

The Challenge of a “Triple Diagnosis”: Identifying and Serving Homeless Canadian Adults With a Dual Diagnosis

Donna C. Lougheed and Susan Farrell
University of Ottawa, Ottawa, ON, Canada

Abstract Adults with both a mental illness and intellectual disability (in Canada, a “dual diagnosis”) and who reside in shelters for the homeless are vulnerable and at risk for physical, sexual, and financial abuse. The same factors that make them vulnerable may result in neglect by the very services designed to help them. Their mental illnesses are difficult to diagnose and treat, and their intellectual impairments are difficult to ascertain. The authors review the existing literature on homelessness and intellectual disability, and use this and their extensive clinical experience with the homeless in a large Canadian city to identify and extrapolate reasons for the challenges facing both these individuals and the agencies and organizations that serve them. The authors identify several challenges to providing appropriate services, such as identifying and linking with these adults; recognizing the implications of the level of the intellectual delay and the mental illness on the individual’s ability to cope, and stay safe; understanding the wants and needs of the individual; expanding the mandate of the agencies and professionals wanting to serve this group; and developing policy that will both provide appropriate support of the individual, but also provide protection, if necessary by legal means. They further suggest that focal services should be based on the following characteristics: flexibility, meeting the client where he or she lives, consideration of capacity to consent in order to avoid neglect issues, and understanding of the lifelong and pervasive effects of intellectual delay in all facets of life. Though the population discussed is resident in Canada, these issues apply to individuals in other countries, as well, where there are concerns about these vulnerable adults with a “triple diagnosis.”

Keywords: dual diagnosis, homeless persons, intellectual disability, mental illness, vulnerability

INTRODUCTION

The Canadian system of comprehensive social support and universal healthcare can still not prevent homelessness or its associated vulnerabilities. Although there are many pathways into homelessness, agencies that provide support to mentally ill homeless adults recognize that there is a subgroup of homeless individuals who are even more vulnerable, hard to serve, and at risk of abuse and neglect. These are the homeless adults with intellectual disability (ID). The reasons that men and women with ID become homeless and continue to be homeless in Canada, despite the availability of free outreach social and medical services, are poorly understood and challenging to clarify. Research on identification of and effective treatment of adults with mental illness and intellectual impairment is limited.

Fletcher and his colleagues have reported that the 2 to 3% of the population who have an ID have an incidence of mental

illness somewhat greater than the general population (Fletcher, Loschen, Stavrakaki, & First, 2007). Canadian researcher Burge (2009), when discussing challenges facing adults with ID, noted that “cognitive and functional impairments are often compounded by stressors related to communication difficulties, socioeconomic disadvantages, inadequate housing and supervision supports, lack of access to case management and vocational services, and wide-spread discrimination.” The authors’ clinical experience with homeless adults and with the agencies that serve them reinforces the belief that this is a challenging group to recognize, understand, and to serve. There is limited research to guide goals and services planning.

IDENTIFICATION OF ADULTS WITH A DUAL DIAGNOSIS IN THE HOMELESS POPULATION

ID in adults is only sometimes recognized clinically by service providers in homeless shelters. From a formal evaluation research perspective, little is known about needs and challenges of this population. Clinically, as a group they appear to be extremely vulnerable, and more at risk for financial, sexual, and emotional abuse and neglect than other homeless adults. They may have symptoms of mental illness, but it is not clear

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Correspondence: Donna C. Lougheed, MD, Medical Head, Dual Diagnosis Consultation Outreach Team, Royal Ottawa Health Care Centre, Community Mental Health Program, Suite 2000, 320 Catherine St, Ottawa, ON, Canada K1R 5T5. Tel: +1 613 722 6521 ext. 7128; E-mail: dclougheed@yahoo.com

how often these illnesses are primary (existing prior to and contributing to the cause of homelessness), such as a psychotic disorder, or secondary to (due to) homelessness, with its accompanying stressors of abuse and neglect, exposure to street drugs, and confusion due to lack of appropriate support.

In a recent literature search using keywords of “homelessness” and “developmental delay,” very few reports were identified, which reported on developmentally disabled individuals in the homeless population. The majority of the reports, from the United States, looked at developmentally delayed children who were living in shelters with a parent (Chiu & DiMarco, 2010; Fox, Barnett, Davies, & Bird, 1990; Rubin et al., 1996; Zima, Wells, & Freeman, 1994). Oakes and Davies (2008) from Great Britain reported an attempt to determine the prevalence of ID in a group of 50 adults in a homeless shelter. After testing, the authors determined that IQ was significantly lower than would be expected in the general population. A 2009 Canadian review by Burra, Stergiopoulos, and Rourke (2009) looked at the prevalence of cognitive deficit in homeless people in 22 published studies of homeless adults. Those studies using the Folstein Mini Mental Status Exam reported that between 4 and 7% had cognitive deficits. However, the report did not specify whether the deficits were due to intellectual delay (which by definition exists prior to age 18), or another reason (such as traumatic head injury or alcohol-related dementia) after the age of 18.

Farrell (1999) reported on 230 homeless men and women not screened for ID in five Canadian shelters. Average age was 38 (40% were women) and 60% reported having a mental illness. They found that 12% reported stopping school at Grade 8 or less (in Canada generally completed by age 14), despite secondary school education being free to age 21, and compulsory to the age of 16. These individuals reported an average length of stay in the shelter of 235 days; 15% had spent more than 1 year homeless. Farrell and Lougheed (2012) reported on a review of 800 charts of a multidisciplinary psychiatric outreach team, which served homeless adults with mental illness in a major Canadian city. Clinical staff identified at time of early contact that 5% of clients had a dual diagnosis. The authors reported this to likely be an underestimation due to the difficulties clinical staff experience identifying with accuracy this subgroup of the shelter population. Clinically, it was noted that there were significantly cognitively impaired adults living in the homeless shelters, especially in the older population. The etiology of their cognitive impairment was not invariably intellectual delay but also included organic brain syndrome secondary to traumatic brain injury, alcohol abuse, or another dementing process.

DUAL DIAGNOSIS: INDIVIDUALS WITH MENTAL ILLNESS AND INTELLECTUAL DELAY IN THE SHELTERS

Clinically, it appears that there are limited services available to support adults with mild or moderate ID in the community, whether they live in their parents' homes, or in semi-independent or independent living. When there is a breakdown in the living situation, there are few social support services available to prevent the journey to homelessness and the shelters. Homeless shelter managers have reported that the numbers of

intellectually impaired adults using shelters is growing. They do not feel they can accurately identify this group and their needs, or provide adequate support services (Muckle, 2012).

Homeless adults with ID may have engaging social skills or facile verbal abilities, or an irritable, challenging personality that keeps others at a distance. They may have lost their previous housing due to difficult behavior directed at family or landlords, or have drifted into the shelter system after staying with friends (often called “couch surfing”). They may have challenges with budgeting or accessing welfare due to poor reading and writing skills. They may have difficulty maintaining working relationships with health-care or other service providers due to their challenging personality. Financial skills are often poor, with credit not understood, a lack of awareness of basic budgeting, and bank machines seen as “free money machines” and not as gatekeepers to bank accounts that need to have money deposited.

It has been observed clinically that adults with intellectual delay and mental illness appear to access psychiatric care in the general hospital emergency departments. The emergency room nurse or physician is usually not skilled in screening adults to identify mild and moderate cognitive impairment. These patients do not offer this information readily, often because of stigma issues. The adult with mild or mild-moderate cognitive impairment may present to an emergency department with unstable affect and regressed behavior, and may threaten self-harm. These patients are sometimes given the diagnosis “Borderline Squared,” referring to both their problematic and challenging personality characteristics (similar to borderline personality disorder) and their “borderline” or mild ID (C. Mann, personal communication, 2012). They are often victims of “revolving door” presentations to the emergency department, and are described as “not following the plan.” Mental health professionals who have little experience with adults with ID may not be aware that these highly stressed, poorly functioning individuals have difficulty keeping track of phone numbers and their own healthcare cards, have no access to bus tickets or money, and may not know how to get to the hospital outpatient department, let alone be at risk of ongoing abuse at the shelter.

Hospital staff standardly have no access to previous cognitive testing (IQ) results and are not trained in bedside assessment of cognitive ability. A commonly used clinical technique to identify cognitive disability, assessment of the patient's language skills, is inadequate when there are emotional issues or second or third language issues compounding the assessment (as in major urban centers in bilingual Canada, and with immigrant or refugee populations).

Appropriate community services, including supportive housing or day/activity programs, are not quickly or easily available. There may be lengthy waits for assessments by agencies that provide the gateway to starting or increasing developmental sector service support. If these patients are hospitalized in an inpatient psychiatric unit, physicians anecdotally report they can be challenging to discharge in a timely manner to appropriate supportive housing, and so they are discharged back to the shelter. IQ testing by a psychologist, often necessary to access adult developmental sector services, is not often available due to lack of psychological resources. This is despite the need for documentation of “mental retardation” using numerical IQ results in some Canadian jurisdictions for access to service provision.

CHALLENGES FACING THE ADULT WITH DUAL DIAGNOSIS IN THE HOMELESS SHELTER SYSTEM

Substance abuse, mental illness, and personality issues in other shelter residents often create an atmosphere that is threatening and stressful for the adult with dual diagnosis. Clients are at risk of verbal and physical assault, and theft of money and belongings. They have limited personal space (often living in quarters with upwards of 30 in a room), and lack access to quiet space. Drugs of abuse are easily available, as are sex trade opportunities. These factors combine to create a milieu that can be frightening, and encourages defensiveness and distrust. It can also result in poor choice of acquaintances in the individual with high affiliation needs.

In an individual at risk for anxiety or depressive disorders, lack of sleep and constant worry provide triggers for the development of mental illnesses. High level stress in an adult with an ID may result clinically in a picture of psychosis due to behavioral and emotional regression. The individual who arrives at a shelter with a preexisting mental illness has little opportunity to seek or continue treatment, and is at high risk of exposure to conditions that can worsen the illness.

Poor functioning in the homeless person with a dual diagnosis can have several etiologies: a mental illness, a developmental delay, lack of support, and living in a chaotic environment, or an interaction among all of these. The cognitive impairment itself may result in difficulty learning and immature judgment (due to decreased executive function, and impairments to decision making skills). Examples of poor judgment are reflected in client comments such as “I don’t have any problems,” “you can’t tell me what to do,” “but this (the shelter) is my home,” “I guess I’ll go stay in the [convenience store] all night,” and “I don’t care if I go to jail—at least the staff there are nice to me.” These developmental age typical levels of reasoning are often understood by social services or healthcare professionals to reflect choice, stubbornness, or “behavior” (a vague term used both in the developmental sector and the mental health sector). There is an implication that the “behavior” or statements that are willfully being used to manipulate others are based on “informed choice” and reflect poor motivation to change. However the statements may in reality reflect long-standing and impaired cognitive reasoning that will not “get better” if staff ignore them, or if the individual experiences negative consequences. The immature reasoning may result in actions that are dangerous without an understanding or appreciation of the danger, such as financial loss, physical assault, sexual abuse, or legal charges.

Shelter and outreach staff may become angry or discouraged due to interactions with clients with an angry demeanor, and the client may have difficulty maintaining a working relationship with healthcare professionals. These challenges may contribute to the loss of permanent housing, or frequent change of shelters with resultant instability in services.

RESPONDING TO THE NEEDS OF HOMELESS PEOPLE WITH DUAL DIAGNOSIS

Homeless adults with a dual diagnosis appear to require a different kind of support from the general shelter population, in

order to move out and stay out of shelters successfully. This appears to be due to both the cognitive deficits associated with their intellectual delay, as well as their challenging personality defenses, which may have developed as coping strategies, or be aggravated by preexisting mental illness. Though this conclusion is based on clinical experience rather than research, it is evident clinically this population experiences challenges accessing services that are available and to which they are entitled.

When the adult also has a mental illness (whether it be an adjustment disorder due to environmentally related stressors, or schizophrenia), he or she may regress to a more immature level of functioning. This makes it more challenging for the healthcare professional to understand and appreciate baseline (best previous level) functional strengths and weaknesses. The client who is offered support that does not recognize baseline function may start to avoid the support person or professional who offered it, because of fear of being criticized or blamed for not following directions they did not understand or did not have the skills to accomplish.

These clients may present with an inability to trust authority figures because of negative experiences in the past: for instance, with children’s aid organizations when they were young, school teachers and principals, police and transit authorities, and security guards in malls. This lack of trust of people in positions of authority may generalize to their not being willing to trust healthcare outreach workers who approach them to offer help.

Information on identifying and responding to the challenges to providing diagnosis and treatment of mental illness in adults with developmental delay is not widespread, and tends to be what is described in the literature as “evidence-informed” rather than “evidence-based” (Whitley et al., 2011). Few studies address interventions for the homeless population. A Canadian study by Bedard, Drummond, Ricciardi, and Husband (2003) described a women’s support group model that provided help with coping skills for homeless or poor women. Farrell, Huff, MacDonald, Middelbro, and Walsh (2005) described an outreach model that provided assessment and support to adults in shelters, but this was not specifically directed at adults with developmental delay.

CHALLENGES TO PROVIDING SERVICES: ISSUES AROUND ABUSE AND NEGLECT

Professionals in the field of developmental disabilities are aware of the concept of “cloak of competence.” However, this concept is not known to generic professionals. Cognitive deficits are frequently not identified in adults with borderline and mild intellectual ability. Lack of expertise may result in professionals with little experience making false assumptions about their clients’ ability to follow directions, complete tasks, read instructions, manage money, and assess trustworthiness in others. This may result in further experiences of failure by the client and the inappropriate and unhelpful label of “noncompliant with treatment recommendations.”

Despite clinically apparent cognitive impairment of any etiology, this population in the shelter system is often not identified as needing significant intervention, as reflected by the paucity of assessments of capacity to consent or refuse treatment, whether considered, performed, or recorded by healthcare professionals.

This may be despite the individual's challenges recognizing and managing both significant mental illnesses and physical illnesses such as gall bladder disease or diabetes.

Homeless adults with dual diagnosis appear to become at risk of neglect and abuse by helping services due to several factors. These include a "romantization" of homelessness as a choice; the sometimes inappropriate expectation by professionals that individuals of "limited ability" be "allowed" to make poor choices; and the disregard by professionals of the cognitive challenges to ability to assess risk that defines the impairment associated with developmental or intellectual delay.

The intellectually impaired client may have problems with calculating (estimating or anticipating) risk. This may result in "friends" being poorly chosen from available shelter or street acquaintances. The client may be unable to predict that the action he or she is about to undertake is dangerous: for instance, sleeping outside in the winter, at the side of a road, or in a parking lot, behaviors the homeless often resort to.

Guidelines for what constitutes neglect and when to intervene are also not well described, with different groups of professionals having different perspectives. There is limited consensus clinically on what amount of risk is acceptable before it is identified as neglect or abuse. There is little agreement by professionals on using and applying capacity to consent assessments, whether it be for finances or for personal care, based on finding of functional impairment and level of ID. This may be because of clinician concerns about appropriate housing not being available and hospitalizations being either not helpful or overly long, or a belief that shelters can provide more support than they do.

Clinically, it appears that homeless women with an ID may be particularly vulnerable to abuse due to their significant affiliation needs (the desire to have friends, to feel wanted, to be part of a group, or to have a "boyfriend" or "husband"). This can result in serial or multiple sexual relationships, financial and physical abuse, participation in prostitution and other sex-trade activities, and substance use and abuse. Although seen clinically, objective data on the extent of the problem or appropriate effective interventions are not available at this time.

Unfortunately service providers may be unknowingly contributing to neglect and abuse in this population. Traditionally, in psychiatry, areas of personal decision making are considered as encompassing three areas; decisions in the areas of personal medical care, financial decisions, and decisions about place of abode. Adults who are homeless often have challenges in these areas. Supportive agencies often help adults with finding shelters; however, it can be difficult to leave the shelter to find permanent housing, for reasons that have to do with both symptoms of mental illness as well as cognitive abilities and personality issues. This can lead to issues of what might be considered neglect and abuse by the agency. For instance, staff will sometimes attempt to help their client by taking over the care and supervision of government checks, for well-intentioned reasons (e.g., to keep the person from being assaulted for his money). Staff taking a client's personal belongings into care appears to happen less, for reasons that are not clear—however, possessions end up being stolen too, so the rationale is unclear. There appear to be rules and guidelines prohibiting shelter staff from doing this, possibly to protect the shelter from false accusations of theft. Adults staying in homeless shelters often do not have

access to storage or personal spaces, and must vacate the premises during the day, even in winter. There is an expectation that clients' medications are routinely kept by shelter staff at a front desk due to internal policy. This effectively cuts down on medication sharing, stealing, or overdosing, but does provide challenges around autonomy, as well as access if the individual moves elsewhere suddenly.

Mentally ill adults may leave the shelter without proper clothes, or without medication and belongings, and spend the night outside or not return at all. Staff are often reticent to report this to the police as a "missing person" event, or to go to the justice of the peace to obtain a mental health form, which would allow the individual to be taken to the hospital for a psychiatric assessment, despite the risk posed by the behavior associated with the mental illness.

These acts and others, while well-meaning, may constitute abuse and neglect of the adult with ID, specifically by the social and healthcare systems, which do not recognize these deficits, and therefore do not properly protect by the legal means available, by assessing and respecting capacity issues.

Significantly, there are limited resources available if the person is found incapable or in the need of support in the community, for minimally invasive interventions, such as access to case management, appropriate housing with developmental system support, or safe day programming that can deal with the behavior challenges of seemingly streetwise but vulnerable adults.

It is of concern that the local developmental disabilities agencies appear to be overwhelmed by the needs of the many adults who have been moved into the community system with the closure of institutions for adults with ID. In one locale in Canada, some 270 adults were transferred to placement in their local urban community over a 5-year period (Lougheed, 2006). This transition resulted in a limitation on new services for those who were marginally served by community agencies before, or those who were supported by their families, until with the natural progression of life with aging parents, development of significant medical illnesses, or family breakdown, they required new or expanded services.

CHALLENGES AND OPPORTUNITIES

The principal of integration of services and treatment for adults with ID within the general population is desirable as a general principle; however, it is not always appropriate or adequate for many individuals. The adult with dual diagnosis who is homeless appears clinically to require specific targeted services. There are several challenges facing agencies and organizations. The first is identifying and linking with these adults; the second is recognizing the implications of the level of the intellectual delay and the mental illness on the individual's ability to cope, and stay safe; the third is understanding the wants and needs of the individual; the fourth is expanding the mandate of the agencies and professionals wanting to serve this group; and the fifth is developing policy that will both provide appropriate support of the individual, but also provide protection, if necessary by legal means.

Information that can inform appropriate management is gathered initially by clinical observation, often followed by consensus discussion and agreement by experts in the field, ultimately resulting in substantiation by good caliber research. However, gold-standard “evidence-based” data are difficult and expensive to obtain, especially when the clinical population is found in shelters as opposed to university-affiliated health clinics. At this point, clinical observation guides much of our understanding as well as our interventions until appropriate data collection.

Conducting field research can also present challenges. Individuals may not read well enough to understand consent forms (which often require a Grade 6 reading level). They may hesitate to sign a consent form, to complete a questionnaire even if it is read to them, or even refuse to meet with the researcher. The researcher may not find it practical to contact a substitute consent giver. One way to obtain information on consumer-informed understanding of the challenges faced by these adults might be to hold focus groups of invited adults with ID in the shelters. Though this may not be a representative group, helpful information can be obtained.

Morton and Cunningham-Williams (2009) looked at predictors of homeless adults' capacity to give consent, and noted the most accurate factor was Grade 8 education. They reported that chronic homelessness, and a diagnosis of intellectual disability were also predictors, but with less weight. McCreary, as well as other Canadian authors, have advocated more and better follow-up of these adults (Burge, 2009; Lougheed & Farrell, 2007; B. D. McCreary, 2005). Follow-up services should be aware of and provide support to the social, affiliation, financial, medical, and psychiatric needs of adults with mild and moderate delay who are living in fragile situations. Elements of this support should include time-unlimited and possibly lifelong service. These adults are at risk of recurrent decompensation if significant support is withdrawn, or if they face challenges such as a new and serious physical illness such as diabetes, or a relapse of a significant mental illness such as a mood disorder. An option for serving adults who are homeless may include a model called “wrap-around mental health case management.”

Legal charges may be decreased by community supports and services that provide easily accessible meals, recreation, and informal supervision to encourage healthier community and peer involvement. Programs can include modification of standard court diversion for individuals with a mental illness who have been legally charged. There should be easy access to developmentally appropriate programs that support financial planning and management to help with basic budgeting, understanding the risk of credit, tips to discourage borrowing or lending money. It is important that these programs not be literacy based, but rather “plain-talk” based. To avoid financial abuse of extremely vulnerable adults, there should be provision of easier community access to financial capacity assessment. There may be a need for consideration to be given to new laws making it mandatory for professionals to report suspected abuse and neglect of developmentally delayed adults, as is present in the Child Welfare Act for children up to the age of 16 in Canadian provinces.

Supportive housing should have a community integration focus, to allow safe community involvement and encourage a

sense of belonging. A program in the Netherlands described by Clercx and Trentelman (2008) provided targeted supports including housing for homeless adults with “learning disabilities” (a term used in the Netherlands that includes both all levels of intellectual delay, as well as specific learning disabilities) in order to improve quality of life through supporting use of specialized services for mental healthcare and housing.

There is a need for “plain language” information to be provided for people with very limited reading ability, on topics such as healthcare and personal responsibility, access to healthcare, mental illness, tenants and landlord responsibilities for housing, financial issues, and others. The Psychiatric Patient Advocate Office—Ontario (2003) has provided information on understanding community financial capacity assessment for clients themselves using simple language.

SUMMARY AND CONCLUSION

There are many challenges to understanding the issues faced by both the adults with multiple challenges (the “dual diagnosis” group) who are homeless, and the services that wish to provide support and care for them. There needs to be, first, accurate identification of those who are intellectually disabled and currently residing in the homeless shelters; second, a high suspicion of and accurate diagnosis and treatment of their mental illnesses; third, an understanding and addressing of the challenges in obtaining and understanding in what way and why this population is both vulnerable and hard-to-serve; and finally, a provision of services that foster personal autonomy and choice within a community, while preventing neglect and abuse.

The four mental health principles of clinical care, advocacy, research, and education can guide the development of support that is helpful, client centered, and morally and ethically appropriate. Professionals need to be aware that providing choice and empowerment with appropriate support is qualitatively different from providing superficial choice without support, which can and does result in vulnerable adults becoming even more at risk of abuse and neglect.

Clinical care includes services based on the following characteristics: flexibility, meeting the client where he or she lives, consideration of capacity to consent in order to avoid neglect issues, and understanding of the lifelong and pervasive effects of intellectual delay in all facets of life. Effective and directed research is necessary to confirm information that has been clinically identified, and that services offered to this population have the effect that is planned. It will be necessary to address the impression that adults with intellectual delay are not clinically identified.

Appropriate advocacy will ensure that the challenges that adults with a triple diagnosis experience do not exclude them from either clinical and social support, or the scientific study of the homeless population. In addition, there is a need for ongoing education of clients, staff, family members, and healthcare professionals.

In summary, to help adults with a triple diagnosis to function at their best, benefitting from comprehensive supportive treatment and care based on a solid understanding of their needs and abilities, is an important goal. However it is also important to provide these vulnerable adults with protection from both

neglect and abuse by individuals and by society. Respecting an individual's human rights including removing barriers to health-care, housing, freedom of the person, and protection of the law. To be treated with respect is the foundation of this care. Homelessness should not be an acceptable outcome.

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