

Self-reported care needs of Dutch homeless people with and without a suspected intellectual disability: a 1.5-year follow-up study

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What is known about this topic

- Cognitive impairments are prevalent among homeless people.
- Homeless people with a suspected intellectual disability have more psychosocial problems.

What this paper adds

- Using the Hayes Ability Screening Index, 31% of homeless people who reported themselves at a central access point for social relief in four major Dutch cities had a suspected intellectual disability.
- Homeless people with a suspected intellectual disability have care needs for a longer period of time than those without a suspected intellectual disability.
- Homeless people with a suspected intellectual disability want to live independently, but with ongoing housing support by appointment.

Abstract

Cognitive impairment is a prevalent problem among the homeless and seems related to more psychosocial problems. However, little is known about the care needs of the subgroup of homeless people with an intellectual disability compared to those without an intellectual disability and how their care needs develop over time. This study explores self-reported care needs within a broad range of life domains among Dutch homeless people with and without a suspected intellectual disability to gain insight into the transition of self-reported care needs from baseline to follow-up in both subgroups. This longitudinal study is part of a cohort study among homeless people who had been accepted for an individual programme plan in four major Dutch cities. The initial cohort consisted of 513 participants who were interviewed in 2011. At 1.5-year follow-up, 336 participants (65.5%) were also interviewed and screened for intellectual disability. Of these participants, 31% (95% CI 26.2–36.1) had a suspected intellectual disability. For both groups, between baseline and follow-up, the number of 'unmet care needs' decreased significantly and the number of 'no care needs' increased significantly, while at follow-up, participants with a suspected intellectual disability reported 'no care needs' on significantly fewer life domains than those without a suspected intellectual disability (mean numbers 16.4 vs. 17.5). Between baseline and follow-up, 'met care needs' decreased significantly on housing for both groups, and increased on finances and dental care for participants with a suspected intellectual disability. At follow-up, participants with a suspected intellectual disability more often preferred housing support available by appointment than those without a suspected intellectual disability. These findings suggest that homeless people who had been accepted for an individual programme plan with a suspected intellectual disability have care needs for a longer period of time than those without a suspected intellectual disability. Providing care to homeless people with a suspected intellectual disability might require ongoing care and support, also after exiting homelessness. Support services should take this into account when considering their care provision and planning of services.

Keywords: cohort studies, homelessness, intellectual disabilities, social care

Introduction

Cognitive impairment is a prevalent problem among homeless people and is receiving increased attention. A review on cognitive function in homeless adults showed that 30%–40% of homeless adults have a cognitive impairment (Spence *et al.* 2004). Within a cohort of homeless people in the Netherlands, around 30% had a suspected intellectual disability (Van Straaten *et al.* 2014). However, little is known about the care needs of this relatively large subgroup within the homeless population.

Among homeless people in general, a well-explored area is service use and care needs. Homelessness is associated with higher rates of mental health problems, substance use problems (Fazel *et al.* 2008) and medical problems (Hwang 2001); moreover, unmet care needs and underutilisation of services are reported (Baggett *et al.* 2010, Krausz *et al.* 2013, Palepu *et al.* 2013). Research into intellectual disability also focuses on health disparities and unmet health-care needs of people with an intellectual disability compared to the general population (Krahn *et al.* 2006). For example, psychiatric conditions of persons with an intellectual disability are not always adequately addressed (Lewis *et al.* 2002). Also, in a population of homeless people, those with a suspected intellectual disability are reported to have more psychosocial problems in terms of psychological distress and substance dependency than those without a suspected intellectual disability (Van Straaten *et al.* 2014); all this implies greater care needs for this subgroup.

Because of the unmet care needs among people with an intellectual disability and the increased psychosocial problems of homeless people with a suspected intellectual disability, more insight is needed in the care needs of homeless people with a suspected intellectual disability. Moreover, in addition to (mental) healthcare needs, a broader range of care needs should be examined, including (among others) housing, finances, basic skills (i.e. reading, writing), empowerment and social contacts, because fulfilling care needs for these life domains might enable homeless people to better participate in the community. This will also enable us to present a more comprehensive overview of the care needs of homeless people with and without a suspected intellectual disability, because most reports on care needs among the homeless have focused mainly on (unmet) health-care needs (Desai & Rosenheck 2005, Baggett *et al.* 2010, Kertesz *et al.* 2014).

The present study adds a longitudinal component by reporting the care needs of homeless people in the Netherlands with and without a suspected intellec-

tual disability, at the time they reported to the social relief system and 1.5 years later. The follow-up measurement allowed us to explore changes and transitions of care needs of the homeless over time, and examine whether these patterns differ between homeless people with and without a suspected intellectual disability.

To our knowledge, no longitudinal study has compared the self-reported care needs of homeless people with and without a suspected intellectual disability. With regard to homeless people with and without a suspected intellectual disability, this study aims to (i) report the number of life domains with an 'unmet care need', with a 'met care need' and with 'no care need' at baseline and at follow-up; (ii) explore the specific life domains in which care needs are reported and the extent to which needs were met at baseline and at follow-up; (iii) provide insight into the transitions of 'unmet care needs' from baseline to follow-up on the five domains with the highest reported 'unmet care needs'; and (iv) explore the relationship between a suspected intellectual disability and housing support needs.

Understanding the similarities and differences in the care needs of subgroups of the homeless is essential for organising services and improving the quality of life of homeless people. This study may help to develop care programmes which fit the self-reported care needs of homeless people in general and, in particular, of those who are more vulnerable due to an intellectual disability.

Methods

Ethics statement

This study complies with the criteria for studies which have to be reviewed by an accredited Medical Research Ethics Committee. Upon consultation, the Medical Review Ethics Committee region Arnhem-Nijmegen concluded that the study was exempt from formal review (registration number 2010/321). The study was conducted according to the principles expressed in the Code of Conduct for health research with data (<http://www.federa.org/>). All participants were aged ≥ 18 years and gave written informed consent.

Design and participants

This study is part of a larger observational longitudinal multi-site cohort study following homeless people for a period of 2.5 years, starting from the moment they reported themselves at a central access point for

social relief in 2011 in one of the four major cities in the Netherlands (Amsterdam, The Hague, Rotterdam and Utrecht) and were accepted for an individual programme plan. The main aim of the study was to determine predictors of an improved quality of life and stable housing among homeless people, and to explore their experiences with an individual programme plan. More than 500 homeless people were included in this study to maintain adequate statistical power to achieve the main aim, even with a dropout rate of around 30%. In the Netherlands, it is obligatory for every homeless person to report at a central access point for social relief in order to gain access to social relief facilities, such as a night shelter. After accepting an individual programme plan, the delivery of care and the supply of living accommodation are provided by local care agencies. The municipalities act as policy co-ordinators and case managers are responsible for monitoring the execution of the individual programme plan.

At baseline, all study participants satisfied the criteria set by the four major Dutch cities at that time for starting an individual programme plan. These include: aged ≥ 18 years, having legal residence in the Netherlands, residing in the region of application for at least 2 years during the last 3 years, having abandoned the home situation and being unable to hold one's own in society.

The participants, consisting of homeless adults (aged ≥ 23 years) and young adults (aged 18–22 years), were divided over the four cities in accordance with the inflow of homeless people at the central access points for social relief.

No data were available on how many potential participants were approached and how many refused to participate. Therefore, in order to obtain information about the representativeness of the study participants, we compared the total population of homeless adults and young adults who reported themselves at a central access point for social relief in the four major cities in 2011, with the study participants, on age and gender.

Study procedure at first measurement

At the start of the study in January 2011, potential participants were approached either at a central access point for social relief (one in each city) by an employee of the access point, or at a temporary accommodation where they stayed shortly after entering the social relief system, by the researchers or interviewers. Potential participants were informed about the study by means of leaflets, posters and face-to-face information provision. When a potential

participant expressed interest in taking part in the study, the researchers contacted that person to explain the study aims, the interview procedure and the informed consent. When the participant then agreed to participate based on the terms explained to them, an interview appointment was scheduled.

A trained interviewer met the participant at the participant's location of choice (generally a shelter facility, public library or the researcher's office). All participants gave written informed consent. Participants were interviewed face-to-face using a structured questionnaire (mean duration of 1.5 hours) and received €15 (\pm \$19) for their participation. The interviews were held in Dutch, English, Spanish or Arabic.

We anticipated problems that may occur when using questionnaires designed for the general population among people with an intellectual disability (e.g. acquiescence, not understanding the question, getting tired during the interview). Participants were told at the start of the interview that they could take a break during the interview whenever they wanted to. Also, they were allowed to have missing answers in case they did not know what to answer or did not want to answer ('Don't know' and 'No answer' options were available and were regarded as missing answers); this procedure is recommended for the use of questionnaires among people with an intellectual disability (Finlay & Lyons 2001). We presented the questionnaires orally to take into consideration participants who may have trouble with reading.

Study procedure at follow-up measurements

Participants were contacted for the second measurement 6 months after the first measurement (T1) and for the third measurement 18 months after the first interview (T2) by telephone, e-mail, letter, their social contacts, their caregiver/institution or private messages via social media. Participants were interviewed in the same way as during the first measurement, i.e. face-to-face, with a structured questionnaire (mean duration of 1.5 hours), and with the same support options (optional break during the interview, cards with answering categories, etc.). The participants received €20 (\pm \$28) for participation in the second interview and €25 (\pm \$34) for participation in the third interview.

We compared respondents with non-respondents on demographic variables (age, gender, education, ethnicity) as reported at the first measurement and on results of the intellectual disability screener to assess potential selective dropout.

Measurements

Demographic characteristics

Demographic characteristics including gender, age, ethnicity and educational level were assessed. Ethnicity was categorised into 'native Dutch' when the participant and both parents were born in the Netherlands, 'first-generation immigrant' when participants were foreign born, and 'second-generation immigrant' when participants were born in the Netherlands but one or both of their parents were foreign born. Education was categorised as 'lowest' when the participant completed primary education at the most, as 'low' when the participant completed pre-vocational education, lower technical education, assistant training or basic labour-oriented education, as 'intermediate' when the participant completed secondary vocational education, senior general secondary education or pre-university education, and categorised as 'high' when the participant completed higher professional education or university education.

Housing status

Housing status was assessed by asking the participants where they slept the previous night. These locations were then divided into four categories: (i) Homeless: staying in an emergency shelter or night shelter; residing in transitional accommodation (where the period of stay is intended to be short term); living rough, i.e. living on the streets or in public spaces; (ii) Institutionalised: residential care or supported accommodation; staying in a medical institution, addiction care institution or psychiatric hospital; staying in a correctional or penal institution; living in residential care or supported accommodation for people with mental health or substance abuse problems; (iii) Marginally housed: staying with friends, relatives or acquaintances (temporarily); and (iv) Independently housed: renting a house, room or apartment or owning one; residing with friends, relatives or acquaintances (permanent). The few participants who were housed at baseline (see Table 1) had already been accepted for an individual programme plan because of a forthcoming eviction.

Service use

Service use was assessed using a questionnaire developed by Impuls – Netherlands Center for Social Care Research (Lako *et al.* 2013) that assesses whether participants have used different types of services during the last 6 months. Data were collected on the use of medical care, mental healthcare and housing assistance during the past 6 months.

Table 1 Baseline characteristics of participants with and without a suspected intellectual disability

| Baseline characteristics | Suspected intellectual disability (<i>ns</i> range* = 102–104) | No suspected intellectual disability (<i>ns</i> range* = 227–232) | <i>P</i> -value |
|--------------------------------|--|---|------------------------------|
| Mean age in years (SD) | 40.7 (12.8) | 36.6 (13.0) | 0.007 |
| Gender, % male (<i>n</i>) | 84.6 (88) | 70.3 (163) | 0.005 |
| Housing status, % (<i>n</i>) | | | 0.015[†] |
| Housed | 5.8 (6) | 3.9 (9) | |
| Marginally housed | 7.7 (8) | 16.0 (37) | |
| Institutionalised | 5.8 (6) | 13.9 (32) | |
| Homeless | 80.8 (84) | 66.2 (153) | |
| Education, % (<i>n</i>) | | | <0.001[‡] |
| Lowest | 44.7 (46) | 25.5 (59) | |
| Low | 36.9 (38) | 50.2 (116) | |
| Intermediate | 5.8 (6) | 17.7 (41) | |
| High | 12.6 (13) | 6.5 (15) | |
| Ethnicity, % (<i>n</i>) | | | 0.323 |
| Native Dutch | 37.3 (38) | 41.4 (94) | |
| First-generation immigrant | 45.1 (46) | 36.6 (83) | |
| Second-generation immigrant | 17.6 (18) | 22.0 (50) | |
| Service use, % (<i>n</i>) | | | |
| Medical care (% used) | 69.2 (72) | 71.6 (166) | 0.665 |
| Mental healthcare (% used) | 32.7 (34) | 25.9 (60) | 0.197 |
| Housing assistance (% used) | 24.0 (25) | 23.7 (55) | 0.947 |

P-values in bold indicate a significant difference ($P < 0.05$).

**ns* range was given due to occasional missing data.

[†]Post hoc chi-squared: marginally housed; intellectual disability <no ID; $\chi^2(1) = 4.090$, $P < 0.05$, OR = 0.437; institutionalised; intellectual disability <no intellectual disability; $\chi^2(1) = 4.375$, $P < 0.05$, OR = 0.381; homeless; intellectual disability >no intellectual disability; $\chi^2(1) = 7.133$, $P < 0.01$, OR = 2.141.

[‡]Post hoc chi-squared: lowest; ID >no intellectual disability; $\chi^2(1) = 11.797$, $P < 0.01$, OR = 2.353; Low; ID <no intellectual disability; $\chi^2(1) = 5.041$, $P < 0.05$, OR = 0.580; Intermediate; ID <no intellectual disability; $\chi^2(1) = 7.556$, $P < 0.01$, OR = 0.287.

Suspected intellectual disability

To measure a suspected intellectual disability, the Hayes Ability Screening Index (HASI) (Hayes 2000) was used. The HASI is a brief, individually administered screening index of intellectual abilities. It was initially developed to indicate the possible presence of an intellectual disability among people in contact with the criminal justice system and was designed to be culture-fair. Because it is not a full-scale diagnostic instrument in itself, it only gives an indication of whether a person has an intellectual disability (IQ < 70) and whether full-scale diagnostic assessment is recommended. Only after a full-scale diagnostic

assessment, including intellectual functioning, concurrent deficits in adaptive behaviour and manifestations before the age of 18 years (Schalock *et al.* 2010), can a diagnosis of intellectual disability be made. Therefore, in the present study, we used the term 'suspected intellectual disability' to clarify that we can only indicate that there might be an intellectual disability.

The index consists of four subtests: background items, backwards spelling, a puzzle and clock drawing, and can be administered in 5–10 minutes. The HASI shows a significant correlation with other psychometric tests measuring cognitive ability (0.627 for the Kaufman Brief Intelligence Test and 0.497 for the Vineland Adaptive Behavior Scales) (Hayes 2000). A HASI cut-off score of 85 was found to be the optimum for discriminating between participants with and without a suspected intellectual disability, with a sensitivity of 82.4 and specificity of 71.6 (Hayes 2000). This is the cut-off score used in the present study to distinguish between participants with 'suspected intellectual disability' (HASI score <85, corresponding to an IQ < 70) and 'no suspected intellectual disability' (HASI score of ≥85, corresponding to an IQ ≥ 70). We used the Dutch version of the HASI, which was provided by the developers of the HASI.

Care needs

Care needs were assessed using a questionnaire developed by Impuls – Netherlands Center for Social Care Research (Lako *et al.* 2013). The response categories were based on the format of the Short Form Quality of Life and Care questionnaire (Wennink & Van Wijngaarden 2004). Needs were considered on seven domains, which were subdivided into several items: Housing and daily life (finding housing, household care, self-care); Finances and daily activities (finances, daily activities, finding work, basic skills (reading, writing, calculating), transport; Physical health (physical health, alcohol use, drug use, dental care, nutrition); Mental health [mental health, empowerment (assertiveness, self-defence courses)]; Safety and protection against violence (own safety, safety of other people); Social relations (family contacts, social contacts, relationship with partner) and Children (relationship with own children, help for own children) (22 life domains in total). For each item, two questions were asked: (i) 'Do you want help on. . . ?' and (ii) 'Do you get help on. . . ?' A confirmative response on both questions was categorised as a 'met care need', a confirmative response on the first question and a negative response on the second was categorised as 'unmet care need' and two negative responses or a negative response on the first question and a confirmative response on the second question was cate-

gorised as 'no care need'. A negative response on the first question and a confirmative response on the second ('unsolicited care') was rare (9.6% at the most for finances at follow-up). For statistical purposes, and because these latter participants reported no care needs, they were categorised as having 'no care need'.

When a care need was not relevant, e.g. concerning 'relationship with own children' because the participant had no children, that care need was handled as missing for that participant. Due to missing values on a limited number of life domains, in Table 2 the counts for 'unmet care need', 'met care need' and 'no care need' do not add up to 22. For both measurements, no significant relationship was found between a suspected intellectual disability and the number of missing values on care needs.

The questionnaire has been used in research among homeless youth (Krabbenborg *et al.* 2013) and abused women (Wolf *et al.* 2006, Jonker *et al.* 2012).

Housing support needs

To assess the housing support needs, questions were asked regarding where participants would like to live (e.g. independent housing, a facility, no permanent place), whether they would like to have housing support and, if so, what type of support they would like. The two support options were: (i) support on-call, i.e. the participant prefers to ask for support himself/herself in case of a demand for services, or (ii) support by appointment, i.e. the participant prefers to have regular appointments (e.g. once every week). The questionnaire for this was developed by Impuls – Netherlands Center for Social Care Research and has

Table 2 Number of life domains (22 in total) with an 'unmet care need', a 'met care need' or 'no care need' at baseline (T0) and after 1.5 years (T2) for participants with a suspected intellectual disability and without a suspected intellectual disability*

| | Suspected intellectual disability (<i>n</i> = 104) | | No suspected intellectual disability (<i>n</i> = 232) | |
|-----------------|--|---------------------------|---|---------------------------|
| | T0 | T2 | T0 | T2 |
| Unmet care need | 3.6 (2.7) | 1.9 (2.1) [†] | 2.9 (2.7) | 1.6 (1.9) [†] |
| Met care need | 2.3 (1.8) | 2.4 (2.1) | 2.2 (1.9) | 1.8 (1.8) |
| No care need | 15.0 (3.5) | 16.4 (3.2) ^{†,‡} | 15.7 (3.0) | 17.5 (2.7) ^{†,‡} |

Values are presented as mean (SD).

*Repeated-measures ANCOVA adjusted for age and gender.

[†]*P* < 0.05 for time of measurement (within subjects).

[‡]*P* < 0.05 for suspected intellectual disability vs. no suspected intellectual disability (between subjects).

been used in research among homeless people (Vocks *et al.* 2008).

Statistical analysis

Descriptive analyses were performed to describe the housing status, demographic characteristics and care use for participants with and without a suspected intellectual disability. Relationships between suspected intellectual disability and demographic characteristics were analysed using chi-squared tests for categorical data (gender, housing status, education, ethnicity, service use) and a *t*-test for the continuous variable (age). To determine the effect of these factors on the number of life domains with an 'unmet care need', a 'met care need' and 'no care need', a repeated-measures analysis of covariance (ANCOVA) was performed. The follow-up period (T0–T2) was included as a within-group factor, suspected intellectual disability (yes or no) as a between-group factor, and the baseline variables age and gender as covariates. To test for differences between the two groups on the number of domains with an 'unmet care need', a 'met care need' and 'no care need' at the baseline measurement (T0) and at the follow-up measurement (T2), an ANCOVA was performed for both measurements, with age and gender as covariates.

To analyse changes in care needs between baseline measurement and follow-up, a McNemar–Bowker test was used (3×2 categorical data) separately for those with and those without a suspected intellectual disability. After a significant result ($P < 0.05$) of the McNemar–Bowker test, McNemar's test was used for 2×2 categorical data for each care need category (unmet care need, met care need, no care need). Missing values were removed from the analyses. Life domains with no occurrence in one or more of the three categories of care needs for either the baseline or the follow-up measurement could not be analysed. This was the case for self-care (both suspected intellectual disability and no suspected intellectual disability group), transport (no suspected intellectual disability group) and safety of other people (both suspected intellectual disability and no suspected intellectual disability group).

Relationships between a suspected intellectual disability and housing support needs were analysed using chi-squared tests for categorical data. All statistical analyses were conducted with the statistical software package IBM SPSS Statistics version 19.

Results

Of the initial cohort of 513 participants, 344 (67.1%) were also interviewed for the two follow-up measure-

ments. For the purpose of the present study, we excluded eight participants who did not complete the screener for intellectual disability. Of the latter, four were not screened for intellectual disability because of a language barrier and four refused to be screened for intellectual disability. Therefore, this study consists of 336 participants (65.5% of the initial cohort) who were interviewed for the two follow-up measurements and completed the screener for intellectual disability. Compared to respondents, non-respondents were on average younger (33.4 years vs. 37.8 years) and more often had a non-native Dutch ethnicity (71.6% vs. 59.8%). No selective non-response was found with respect to gender (74.7% of the respondents was male, 80.2% of the non-respondents was male), education and the result of the intellectual disability screener (having a suspected intellectual disability or not).

No data were available on how many potential participants were approached and how many refused to participate. Comparison of the total population of homeless adults and young adults who reported themselves at a central access point for social relief in one of the four major cities in 2011 revealed that adult participants (aged ≥ 23 years; $n = 410$) were representative in terms of age and gender. Young adult participants (aged 18–22 years; $n = 103$) were representative in terms of age but, in this subgroup, males were over-represented (60.2% younger males in the cohort vs. 49.2% younger males in the total group).

Baseline characteristics of participants with and without a suspected intellectual disability

In this sample of 336 participants, 104 (31.0%, 95% CI 26.2–36.1) had a suspected intellectual disability and

Box 1 Case description 1.

Chantal is a woman who is almost 50 years old, with short hair and wearing a jogging suit. She has a loud voice, is very straightforward and talks a lot. Although she had her own apartment for a long time, her debts and problems piled up and she was eventually evicted. She has strong opinions about the social workers in the facility where she now lives, which is specifically for homeless people with an intellectual disability. She says that most of them are good – but they shouldn't think that they know better than herself, what is actually good for her. 'I may have a . . . ehm . . . how do they call this again . . . (mild intellectual disability, ed.) but that doesn't mean they can treat me like a child'. Eventually, she wants to live independently again – but with some assistance for her finances and administration: she says 'I'm not an expert in these things'.

232 (69.0%, 95% CI 63.9–73.8) did not have a suspected intellectual disability; Table 1 presents the baseline characteristics of these two subgroups. The mean age of participants with a suspected intellectual disability was significantly higher than that of those without a suspected intellectual disability, and significantly more participants with a suspected intellectual disability were male. Participants with a suspected intellectual disability were less likely to be marginally housed and less likely to be institutionalised, but more likely to be homeless at baseline than participants without a suspected intellectual disability. Participants with a suspected intellectual disability were more likely to fall in the lowest category of education and less likely to fall in the low or intermediate category.

Self-reported care needs at baseline and at 1.5-year follow-up

Unmet care needs

Table 2 shows that at both baseline and follow-up, there was no significant main effect of having a suspected intellectual disability on the number of life domains with unmet care needs. However, there was a significant main effect of time of measurement on the number of domains with an unmet care need ($F(1, 332) = 9.57, P = 0.002$): participants with and without a suspected intellectual disability reported unmet care needs on significantly fewer domains at follow-up (1.9 and 1.6 respectively) compared to baseline (3.6 and 2.9 respectively). No significant interaction effect between time of measurement and having a suspected intellectual disability on the number of domains with an unmet care need was found.

Met care needs

At baseline and follow-up, there was no significant main effect of having a suspected intellectual disability on the number of life domains with met care needs (Table 2). Also, there was no significant main effect of time of measurement on the number of domains with a met care need, and no significant interaction effect between time of measurement and having a suspected intellectual disability on the number of domains with a met care need.

No care needs

At baseline, there was no significant main effect of having a suspected intellectual disability on the number of life domains with no care needs. At follow-up, participants with a suspected intellectual disability reported 'no care needs' on significantly fewer

domains (16.4) than participants without a suspected intellectual disability (17.5) ($F(1, 331) = 4.90, P = 0.028$) (Table 2). A significant main effect of time of measurement was found on the number of domains with no care needs ($F(1, 332) = 11.60, P = 0.001$): participants with and without a suspected intellectual disability reported 'no care needs' on significantly more domains at follow-up (16.4 and 17.5 respectively) compared to baseline (15.0 and 15.7 respectively). No significant interaction effect was found between time of measurement and having a suspected intellectual disability on the number of domains with no care needs.

Self-reported care needs at baseline and at 1.5-year follow-up on life domains

For both groups, 'unmet care needs' decreased significantly between baseline and follow-up on: finances, finding housing, physical health, finding work, mental health, empowerment and dental care. For participants without a suspected intellectual disability, 'unmet care needs' also decreased for household care and nutrition (Table 3).

For both groups, 'met care needs' decreased significantly on finding housing. For participants with a suspected intellectual disability, but not for those without a suspected intellectual disability, 'met care needs' on finances and dental care increased significantly between baseline and follow-up (Table 3).

For both groups, 'no care needs' increased significantly on finding housing, finding work, mental health and empowerment. For participants *with* a suspected intellectual disability, but not for those without a suspected intellectual disability, 'no needs' on physical health increased significantly between baseline and follow-up. For participants *without* a suspected intellectual disability, but not for those with a suspected intellectual disability, 'no care needs' on nutrition increased significantly between baseline and follow-up (Table 3).

Transitions of self-reported unmet care needs at baseline

To clarify the transitions of unmet care needs over time, we constructed figures which visually represent these transitions. Figures 1–5 show the transitions of self-reported unmet care needs at baseline for the five life domains with the highest percentage of participants with self-reported unmet needs at baseline, reported by participants with and without a suspected intellectual disability.

Table 3 An 'unmet care need', a 'met care need' and 'no care need' at baseline (T0) and after 1.5 years (T2) for participants with and without a suspected intellectual disability on life domains

| Main domain | Specific life domain | <i>n</i> | Suspected intellectual disability (%) (<i>ns</i> range = 46–104) | | | <i>P</i> -value [†] | <i>n</i> | No suspected intellectual disability (%) (<i>ns</i> range [†] = 102–232) | | |
|-------------------------------|-------------------------|----------|---|-------|--------|------------------------------|----------|--|--------|------------------------------|
| | | | T0 | T2 | | | | T0 | T2 | <i>P</i> -value [†] |
| Housing and daily life | <i>Finding housing</i> | 102 | | | <0.001 | 227 | | | <0.001 | |
| | Unmet need | | 39.2 | 16.7 | <0.001 | | 42.3 | 21.1 | <0.001 | |
| | Met need | | 49.0 | 32.4 | 0.016 | | 51.1 | 26.9 | <0.001 | |
| | | No need | 11.8 | 51.0 | <0.001 | 6.6 | 52.0 | <0.001 | | |
| | <i>Household care</i> | 103 | | | 0.856 | 229 | | | 0.041 | |
| | Unmet need | | 4.9 | 3.9 | | | 5.2 | 1.7 | 0.021 | |
| Met need | 3.9 | | 2.9 | | 1.7 | | 1.7 | 1.000 | | |
| | No need | 91.3 | 93.2 | | 93.0 | 96.5 | 0.096 | | | |
| Finances and daily activities | <i>Finances</i> | 103 | | | 0.001 | 228 | | | <0.001 | |
| | Unmet need | | 23.3 | 12.6 | 0.035 | | 27.2 | 15.4 | 0.001 | |
| | Met need | | 43.7 | 61.2 | 0.005 | | 47.4 | 41.2 | 0.180 | |
| | | No need | 33.0 | 26.2 | 0.281 | 25.4 | 43.4 | <0.001 | | |
| | <i>Daily activities</i> | 103 | | | 0.299 | 228 | | | 0.002 | |
| | Unmet need | | 17.5 | 8.7 | | | 17.1 | 7.0 | <0.001 | |
| | Met need | | 11.7 | 13.6 | | | 7.5 | 8.3 | 0.856 | |
| | | No need | 70.9 | 77.7 | | 75.4 | 84.6 | 0.005 | | |
| | <i>Finding work</i> | 101 | | | 0.012 | 226 | | | <0.001 | |
| | Unmet need | | 42.6 | 23.8 | 0.002 | | 39.4 | 23.9 | <0.001 | |
| | Met need | | 14.9 | 18.8 | 0.523 | | 13.3 | 10.2 | 0.371 | |
| | | No need | 42.6 | 57.4 | 0.024 | 47.3 | 65.9 | <0.001 | | |
| | <i>Basic skills</i> | 103 | | | 0.092 | 231 | | | 0.270 | |
| | Unmet need | | 18.4 | 8.7 | | | 7.8 | 4.8 | | |
| | Met need | | 4.9 | 5.8 | | | 0.4 | 1.3 | | |
| | No need | 76.7 | 85.4 | | 91.8 | 93.9 | | | | |
| <i>Transport</i> | 103 | | | 0.526 | 230 | | | n.a. | | |
| Unmet need | | 6.8 | 3.9 | | | – | – | | | |
| Met need | | 1.0 | 1.0 | | | – | – | | | |
| | No need | 92.2 | 95.1 | | – | – | | | | |
| Physical health | <i>Physical health</i> | 104 | | | 0.002 | 232 | | | 0.023 | |
| | Unmet need | | 27.9 | 9.6 | <0.001 | | 20.7 | 11.6 | 0.003 | |
| | Met need | | 24.0 | 26.0 | 0.878 | | 17.7 | 20.7 | 0.419 | |
| | | No need | 48.1 | 64.4 | 0.021 | 61.6 | 67.7 | 0.135 | | |
| | <i>Alcohol use</i> | 102 | | | 0.532 | 230 | | | 0.506 | |
| | Unmet need | | 3.9 | 3.9 | | | 3.9 | 1.8 | | |
| | Met need | | 5.9 | 6.9 | | | 1.8 | 2.2 | | |
| | | No need | 90.2 | 89.2 | | 94.3 | 96.1 | | | |
| | <i>Drug use</i> | 103 | | | 0.753 | 228 | | | 0.147 | |
| | Unmet need | | 4.9 | 3.9 | | | 3.5 | 0.9 | | |
| | Met need | | 4.9 | 7.8 | | | 4.8 | 5.3 | | |
| | | No need | 90.3 | 88.3 | | 91.7 | 93.9 | | | |
| | <i>Dental care</i> | 104 | | | 0.003 | 230 | | | 0.039 | |
| | Unmet need | | 51.9 | 30.8 | 0.001 | | 36.5 | 26.5 | 0.012 | |
| | Met need | | 13.5 | 26.9 | 0.016 | | 20.9 | 26.1 | 0.182 | |
| | No need | 34.6 | 42.3 | 0.243 | 42.6 | 47.4 | 0.305 | | | |
| <i>Nutrition</i> | 104 | | | 0.077 | 230 | | | 0.005 | | |
| Unmet need | | 17.3 | 5.8 | | | 13.4 | 6.5 | 0.005 | | |
| Met need | | 4.8 | 4.8 | | | 4.8 | 1.7 | 0.118 | | |
| | No need | 77.9 | 89.4 | | 81.8 | 91.8 | <0.001 | | | |
| Mental health | <i>Mental health</i> | 98 | | | 0.005 | 231 | | | 0.002 | |
| | Unmet need | | 21.4 | 7.1 | 0.004 | | 19.5 | 9.1 | 0.001 | |
| | Met need | | 20.4 | 17.3 | 0.648 | | 19.5 | 18.2 | 0.766 | |
| | No need | | 58.2 | 75.5 | 0.001 | | 61.0 | 72.2 | 0.001 | |

Table 3 (continued)

| Main domain | Specific life domain | n | Suspected intellectual disability (%) (ns range = 46–104) | | | No suspected intellectual disability (%) (ns range [†] = 102–232) | | | |
|--|---------------------------------------|-----|---|------|----------------------|--|------|------|----------------------|
| | | | T0 | T2 | P-value [†] | n | T0 | T2 | P-value [†] |
| | <i>Empowerment</i> | 104 | | | 0.001 | 230 | | | 0.002 |
| | Unmet need | | 24.0 | 13.5 | 0.035 | | 16.1 | 6.5 | 0.001 |
| | Met need | | 7.7 | 3.8 | 0.344 | | 5.7 | 3.0 | 0.238 |
| | No need | | 68.3 | 82.7 | 0.004 | | 78.3 | 90.4 | <0.001 |
| Safety and protection against violence | <i>Own safety</i> | 101 | | | 0.378 | 228 | | | 0.053 |
| | Unmet need | | 5.9 | 6.9 | | | 4.4 | 0.9 | |
| | Met need | | 4.0 | 1.0 | | | 2.6 | 1.3 | |
| | No need | | 90.1 | 92.1 | | | 93.0 | 97.8 | |
| Social relations | <i>Family contacts</i> | 98 | | | 0.515 | 222 | | | 0.099 |
| | Unmet need | | 9.2 | 5.1 | | | 6.3 | 3.2 | |
| | Met need | | 1.0 | 2.0 | | | 3.6 | 1.8 | |
| | No need | | 89.8 | 92.9 | | | 90.1 | 95.0 | |
| | <i>Social contacts</i> | 102 | | | 0.362 | 231 | | | 0.097 |
| | Unmet need | | 7.8 | 4.9 | | | 5.6 | 3.9 | |
| | Met need | | 3.9 | 2.0 | | | 3.0 | 0.9 | |
| | No need | | 88.2 | 93.1 | | | 91.3 | 95.2 | |
| | <i>Relation-ship with partner</i> | 90 | | | 0.572 | 212 | | | 0.343 |
| | Unmet need | | 6.7 | 4.4 | | | 7.1 | 4.2 | |
| | Met need | | 2.2 | 4.4 | | | 1.4 | 1.9 | |
| | No need | | 91.1 | 91.1 | | | 91.5 | 93.9 | |
| Children | <i>Relationship with own children</i> | 46 | | | 0.059 | 103 | | | 0.650 |
| | Unmet need | | 28.3 | 8.7 | | | 7.8 | 9.7 | |
| | Met need | | 2.2 | 8.7 | | | 6.8 | 3.9 | |
| | No need | | 69.6 | 82.6 | | | 85.4 | 86.4 | |
| | <i>Help for own children</i> | 46 | | | 0.102 | 102 | | | 0.657 |
| | Unmet need | | 10.9 | 10.9 | | | 4.9 | 4.9 | |
| | Met need | | 2.2 | 10.9 | | | 6.9 | 7.8 | |
| | No need | | 87.0 | 78.3 | | | 88.2 | 87.3 | |

[†]The overall McNemar–Bowker test *P*-value is given on the top row for each life domain. When significant ($P < 0.05$), the *P*-values for the post hoc McNemar tests are given separately for ‘unmet need’, ‘met need’ and ‘no need’.

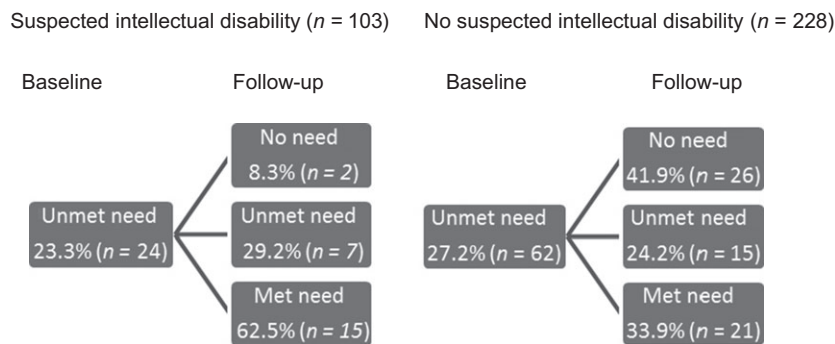


Figure 1 Transitions of unmet care needs for finances at baseline to care needs at 1.5-year follow-up.

Housing support needs

Concerning housing, almost all participants preferred independent housing irrespective of whether they

have a suspected intellectual disability (97.1%) or not (98.3%). Table 4 shows that there was a significant difference in housing support needs between participants with a suspected intellectual disability and

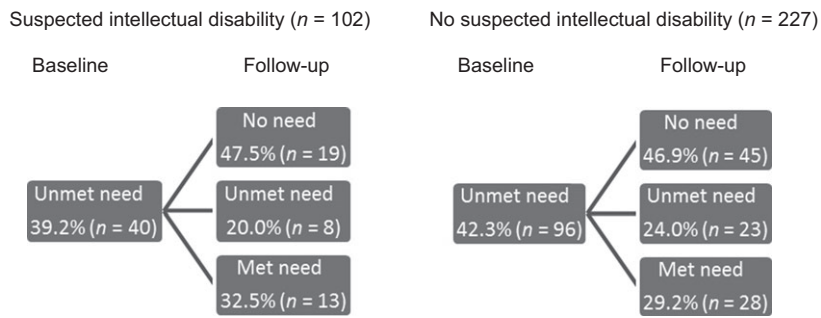


Figure 2 Transitions of unmet care needs for finding housing at baseline to care needs at 1.5-year follow-up.

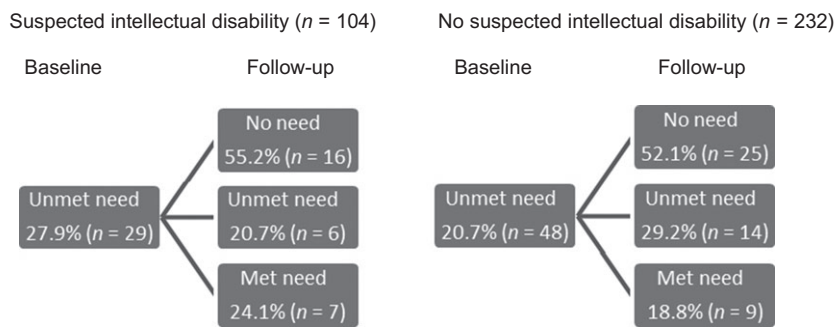


Figure 3 Transitions of unmet care needs for physical health at baseline to care needs at 1.5-year follow-up.

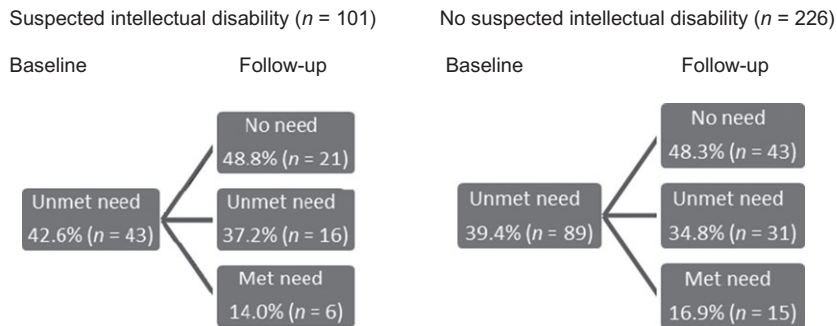


Figure 4 Transitions of unmet care needs for finding work at baseline to care needs at 1.5-year follow-up.

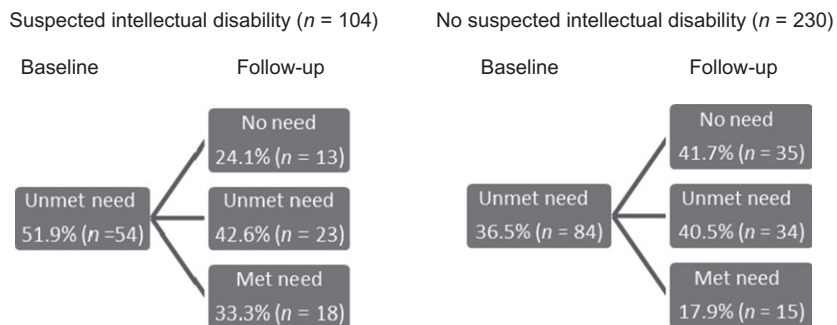


Figure 5 Transitions of unmet care needs for dental care at baseline to care needs at 1.5-year follow-up.

Box 2 Case description 2.

Delano has a tough appearance, and is wearing hip-hop clothes and large headphones. He is 36 years old, but looks younger. He has been using cannabis every day since his adolescence and, whenever he has some money, he also likes to drink beer. He spent some time in a mental health clinic because he often feels gloomy and anxious. At the moment he lives temporarily with his aunt, who is one of his few relatives who are not still in the Netherlands Antilles. It quickly became clear that he finds the research questions rather complicated; nevertheless, when asked what he would like, he answered straightaway: ‘...my own house, a bit of peace in my head, and nice parties now and again’.

Table 4 Housing support needs of homeless people with and without a suspected intellectual disability at 1.5-year follow-up

| Housing support needs | Suspected intellectual disability (n = 104) | No suspected intellectual disability (n = 231) | P-value |
|--|---|--|---------------|
| No need for housing support, % (n) | 36.5 (38) | 40.7 (94) | 0.001* |
| Need for support available on-call, % (n) | 15.4 (16) | 29.9 (69) | |
| Need for support available by appointment, % (n) | 48.1 (50) | 29.4 (68) | |

P-value in bold indicates a significant difference ($P < 0.05$).

*Post hoc chi-squared: Support on-call; intellectual disability <no intellectual disability; $\chi^2(1) = 7.832$, $P < 0.01$; Support by appointment; intellectual disability >no intellectual disability; $\chi^2(1) = 11.099$, $P < 0.01$.

those without a suspected intellectual disability ($\chi^2(2) = 13.318$; $P = 0.001$): participants with a suspected intellectual disability preferred support available by appointment significantly more often than participants without a suspected intellectual disability, and less often support available on-call.

Discussion

In the present study, around 30% of all homeless people had a suspected intellectual disability. No significant differences between participants with and without a suspected intellectual disability were found on the number of life domains with an unmet and a met care need both at baseline and at follow-up, and on ‘no care need’ at baseline. However, at follow-up, participants with a suspected intellectual disability reported ‘no care needs’ on fewer domains than participants without a suspected intellectual disability,

while at baseline there were no differences between the groups. This indicates that the number of life domains with care needs between these groups of homeless people is similar when entering the social relief system, but that the care needs of those with a suspected intellectual disability last longer than those without a suspected intellectual disability. As Thompson *et al.* (2009) stated, ‘Support needs reflect a limitation in functioning as a result of either personal capacity or the context in which the person is functioning’. From that viewpoint, the care needs of homeless people without a suspected intellectual disability may be seen more as a result of the context (i.e. their acute homelessness at baseline), while the enduring needs of those with a suspected intellectual disability may to a larger extent be explained by their personal capacity. Therefore, the care needs of homeless people with a suspected intellectual disability can be seen as an enduring rather than a temporary characteristic.

In both our subgroups, examination of the transitions of care needs on a broad range of life domains revealed some differences in their patterns of care needs over time.

For example, of participants with a suspected intellectual disability and an unmet need at baseline on finances, >90% still report having care needs at follow-up. On the other hand, <60% of participants without a suspected intellectual disability and an unmet care need at baseline on this domain still report having care needs at follow-up, while at baseline the percentages of unmet care needs on this domain were similar. To summarise, on this life domain, most participants with a suspected intellectual disability made a transition from an unmet care need to a met care need, whereas participants without a suspected intellectual disability mostly made a transition from an unmet care need to no care need. Financial support (which includes improvement of basic financial understanding) may benefit those with a suspected intellectual disability, and might increase decision-making abilities and enhance the quality of life and self-confidence of those with a suspected intellectual disability (Suto *et al.* 2005). However, although providing support to people with intellectual disability might enable functioning in daily life activities, it does not eliminate the possibility that they will need support for a longer period of time (Thompson *et al.* 2009).

Of the 22 life domains for which we investigated the care needs, it is noteworthy that care needs were reported for relatively few of these domains by the homeless who reported themselves at a central access point for social relief. Although homelessness is often associated with mental health and substance use

problems (Fazel *et al.* 2008), in the present study the prevalence of self-reported care needs reported on these domains is relatively low. For example, only about 10% of the participants reported a care need for drug or alcohol use. This was the case for participants with and without a suspected intellectual disability, even though those with a suspected intellectual disability were earlier identified as having relatively high rates (about 30%) of substance dependence (Van Straaten *et al.* 2014). Participants in need of mental health or addiction treatment services may be in denial about the importance of treatment. However, the low prevalence of care needs on these domains seems to indicate that they are not (yet) willing or ready to accept such services. This study reveals that care needs at baseline are most frequently seen on finding housing, finances, dental care, finding work and physical health, and this applies to homeless people with and without a suspected intellectual disability. To meet the self-reported care needs of these individuals, our results emphasise that care providers should initially focus on basic needs such as housing, finances and physical health (including dental care) rather than on life domains such as mental health or substance use. These findings are consistent with Maslow's hierarchy of needs (Maslow 1943), which states that without having fulfilled basic needs, it is difficult to deal with higher order needs. Longer follow-up of the self-reported care needs of homeless people will provide more insight into how these needs further develop. One extensive longitudinal study among formally institutionalised mentally disabled individuals provided an interesting insight into community participation during the 30-year follow-up (Edgerton 1993). This latter study suggests that, whereas cognitive skills change relatively little, adaptive behaviours can change dramatically. Edgerton's study showed that as the participants became older, they increased their ability to participate in the community and perform activities of daily living independently. This might also apply to our participants; however, long-term follow-up is required to substantiate this. In addition, a qualitative study would help elucidate the underlying reasons and processes with regard to the self-reported care needs.

In the present study, most participants preferred independent housing and about 60% would like to receive housing support. At follow-up, participants with a suspected intellectual disability more often preferred housing support available by appointment (instead of on-call) than participants without a suspected intellectual disability. Due to the fact that most participants with a suspected intellectual disability want to live independently but with housing

support by appointment, 'Housing First' may be an appropriate approach to fit their needs. 'Housing First' focuses on providing homeless people with housing before providing services as needed; this approach has shown promising results among homeless people with substance use problems and psychiatric problems (Tsemberis *et al.* 2004, 2012, Wolf *et al.* 2012). This approach may also be appropriate for homeless people with a suspected intellectual disability but, to our knowledge, has not yet been investigated.

Strengths and limitations

Among homeless people (unmet) care needs is a well-studied area, but no longitudinal study has compared the self-reported care needs of homeless people with and without a suspected intellectual disability. Because having a suspected intellectual disability is prevalent among the homeless, this study adds valuable information on the characteristics of this subgroup. Other strengths of the study include the relatively large sample size, the broad range of care needs investigated and the use of self-reports: reflecting the needs of this group from their own viewpoint. However, although problems can occur when using questionnaires designed for the general population among persons with an intellectual disability (e.g. acquiescence, not understanding the question), we anticipated these problems in several ways (as described in the Methods section).

A limitation of this study is that we have no data on the number of potential participants who were initially invited, as it was not feasible to systematically collect data on how many potential participants were approached and how many refused to participate. Consequently, no initial non-response data are available. However, comparison between the total group of homeless adults/young adults who reported at a central access point for social relief in 2011 and our study participants shows that our adult participants were representative in terms of age and gender, and that our young adult participants were representative in terms of age but, in this subgroup, males were over-represented. This over-representation of males among the young adult participants might influence the generalisability of the results.

With regard to the intellectual disability screener, a relatively large number of false positives might have occurred because the intellectual disability screener was designed to be over-inclusive and may identify those who have other types of learning difficulty, those who are intoxicated by some substance or those who have a psychiatric disability (Hayes

2000). It should be noted that the present study aimed to identify a subgroup of homeless people whose daily functioning was restricted due to low intelligence. However, only after a full-scale diagnostic assessment (including intellectual functioning, concurrent deficits in adaptive behaviour and manifestations before the age of 18 years) (Schalock *et al.* 2010) can a diagnosis of intellectual disability be made. We cannot make any assumptions with regard to aetiology, because we do not know whether, for example, the cognitive impairment is due to traumatic head injury or long-term substance use and, thus, did not manifest itself before the age of 18 years. On the other hand, concerning practical relevance, the results of the screener do represent the level at which homeless people with a suspected intellectual disability are currently functioning, and have implications for their current situation and care needs.

A validation study on the Dutch version of the HASI indicated lowering the cut-off score from 85 to 81 to prevent potential unnecessary referrals to care institutions (Barendregt *et al.* 2013); however, for screening in a research setting, this drawback is less important. Also, the inclusion of individuals with borderline intellectual disability (IQ 70–85) as having a suspected intellectual disability (instead of only those with an IQ < 70) as a result of over-inclusiveness is acceptable in the present study, as those persons also need to be taken into account.

The present study included a broad range of care needs. While some of these life domains clearly contain care needs, e.g. needs related to physical or mental health, some domains (e.g. related to finances and daily activities) might comprise more of a 'support need', i.e. indicating that support is needed to fully participate in the activities of everyday life as a full citizen in society. However, for the sake of simplicity and consistency, we have used the term 'care needs' for all the life domains.

It should also be noted that our study population, consisting of homeless persons accepted for an individual programme plan, may not be fully representative of the entire population of homeless people in the Netherlands. Subgroups of homeless people not included in this study were undocumented homeless people, and homeless people who do not make use of social relief facilities.

Conclusion

Our findings suggest that homeless people who had been accepted for an individual programme plan with a suspected intellectual disability have care

needs for a longer period of time than those without a suspected intellectual disability. Among the specific life domains, this applies in particular to finances. With regard to housing, homeless people with a suspected intellectual disability express a preference for independent housing with support available by appointment. Providing care to homeless people with a suspected intellectual disability might comprise ongoing care and support, also after exiting homelessness. Support services should take this into account when considering their care provision and planning of services.

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