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INTELLECTUAL DISABILITY (Y LUNSKY, SECTION EDITOR)

Intellectual Disability and Homelessness: a Synthesis of the Literature and Discussion of How Supportive Housing Can Support Wellness for People with Intellectual Disability

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Abstract

Recent Findings Although rates of intellectual disabilities (ID) may be elevated in homeless populations, there is little research on homeless adults with ID whose cognitive and adaptive functioning deficits may affect how they respond to usual supports.

Purpose of Review This literature synthesis describes the prevalence of ID among homeless adults, the needs of adults experiencing homelessness who have ID, and discusses implications for providing Housing First to people with ID. Housing First is an evidence-based intervention commonly delivered to homeless populations.

Summary People with ID are vastly overrepresented in homeless populations, with prevalence estimates ranging from 12–39% across countries, although none are population-based. Limited evidence also suggests that homeless people with ID may have more enduring needs than other homeless people, suggesting a need for longer term supports. More research will be instrumental in determining if Housing First models are appropriate for this population and if adaptations are necessary to account for their unique needs.

Keywords Developmental disability · Homeless persons · Housing First · Intellectual disability · Mental health · Supportive housing

Introduction

There is speculation that adults with intellectual disabilities (ID) are overrepresented in homeless populations and that this group can be extremely vulnerable, with greater potential than other homeless adults for neglect as well as financial, sexual, and emotional abuse [1]. It has also been suggested that this group may struggle more to transition out of homelessness [2].

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However, there is very little research on homeless adults with ID. This leaves large gaps in our knowledge of the prevalence of ID among homeless people and their needs, and makes it more difficult to deliver services that adequately support their wellness. One key determinant of wellness is housing [3], which is the focus of this review.

The purpose of this review is to summarize existing literature on the prevalence and needs of homeless adults with ID and discuss implications for supportive housing via Housing First (HF) models. Specifically, this review will describe:

(1a) The estimated prevalence of ID among homeless populations, and how prevalence was measured,
(1b) Needs of adults experiencing homelessness and ID relative to other homeless people that can pose barriers to wellness, and
(1c) HF as an example of a supportive housing model that may be adapted for homeless adults with ID to promote wellness.

Methods

ID is characterized by lifelong limitations in cognitive and adaptive functioning that impact activities of daily living and originate before age 18 [4]. The prevalence of adults with ID in the general population has been estimated to be at or under 1% in several jurisdictions [5–7].

We reviewed quantitative empirical studies (i.e., review studies or case studies and studies on youth/adolescents were excluded) on the prevalence of ID among homeless adult populations and needs among homeless adults with ID. For these studies to be eligible for inclusion in this review, they had to provide the number of adults with intellectual functioning scores below the cutoff associated with an ID (IQ < 70 or IQ ≤ 70). No exclusions were made related to language; although for some studies, details could not be provided if the article was written in a language other than English.

Prevalence of Intellectual Disabilities in Homeless Populations

The search for literature on prevalence of ID among homeless adults with the criteria noted above yielded ten studies conducted from the mid-1990s to March 2018 in the UK, the USA, the Netherlands, and Japan. Study findings suggesting a much higher prevalence of ID among homeless adults compared to the general population are summarized below by country.

UK, $n = 2$ studies: One study [8] used the National Adult Reading Test (NART) with scores converted to the Weschler Adult Intelligence Scale (WAIS)-Revised and the Raven's Progressive Matrices to study intellectual functioning of entrants to a hostel for homeless men in London, England, in 1991. The authors concluded that 15 of 54 participants (28%) had an IQ in the ID range (IQ score ≤ 70). In another UK study conducted in 2006/7 in northeast England, researchers [9] administered the Wechsler Abbreviated Scale of Intelligence (WASI) to measure IQ for 50 homeless individuals who were registered at a general practice for socially excluded groups, and staying in temporary accommodation for homeless persons. Of the 50 participants, six (12%) satisfied the criteria for an ID.

USA, $n = 1$ study: A 2004 US study [10] examined homeless men living in a shelter in Wisconsin, USA, using the WASI as an IQ measurement tool. Of the 90 participants, 18 (20%) scored in the ID diagnosis range (IQ score ≤ 70).

The Netherlands, $n = 2$ studies: A Dutch research group followed 513 homeless people who had been accepted for an individual program plan in four major Dutch cities (Amsterdam, The Hague, Rotterdam, and Utrecht) over a period of 2.5 years [11, 12•]. The Hayes Ability Screening Index (HASI) was administered to determine the prevalence of ID in the program group. A HASI cutoff score of 85, which corresponds with an IQ of 70 or less, was used to determine the presence of a suspected ID. During 2011/12, the first study on this sample reported that at 6 months after follow up, 29.5% (114 of 387 participants) had an ID [11]. In 2013, the second study [12•] examined measurements at 18 months after 51 participants had been lost to follow-up, resulting in a sample of 336 individuals. The suspected rate of ID (31%, 104 of 336 participants) was similar to the rate observed in the first study.

Japan, $n = 4$ studies: Four studies were conducted in Japan. Of them, three took place in the city of Nagoya where recruitment occurred through the Sasashima Support Center, a social welfare agency [13–15]. The WAIS III and the Japanese Adult Reading Test (JART) were to measure current and premorbid IQ respectively [13, 14]. Measuring both concepts helped the authors determine if a participant's lower mental capacity was congenital or acquired. Based on the WAIS III, 7 of 18 participants (39%) met criteria for ID (IQ < 70) [13]. Two other papers published on a larger sample concluded that 39 of 114 (34.2%) participants had an ID [14, 15]. Findings from the fourth Japanese field study concluded that 56 of 164 participants (34.2%) had an IQ less than 70 [16]. No additional details are available on this study because the article [16] is in Japanese.

In summary, estimates of prevalence of ID in homeless samples studies varied considerably within and across

countries (12–39%). There may be several reasons for this variability, although most studies did not provide enough detail to adequately evaluate their methodology. First, the studies may have applied different eligibility criteria which would have affected whether people with ID were included in the study. Specifically, some studies may have excluded some people with severe ID, believing that they were not able to consent. Second, the samples may have proportion of people with English language proficiency or who are newcomers, which could affect their performance on the IQ assessment measures and identification of ID. Third, differences in the timing of recruitment or location of shelter may have affected who was included in the sample, and their rate of ID. Fourth, several different assessment tools (WAIS, NART, WASI, HASI, and JART) were used to measure IQ. Of those measures, only the WAIS is a standardized IQ test. It provides a complete profile of intellectual functioning and is the gold standard. The WASI (a short form of the WAIS) correlates highly with the full WAIS and takes less time to administer because it includes four subtests instead of eight or nine included in the WAIS. The WASI includes two of the Verbal Comprehension and Perceptual Reasoning indices but ignores two other indices (Working Memory and Processing Speed). The HASI is a screening tool that can be used to screen for the presence of an ID. The NART and JART are reading tests used to estimate premorbid IQ by assessing participants' pronunciation of words on a reading list; scores on these tests also correlate with tests of full-scale IQ, like the WAIS [17]. The result is that the criteria for determining the presence of ID were varied across studies. Fifth, none of studies used measures of adaptive functioning, which may have contributed to overestimates of ID. Finally, the variations in rates of ID in homeless populations may reflect variation in several key factors that differ across countries, such as newcomer screening, and social and health services. More rigorous research, using representative samples and reliable, consistent measures of ID are needed to better understand the prevalence of ID in homeless populations and the extent to which it is overrepresented among homeless groups.

The Needs of Adults Who Are Homeless and Have Intellectual Disabilities Relative to Other Homeless People

Despite calls to better understand the needs of homeless people with ID, [1, 14, 18•] to the authors' knowledge, only three studies have been published on this topic. Two of these papers came from the Dutch studies noted above and compared homeless people with ID to other homeless people [11, 12•]. The third described research conducted in Montreal, Canada, that looked at homeless people with ID, and drew comparisons to a prior study on a general homeless population sample in a similar geographic region [19].

The first Dutch paper compared 114 participants with a suspected ID to 273 homeless participants with no suspected ID [11]. The group with a suspected ID was more likely to have psychological distress, somatization, and depression, which suggests greater mental health needs. Homeless people with a suspected ID were also more likely to experience substance dependence than homeless people without a suspected ID, although they did not report more substance use overall. In terms of social issues, individuals with a suspected ID also reported higher rates of psychosocial and relationships problems.

The second Dutch study [12•] compared self-reported care needs over time for 104 homeless people with a suspected ID to 232 homeless people with no suspected ID. The need domains examined (housing and daily life, finances and daily activities, physical and dental health, mental health, safety and protection against violence, social relations, and children) can serve as barriers or enablers to wellness. For each domain, needs were categorized as "met," "unmet," or "no need." For most domains, the groups were similar in terms of the proportion reporting no need at baseline. For domains in which the proportion of participants with no need changed across time, this change tended to be similar for both groups (i.e., Domains: finding housing, finding work, mental health, and empowerment). In contrast, for the financial domain, the proportion of participants who reported no need decreased more for the no ID group than the suspected ID group. The opposite pattern was observed for physical health; for this domain, the proportion of participants with no need increased significantly from baseline to follow-up for those with a suspected ID, but not for the other group. The proportion of participants whose unmet needs decreased across time was similar for both groups. At the 18-month follow-up, there were fewer domains where individuals with suspected ID reported having no needs compared to those with ID. Despite many similarities, the authors interpreted these trends as evidence that the enduring nature of their deficits (e.g., struggles to preform risk assessment or follow care instructions) means that they may require long-term supports [12•].

A study conducted in Montreal, Canada, in the 2000s described 68 homeless people with ID [19]. Thirty-seven percent of participants attributed their homelessness to a substance abuse problem, while 31% cited the loss, or breakdown, of a relationship with a parent or loved one as the reason for their homelessness. Common issues were mental disorders (60%), substance abuse (56%), physical health problems (43%), and legal problems (31%). This sample of homeless people with an ID was compared to a sample of 757 homeless people from an earlier study [20]. This 1998 study recruited their sample from soup kitchens, shelters, and day centers for homeless people in Montreal and Quebec City. Comparisons between the two samples showed that in the sample with ID may have had different needs because a lower proportion of persons

were living on the street and/or in shelters (21 vs. 45%) and more people who maintained contact with their family (47 vs. 18%). Physical health problems (47 vs. 73%) and criminal justice involvement (38 vs. 80%) were less common among homeless persons with ID compared to the other homeless sample. The proportions of individuals with mental health, substance use, or sex trade involvement were comparable between the two groups.

Although these studies suggest that homeless people with ID may have challenges that require more intense or more enduring supports, more research is needed to identify the need domains for which this is accurate and to clarify the nature of supports that would best serve this population. Building this body of research could provide more compelling evidence that homeless individuals with ID may benefit from customized support programs and housing arrangements [11, 12•].

Housing First Interventions for Homeless Adults with Intellectual Disabilities

In many countries, current policies and practice for homeless adults favor a HF approach [21]. HF has been shown to be effective in increasing tenure in housing, decreasing use of hospital services addition, and in improving quality of life [21–24].

Originally developed in New York City in the early 1990's [25], HF was designed to address homelessness in individuals with mental illness, a large proportion of whom also have substance use issues. In HF approaches, housing is viewed as a basic human right, as well as a prerequisite for achieving progress in other areas, such as mental health and substance use [25]. A core tenet in HF is to provide housing with no "readiness" conditions, including no requirement for participants to be drug or alcohol free. This contrasts with the previously dominant approach (Treatment First) in which receiving housing is contingent upon certain readiness requirements that include abstinence (i.e., individuals must demonstrate abstinence from alcohol and drug use to qualify for housing). Critics argue, however, that the rigidity of Treatment First can create obstacles to program retention [24].

Other key elements of HF are an emphasis on consumer choice and self-determination, a recovery orientation that includes strengths-based and harm reduction strategies, and a focus on community integration [21, 23]. In HF other services such Intensive Case Management (ICM) or Assertive Community Treatment (ACT) are generally also provided, in addition to housing. ACT is a well-established and effective model for providing intensive treatment and psychosocial rehabilitation services to small caseload of clients with severe mental illnesses [29]. ACT is usually provided by an interdisciplinary team and assist clients with crisis supports, medication administration, and attending health care appointments. ACT teams often also assist clients with social and employment finding effort. ICM is a less intensive intervention than ACT. As part of ICM, individual case-managers broker necessary services to other supports in the community [26].

Several studies comparing HF to treatment as usual among the general homeless population have shown the effectiveness of HF in increasing tenure in housing, decreasing use of hospital services, and improving quality of life [21, 23–25, 27]. However, we found no published studies investigating the implementation or effectiveness of HF or any other type of housing interventions for homeless adults with ID. This means there is an absence of knowledge on what subgroups of individuals with ID are more likely to succeed in HF and which individuals with ID may struggle more in HF.

While some researchers have speculated that HF is a viable option for homeless adults with ID [12•], others have cautioned against implementing HF without careful consideration of the needs of the subgroup being served [21]. Building on the first two sections of this review, in the third section we discuss the aspects of HF that could be suitable for homeless adults with ID and adaptations that may be needed for this unique population.

Aspects of Housing First Suitable for Individuals with Intellectual Disabilities

There are several key components of HF which are applicable to serving people with ID. First, viewing housing as an unconditional human right is a tenet that should apply to all people, regardless of disability status. Second, the emphasis on choice, self-determination, strengths, and increased community participation embedded in HF is consistent with current philosophy underpinning services and supports provided to adults with ID [28•]. Finally, ICM and ACT, which are commonly integrated into HF programs, have been employed to support adults with ID although more research is needed on the effectiveness of these programs for this population [29, 30]. A UK trial of ICM found that people with borderline IF fared better than people with normal IF [31]. Two other UK studies found that ACT was as effective for people with and without ID [32, 33].

Adapting Housing First to Individuals with Intellectual Disabilities

In some ways, the needs of homeless people with ID overlap with the general homeless population. For example, as demonstrated above, the rates of mental illness and substance use issues are elevated in both populations, although possibly more common in homeless persons with ID. It seems that there are, however, ways in which the populations differ.

One important finding is that the needs of those with ID in particular domains can be more enduring, requiring high support for longer duration [12•].

A second important difference in the two populations is the rate of cognitive deficits. It is well established that homeless people are more likely to have cognitive deficits compared to the general population [34]. These impairments often lead to difficulties engaging with services [34]. Since, by definition, all homeless adults with ID have cognitive deficits, they are more likely than their other homeless counterparts to miss appointments because they forget the time or struggle to navigate their way to the office. They may also have trouble adhering to treatment recommendations or follow-up instructions without support. Difficulties with social skills, social problem solving, and living independently may also be more prominent for this group [34].

Unfortunately, research on people experiencing homelessness has not treated people with ID as a separate subgroup. Based on clinical observation, Lougheed and Farrel argue that homeless people with ID have unique issues beyond those noted above that inhibit service engagement [1]. They may have a "cloak of competence" that masks poor judgment and decision-making abilities. These characteristics can have several negative effects, such as increased vulnerability to abuse and service providers overestimating their capabilities and failing to understand why they are not adhering to treatment. These individuals also may have developed challenging personality defenses and a mistrust of authority, which make them difficult for providers to engage [1].

Due to the complex needs and deficits in cognitive and adaptive functioning associated with ID, it is important to determine if the common HF approach applied to the general homeless population is appropriate for homeless adults with ID. The only example of a HF approach applied to adults with ID we found was undertaken in Ontario, Canada, and has yet to be published [35]. Data from that project showed that about one-third of homeless adults with more mild ID could live in the community. Many of these people lived in scattered housing units that followed a HF approach and had intensive supports (e.g., case management with a ratio of 1 case manager to 8 clients). For a subset of these individuals, however, living in the community required congregate living arrangements and 24-h on-site supports. The remaining clients with ID (roughly two-thirds) were deemed too complex for the available housing due to their need for intensive medical, behavioral, and addiction supports, in addition to their limited adaptive living skills. Support needs for many of these individuals were so high that even the congregate housing with 24-h on-site support was not sufficient, often because desired programming (e.g., managed alcohol programs) were not provided or because staff lacked sufficient training or capability to support this group [35]. Given that evidence on the success of HF for homeless adults with ID is limited, HF variations that have been provided to other complex groups should be considered. One example is that for homeless adults with alcohol dependence and other complex needs, HF provided in a congregate format has been linked to positive clinical outcomes and cost savings [36, 37].

Another consideration is, contrary to commonly held assumptions, rates of substance abuse in the ID population are comparable to those in the general population [38–41]. The high prevalence of substance use challenges suggests that supplementing housing with access to addiction services is important. Unfortunately, the substance use support that is common in other sectors (e.g., HIV) continues to be largely absent in the ID sector, and there is little evidence of effective substance use treatments for people with ID [42, 43]. While substance use support is an integral part of HF, it may need to be adapted to take into account the unique needs of homeless people with ID.

While HF approaches also typically provide access to physical and mental health services, evidence has consistently shown people with ID have complex needs due to multiple comorbidities and communication deficits [5, 44]. Managing these needs requires more expertise and training than is possessed by most healthcare professionals, [45, 46] and as a result, people with ID lack access to appropriate and targeted care [47–49]. However, building capacity and interest in health care providers is difficult. Providing regular workshops or rounds can update providers about best practice approaches for this population. However, since caring for this group is often already time consuming, determining how to incentivize providers to participate in on-going training and other activities to stay up to date on best practices may be difficult [45, 46]. HF initiative for adults with ID may require access to medical professionals who have experience and expertise serving patients with ID.

Finally, if adapting HF to persons with ID, additional services commonly provided to enhance the functioning of adults with ID in general should be considered. For example, these include behavior therapy, occupational therapy, audiology, counseling/psychotherapy, and speech language pathology [50–52].

Summary and Conclusion

Overall, the literature on homelessness and ID is small but suggests that people with ID are overrepresented in homeless populations. The range of prevalence estimates across countries extends from 12 to 39%, although none are population-based estimates.

We know little about the needs of this population of homeless adults with ID, highlighting the need for further research to inform service planning and delivery. Based on the limited available evidence, it is difficult to identify the unique needs of this group compared to the general homeless population, although the potentially more enduring nature of their support

needs could require comprehensive longitudinal supports. There is a large gap in knowledge on housing interventions which promote wellness for this population. It can be argued that many aspects of the HF model may be applied to supportive housing for homeless people with ID. We need more research to determine what adaptations to HF may be required for this population, given their cognitive and adaptive functioning.

More literature will be instrumental in understanding how to adapt existing housing models for adults with IDD experiencing homelessness with ID to improve outcomes for this population.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interests.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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