the shelter) who agrees to pay \$500 or more for this assessment is clearly making a poor choice!

Finally, a type of service which would help adults with a 3TD should include some of the features of wrap-around case management. This includes a client-centered approach that is not time limited. It needs to be recognized by the service-provider that this client will always need some help, although possibly of a different form at different times owing to the level of ID and life-stage. One does not grow out of ID, but one can learn to manage better because one is better supported by individuals whom the client trusts. Case-management for the adult with 3TD should include supportive housing targeted for adults with ID, with a community focus to allow community involvement and a sense of belonging. A main goal should be harm-reduction approach to risks that include financial, health, social, sexual, legal and others. Ongoing observations should be made to evaluate whether the person's cognitive abilities and functional impairment will place him or her in a situation of abuse or neglect. Also, legal issues of capacity need to be addressed both formally and informally to protect the person. I sometimes use the concept of 'supportive auntie' to describe the type of service proposed – the supportive professional who is able to anticipate challenges, help with advice, steer the individual from unconsidered consequences, and help with community integration.

Summary and thoughts for the future

In conclusion, the planning of care for adults with 3TD requires the principles of CARE: clinical care, advocacy, research, and education applied by professionals as well as clients. Appropriate clinical care necessitates the understanding of the 'chicken and egg' dilemma related to mental illness and homelessness in the population of adults with ID. The stress of life's functional demands for an adult with mild or moderate cognitive impairment can result in homelessness and can be a cause of mental illness and one of its symptoms, inappropriate behavior; *or*, the primary mental illness can present with symptoms that cause poor care or poor response to care, and thus, result in homelessness. These two paths to 3TD require similar services that meet the client where he or she lives, are flexible, consider capacity to consent issues, and consider the pervasive and life-long effects of ID.

Advocacy for this population includes providing appropriate clinical services, as well as encouraging the understanding of cognitive impairment, and the consideration of possibility

of incapacity to care for self. Advocacy also recognizes that while integration of services and treatment for adults with ID with the general population are desirable as a general principal, it is not always appropriate or adequate. Supportive housing for adults with ID should look different and provide different services than for individuals from the non-ID population with severe and chronic mental illness. This housing also should not be exclusively integrated with services for adults with severe and profound levels of ID with mental illnesses.

Researchers need to address the bias that adults with ID are often not included in scientific medical and social sciences studies. Several challenging reasons can include the individual's refusal to agree verbally or to sign consents because of suspiciousness or a lack of understanding; or the incapacity to consent (either due to mental illness or ID). The research protocol may specifically exclude people who cannot give consent, even if they have an identified substitute decision maker. However, we still need to know how many people in Canadian shelters have ID, the specific needs of this population, and the particular services required to help them (Burra, 2009).

Finally, there is the need for ongoing education of staff, family members, clients and health care professionals. There is a need for 'plain language' information to be provided for people with limited reading ability on topics such as health care and personal responsibility, access to health care, mental illness, or financial issues. All who work with our clients who by definition have impaired memory, must understand the need for repetition of our names, goals, and all other information we wish to convey. Professionals need to continue to help clients and families to function at their best, benefitting from comprehensive care based on a solid understanding of needs and abilities.

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