

Needs of older people with intellectual disabilities: variables influencing inter-respondent (client vs staff) agreement

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Background: The importance of understanding the needs of older people with intellectual disabilities (IDs) is obvious, but the research available is limited. This study identifies the self-reported needs of older adults with IDs and compares them with staff reported needs regarding the same older adults with ID, therefore specifying and explaining agreements and disagreements.

Method: The needs of 96 older adults with IDs were assessed through the Inventory of Identification of Needs (informant and self-report versions).

Results: Both older people with IDs and staff reported quite diverse needs related to all the domains assessed by the IIN: physical health, literacy, information, meaningful activity, participation in the community, mental health, basics needs and accommodation. All the mean scores of the informant version of the IIN were higher than the ones of the self-report version. Agreement amongst informants was influenced by the prominence of needs, the accessibility to and the subjectivity of the information, and social desirability.

Conclusions: A consumer-driven approach implies that services should be based on the needs identified.

Keywords: needs; older adults; intellectual disabilities; inter-respondent agreement; variables

Ageing with intellectual disabilities (IDs) is a relatively modern phenomena, explained by the increase in the life expectancies for people with this disability reported all over the world (e.g. Aguado *et al.*, 2010, Dieckman *et al.*, 2015). Indeed, until recent times, people with IDs were expected neither to live long nor to outlive their parents. Life expectancy figures for adults with IDs now show that a majority will experience a lifespan that is close to that of the mainstream population (Wark *et al.*, 2014, World Health Organization, 2011).

Nevertheless, research on ageing and IDs is presently in its infancy, reflecting a marked focus on issues related to physical health (e.g. Haveman *et al.*, 2011, Hermans and Evenhuis, 2014). Thus, there is lack of information on the day-to-day life experiences of older adults and their needs as they relate to various life domains such as housing, social relationships, meaningful activity (domestic, educational, leisure, etc.), participation in the community, or services.

The identification of needs of older people with IDs seems essential both from a person-centered planning perspective and also from a client-centered service system. In addition, it has been recognized that although the needs of older people with and without IDs may be similar, there will also be significant differences and specific needs to be addressed. For instance, older people with IDs may differ from the general population in respect to poorer health, a higher prevalence of sensory and motor impairments (Haveman *et al.*, 2011, McCausland *et al.*, 2010), as well as mental health problems (Wark *et al.*, 2016, Wormald *et al.*, 2019). They may also have more limited choices, more difficult access to support services (Wark *et al.*, 2016), a greater need for family support and respite services to reduce caregiver burden, and more individualized assistance (Salvatori *et al.*, 2003). Moreover, they may have specific psychosocial needs, as many of them may have smaller informal social networks and may be at greater risk for poverty, segregation and neglect (Weber and Wolfmayr, 2006).

Although the importance of knowing and assessing the needs of older people with IDs is obvious, the research available is sparse. There are studies about

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related topics such as the life experiences (Salvatori *et al.*, 2003) or the future perspectives of ageing adults with IDs (Hole *et al.*, 2013). However, the studies specifically focusing on the identification of the needs of older adults are particularly limited, especially when one excludes those that simultaneously address IDs and other disabilities (Díaz *et al.*, 2005, Shoostari *et al.*, 2012), without clearly differentiating the results obtained with respect to each disability. Proceeding in that way, and to the best of our knowledge, there are just some studies available where needs have been assessed by staff members (Albuquerque and Carvalho, 2020, Strydom *et al.*, 2005), by the people with IDs themselves (Strydom *et al.*, 2005) or where staff- and self-report sources were aggregated (Aguado *et al.*, 2010, McCausland *et al.*, 2010).

Mirroring what was just mentioned, there are also very few needs assessment instruments. The Supports Intensity Scale (SIS; Thompson *et al.*, 2004) and the I-CAN (Riches *et al.*, 2009) assess the need of support in several life domains, and they contain, 46 and 10 scales respectively. They also have a detailed rating system that examines the frequency of support (how often the person needs support in each activity), the type of support that the person would require for each activity, and in the case of the SIS, the amount of support or daily support time for each activity. Thus, SIS and I-CAN assess support more than needs, and both require a long administration time. The Learning Disabilities Needs Assessment Tool (Painter *et al.*, 2016) has been designed to assess the mental health needs of people with IDs and therefore has a very specific focus. The CANDID-S (Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities – Short Form; Xenitidis *et al.*, 2003) was derived from a needs' assessment instrument of persons with mental health problems and does not include all needs relevant for people with IDs (McCausland *et al.*, 2010), and in particular for older people with IDs (Strydom *et al.*, 2005). Therefore, the CANDID-S has some shortcomings regarding persons with IDs.

The Inventory of Identification of Needs (IIN; Albuquerque and Carvalho, 2020) was developed more recently, in order to address the shortage of assessment instruments of the needs of older people with IDs. It is a rating scale that assesses 38 needs across a wide range of domains. It is a checklist for professionals and caretakers of older adults with IDs (informant version), administered through a semi-structured interview. It is easy to apply, accessible, suitable for use by a variety of professionals and has exhibited satisfactory psychometric properties, namely internal consistency, construct validity and criterion-related validity (Albuquerque and Carvalho, 2020). For example, the IIN shows a clear six factor structure (Literacy/Information, Occupation/Community, Physical Health, Accommodation, Mental

Health, and Family/Activities) and is sensitive to disability level, since needs increase according to the level of severity of IDs. After the informant version was developed, a self-report version of the IIN was next considered essential, since people with IDs should be asked to provide their own views on their needs, whenever possible, especially given that ageing is also an individualized process. In addition, it should be noted that a consumer-driven approach inherently implies that services should be based on the needs of people with IDs.

However, an individual's perception of need is necessarily influenced by the values, expectations and daily life contexts of the person making the judgment (Andresen *et al.*, 2000), and so these varying viewpoints must necessarily be taken into account. In addition, the convergence and divergence between two sources of information, such as people with IDs and staff members, is a critical issue. Staff members seem to be a relevant data source on older people with IDs since they are service providers, they have direct and regular contact with them and know them well. Thus far, just one quantitative study has examined the needs of older adults with IDs from self and staff reports and in a very small sample (Strydom *et al.*, 2005). There are also a few studies about the needs of adults with IDs, but of younger adults and not older ones, which found that the agreement between self and staff is usually modest (Claes *et al.*, 2009, Schützwohl *et al.*, 2018, Xenitidis *et al.*, 2000).

As a consequence of the above, the first purpose of the current study is to identify and describe the self-reported needs of older adults with IDs. The second purpose is to compare self-reported and staff-reported needs of the same older adults with IDs and therefore to specify and explain agreements and disagreements. The third purpose is to provide information regarding the inter-respondent reliability of the Inventory of Identification of Needs, thus adding evidence about the psychometric properties of this instrument.

Method

Participants

Inclusion criteria required that the older adults with IDs be aged 45 or over and present mild or moderate IDs. As for this age criterion, a variety of chronological ages have been proposed in the research as the point at which people with IDs begin ageing, but there is no clear consensus about which is most adequate. The age of 45 was chosen as it corresponds to a commonly selected cut-off point (e.g., Aguado *et al.*, 2010, Bowers *et al.*, 2014). Also, a mild or moderate level of disability was established as an inclusion criterion in order to assure the participant's verbal comprehension of the items in the IIN as well as his/her ability to express needs. The level of severity of the ID was

Table 1. Characterization of people with IDs.

	<i>N</i>	%
Age		
≤50	51	53.1
≥50	45	46.9
Gender		
Male	56	58.3
Female	40	41.7
Severity of IDs		
Mild	34	35.4
Moderate	62	64.6
Educational qualifications		
None	31	32.2
Incomplete elementary school	14	14.6
Elementary school	39	40.6
Junior high	4	4.2
High school	5	5.2
Secondary school	4	4.2
Residence		
Family house	71	74.0
Group homes	25	26.0

determined by the staff members of the institutions that the adults with IDs attended. After that, participants were also screened in order to assure that they were able to communicate.

The adults with IDs were 96 in number, from 45 to 73 years of age, with the average being 51.31 ($SD = 6.22$; median = 50). As Table 1 shows, approximately half of the participants were between 45 and 50 years of age (53.1%) while the remainder was over fifty (46.9%). The adults were also predominantly male (58.3% versus 41.7% female) and single (81 or 84.4%). Approximately a third of the participants were identified as having a mild ID (35.4%) while the remaining had a moderate ID (64.6%). Most of the adults with IDs had some educational qualifications, but there was also a group (32.2%) with no educational qualifications because they did not attend a regular school when they were young. The majority of the adults with IDs lived with family members at a family house (74%) and the remaining lived in group homes at the community (26%). All of them attended institutions for individuals with disabilities, namely occupational day care centers (87.5%).

Participants were recruited through contact with institutions for adults with IDs located mainly in the North and Center of Portugal, since these regions were accessible to the researchers. The North and Center of Portugal constitute two of the five regions of the country. They have a similar dimension (North = 21284 km², Center = 28200 km²) and both include urban and rural areas. However, the North region has more inhabitants (North = 3.689.682, Center = 2.217.285) and a more intense economic activity than the Center. Individuals from a total of 15 institutions participated.

Staff members of the occupational day centers served as proxy reporters of the needs of the adults with IDs. The professional who was in regular and close contact with the adult and thus who knew him

best was chosen. In total, 26 professionals participated, predominantly women ($n = 20$) with a mean chronological age of 41.42 ($SD = 10.67$) who were psychologists (38.5%), social workers (38.5%) or auxiliary staff (23%). All of these staff members worked in the institutions for individuals with disabilities and considered themselves well informed about the needs and wishes of their clients.

Instrument

The IIN assesses 38 needs with respect to the following domains: mental health (7 items); basic needs (5 items); physical health (5 items); leisure (5 items); accommodation (4 items); literacy (3 items); specific aids (3 items); information (2 items); relationships (2 items); cognitive rehabilitation (1 item) and individualized support (1 item).

The information regarding its psychometric characteristics is as follows (Albuquerque and Carvalho, 2020). The content validity of the IIN is adequate given that its items were assessed by six experts in IDs and six professionals, with all its items obtaining a mean score of 3 or above on a 6-point rating scale of importance. As for construct validity, the IIN assumes a six factor structure that comprises 33 items and explains 51.64% of the variance. The factors include five or six items and are designated Literacy/Information, Occupation/Community, Physical Health, Accommodation, Mental Health, and Family/Activities. The IIN also showed evidence of criterion-related validity, since needs are influenced by disability level: needs regarding Literacy/Information, Occupation/Community, and Physical Health increase as the disability level increases, with statistically significant differences in the first two factors. As for reliability, the IIN, with its 38 items, revealed a Cronbach's α of .83 and almost all the factors showed similar values (.80 in Literacy/Information; .81 in Occupation/Community; .79 in Accommodation and .77 in Mental Health). Only the factor Family/Activities showed a lower (.65), although minimally acceptable value.

The IIN was initially designed as a rating scale for professionals and caretakers (informant version) administered via a semi-structured interview. A self-report version, to be administered in an interview context as well, was elaborated next for the present study, and above all to have access to the needs directly experienced by people with IDs. The self-reporting design process recognized that the use of self-report measures is demanding for people with IDs, since it requires that they understand questions, recall, retain and order information, form and communicate responses. Thus, several aspects were taken into account. Firstly, questions relative to each need pertain to specific and concrete events or facts of the individual's own life, thus rendering the understanding easier (Finlay and Lyons, 2001). Questions are also short and direct, due to the difficulty

that people with IDs may have with open-ended questions (Booth and Booth, 1996). For instance, in the domain of general physical health, the adult with IDs is asked if he/she is experiencing any health problems, and if so what the problem is and whether the problem is being treated. Secondly, the vocabulary used is common and uncomplicated, with the sentences having a simple structure and the least number of words possible and avoiding negatively phrased questions as they are more difficult to respond to (Finlay and Lyons, 2001). Thirdly, interviewers were instructed to verify understanding and if necessary, they could repeat the questions or paraphrase them. Therefore, interviewers were also instructed to take as much time as needed in the interview.

The items of the IIN are scored on a 3-point rating scale, with 0 points if there is no need, 1 point if there is a mild need and 2 points if there is a serious need. In the informant version, the professional or caretaker rates each item with the help of a small instruction booklet, where examples of ratings are provided. The instruction booklet was developed to assure precision in the rating of the items; for instance, in the item “occupation at holidays”, it indicates that a mild need may be present if the person is somewhat occupied during holidays and does some occasional activities outside the house or group home whereas a serious need would be if the person is engaged in few or no occupations during the holidays, thus tending to stay indoors at the house or group home. In the self-report version, the interviewer rated the items based on the person’s replies to the questions and subsequent probes, and on the instruction booklet.

Procedure

After obtaining approval from the institutions to carry out the study, including ethical approval, informed consent was obtained from both the adult with IDs and the staff member chosen as informant.

The interview with the adult with IDs was conducted one-on-one in a quiet and private setting. The interviewers received training and were instructed as to how they should conduct the interview. Regarding the informant version, the staff member was first provided with the inventory and the instruction booklet, and shortly after that, completed the inventory during a semi-structured interview.

Statistical analyses

Statistical analyses were performed using SPSS 22.0. Descriptive statistics were used to identify the most self-reported and staff-reported needs of older adults with IDs. The needs reported as mild or serious by a third or more of the staff members or of the adults with ID were expressed as binary variables (present or absent) and the following indices were calculated: 1) percent agreement; 2) Holley and Gilford’s *G*; 3)

McNemar chi-square test. In contrast to percent agreement, Holley and Gilford’s *G* coefficient accounts for the effect of chance in achieving agreement. *G* coefficients were interpreted in the following way: slight $\leq .20$; fair between $.21$ and $.40$; moderate between $.41$ and $.60$; substantial between $.61$ and $.81$; and almost perfect if $> .81$ (Landis and Koch, 1977).

Differences in the factors and total score of the IIN according to the information source were analyzed with a paired samples *t* test, and the effects size were calculated with Cohen’s *d*.

Reliability between self and staff reports was examined mainly by Intraclass Correlation Coefficients estimated with a two-way random effects model (McGraw and Wong, 1996). Intraclass Correlation Coefficients (ICC) for consistency and absolute agreement were calculated for the factors and the total score. However, the same factor or total score can be obtained in many different ways. Therefore, in order to truly specify the agreements and disagreements between information sources, the ICC for absolute agreement of the items of the IIN was calculated. Agreement between raters was interpreted based on the guidelines proposed by Cicchetti (1994): $< .40$ = poor; between $.40$ and $.59$, fair; between $.60$ and $.74$, good; and $\geq .75$ = excellent.

Results

To identify the most reported needs, we simultaneously attended to the ones rated mild and serious. Those reported by a third or more of the staff members or of the adults with ID are listed in Table 2 (columns Staff report and Self-report). The table includes 22 needs: the first 14 needs were indicated by a third or more of both groups of participants; the following 4 needs (from family relationships to daytime activities) were identified only by at least a third of the staff members; and the last 2 needs were indicated only by at least a third of the adults with ID. The older adults with IDs identified quite diverse needs, related to physical health (general physical health and eyesight), literacy/information (literacy; handling of money; information on services; information on rights), mental health (other mental health problems; major mental health problems), basic needs (food; financial needs; self-care), cognitive rehabilitation, accommodation (future accommodation) and leisure (occupation at holidays; sport activities; self-expression activities). The staff members also reported quite diverse needs, almost all pertaining to the previously mentioned domains, and in 14 instances identical needs were pointed out by both sources of information (e.g. literacy; general physical health; information on rights; information on services; cognitive rehabilitation; other mental health problems). The convergence between self and staff reports is also evident when one examines the three needs most rated as serious, which were: literacy ($n = 41$ staff report/36 self-

Table 2. Needs most reported.

Needs	Staff report, N (%)	Self-reported, N (%)	Percent Agreeem.	G	McNemar χ^2
Literacy	68(70.8)	54(56.3)	72.9	.46	6.50*
Handling of money	67(69.8)	56(58.3)	82.3	.65	5.88*
General physical health	56(58.3)	56(58.3)	62.5	.25	.00
Other mental health problems	56(58.3)	45(46.9)	63.5	.27	2.86
Information on services	54(56.3)	52(54.2)	75.0	.50	.04
Self-care	54(56.3)	33(34.4)	69.8	.40	13.79**
Information on rights	50(52.1)	47(49.0)	74.0	.48	.16
Cognitive rehabilitation	44(45.8)	47(49.0)	74.0	.48	.16
Occupation at holidays	44(45.8)	36(37.5)	66.7	.33	1.53
Financial needs	41(42.7)	33(34.4)	60.4	.23	1.29
Major mental health problems	40(41.6)	39(40.6)	76.0	.52	.00
Food	40(41.6)	48(50.0)	64.6	.35	1.44
Sport activities	38(39.6)	35(36.5)	59.4	.19	.10
Eyesight	36(37.5)	42(43.8)	83.3	.67	1.56
Family relationships	39(40.6)	18(18.8)	74.0	.48	7.84**
Occupation at weekends	43(44.8)	29(30.2)	68.8	.38	5.63*
Communication	43(44.8)	22(22.9)	67.7	.35	12.90**
Daytime activities	39(40.6)	24(25.0)	66.8	.40	6.76**
Future accommodation	30(31.3)	35(36.5)	78.1	.56	.76
Self-expression activities	30(31.3)	34(35.4)	60.4	.23	.24

* $p < .05$; ** $p < .01$.

report), handling of money ($n = 39$ staff report/24 self-report) and information on rights ($n = 26$ staff report/18 self-report).

Percent agreement values ranged from 59.4% (sport activities) to 83.3% (eyesight), and many were equal or superior to 70%. However, G coefficients showed that, after correcting for chance, agreement was predominantly fair (11 needs) or moderate (6 needs).

Although there were convergences there were also divergences: the McNemar chi-square test (Table 2) showed that the staff members reported significantly more needs than the adults with ID, regarding literacy, handling of money, self-care, family relationships, occupation at weekends, communication and daytime activities.

Considering all the needs assessed by the IIN, one sees that there are also other divergences: staff members reported higher percentages of needs, except 3 needs where the percentages were the same for each informant (hearing- 12.5%; architectural barriers – 19.8%; and participation in the community- 30.2%) and also except in 6 needs where the older adults registered higher values than the staff members (cognitive rehabilitation; food; eyesight; future accommodation; temporary accommodation – 26.1% self-report versus 19.8% informant). Other divergences pertain to the kinds of needs that were most mentioned by each

source of information, as for instance some accommodation needs (future and temporary) that were more stressed by the older adults.

Table 3 shows descriptive data for each factor and the total score of the IIN according to each version. The factor score is the sum of the item scores of each factor and the total score is the sum of the scores of all 38 items. As the factors include a similar number of items, it is possible to observe that the factors Literacy/Information and Occupation/Community obtained the higher mean scores in both versions of the IIN. On the contrary, Accommodation and Mental Health reached the lowest mean values according to staff report and self-report, respectively. The means and standard deviations of all the scores of the informant version were always higher than those of the self-report version. Considering just the total score, the one of the staff report surpassed the self-report in 54.2% of the cases, where the opposite happened only in 37.5% (in the remaining 8.3% of the cases the total scores were equal). When staff report was higher than self-report, the difference between mean scores was larger (staff at 19.71 versus self at 11.50) than when it is the other way round (self at 15.28 versus staff at 12.06). A paired samples t test demonstrated statistically significant differences in the factors Literacy/Information, Occupation/Community and Mental Health and in the

Table 3. Comparison of staff and self-report.

	Staff report.		Self-report.		$t(95)$	d
	M	SD	M	SD		
1. Literacy/information	4.23	2.63	3.25	2.27	5.29**	0.40
2. Occupation/community	3.29	2.87	2.41	2.34	3.51**	0.34
3. Physical health	1.89	1.91	1.59	1.55	0.17	
4. Accommodation	1.73	1.91	1.66	1.66	.39	0.04
5. Mental health	1.88	1.82	1.40	1.49	3.62**	0.29
6. Family/activities	2.24	1.86	1.78	1.58	1.81	0.27
Total	16.35	7.67	13.11	5.78	4.19**	0.48

** $p < .01$.

Table 4. Agreement between staff and self-report.

	Absolute Agreement ICC [95% CI]	Consistency ICC [95% CI]
1. Literacy/information	.81 [.61, .89]	.84 [.76, .90]
2. Occupation/community	.69 [.52, .80]	.71 [.57, .81]
3. Physical health	.65 [.48, .77]	.66 [.48, .77]
4. Accommodation	.67 [.51, .78]	.67 [.51, .78]
5. Mental health	.80 [.68, .87]	.82 [.73, .88]
6. Family/activities	-.07 [-.61, -.28]	-.07 [-.61, -.28]
Total	.51 [.25, .68]	.55 [.33, .70]

total score. The effects sizes were small in the factors and intermediate in the total score.

Intraclass Correlation Coefficients (ICC) for consistency and absolute agreement are indicated in Table 4 for the factors and the total score. The correlations are excellent in Literacy/Information and Mental Health, good in Occupation/Community, Physical Health and Accommodation, fair in the total score and poor in Family/Activities.

The ICC for absolute agreement of the items of the IIN are grouped in Table 5 according to their classification and most can be considered good or fair. Although there is not an obvious pattern in the distribution of the needs, those with good correlations comprise some of those that were most rated by both informants (literacy; handling of money; information on rights). Amongst the needs with poor correlations are those that concern accommodation (actual accommodation; temporary accommodation; and domiciliary support), technical aids, relationships (friends) and leisure (self-expression activities; sport activities). Needs concerning sensitive topics (e.g. risk of exploitation; substance misuse) also registered poor correlations.

Discussion

Both older people with IDs and staff reported quite diverse needs related to all the domains assessed by the IIN. This means that needs go largely beyond the research focus in physical health, and regard literacy, information, meaningful activity, participation in the community, mental health, basic needs and

accommodation. The standard deviations of the IIN factor and total scores were appreciable, and this also indicates that older people with IDs are quite a heterogeneous group of people. The diversity of needs may also signal that services are ill prepared to attend to the needs and challenges that an increasing number of older people with IDs face. As McGinley (2016) stresses, there may be a significant imbalance between the exponential growth in the number of older adults with IDs and their increasing needs on the one hand, and the restricted available services to satisfy those needs on the other.

The items of the IIN most reported by both people with IDs and staff involved Literacy/Information and Physical Health. The items relative to literacy, handling of money and information on rights are the three most serious needs rated by the two information sources. Literacy skills allow access to information, media and technology and, along with the handling of money, are required in many daily living circumstances. They are also a means to promote independence and self-confidence. As indicated in the participants' section, 32.2% of the older adults with IDs did not attend school regularly during their childhood, and 14.6% attended only elementary school for a short duration of time (incomplete attendance). Therefore, many of the participants had limited literacy skills that should be addressed. Regarding information on rights, Portugal signed the Convention on the Rights of Persons with Disabilities, but as this study shows, that does not mean that Portuguese people with IDs know their rights or understand them.

All the mean scores of the informant version of the IIN were always higher than the ones of the self-report version, and some differences were statistically significant. Staff members also reported higher percentages of needs than the adults with IDs, and in some cases, there were also statistically significant differences. The same has been observed in the few studies regarding needs assessment of young adults and both when the

Table 5. Intraclass correlation coefficients of the items of the IIN.

Classification	Items of the INN
Good	Mobility (.67), Epilepsy (.66), Literacy (.62), Handling of Money (.62), Information on Rights (.60), Inappropriate Behavior (.60)
Fair	Future Accommodation (.57), Community Participation (.56), Eyesight (.56), Safety of Others (.54), Cognitive Rehabilitation (.52), Occupation at Weekends (.52), Safety of Self (.52), Daytime Activities (.47), Communication (.46), Family Relationships (.45), Occupation at Holidays (.45), Information on Services (.52), Architectural Barriers (.47), Major Mental Health Problems (.44), Specific Treatment (.43), Hearing (.40)
Poor	Temporary Accommodation (.36), Self-care (.36), Actual Accommodation (.32), Mental Health Problems (.31), Domiciliary Support (.29), Food (.28), Friends (.28), Financial Needs (.25), Technical Aids (.25), Sport Activities (.23), General Physical Health (.21), Substance Misuse (.14), Self-expression Activities (.14), Transport (.11), More Individualized Support (.10), Risk of Exploitation (.01)

informant was a staff member (Claes *et al.*, 2009, Schützwohl *et al.*, 2018, Xenitidis *et al.*, 2000) or a caregiver (Schützwohl *et al.*, 2018, Xenitidis *et al.*, 2000). Strydom *et al.* (2005) also noticed that carers of sixteen older adults with IDs identified significantly more needs than the adults themselves. The tendency toward more favorable perceptions of people with IDs than their proxies has also been noticed by researchers assessing quality of life (e.g. Balboni *et al.*, 2013) or physical health (Scott and Haverkamp, 2018). Nevertheless, it is not an invariable trend in IDs, as it has been shown, for instance, that people with IDs registered more stressful life events and less physical activity than caregivers (Scott and Haverkamp, 2018). It is also worth noting that more positive self-report responses are not exclusive to IDs and occur in people with mental health problems (Fleury *et al.*, 2006) and in people without disabilities (Olino and Klein, 2015). Nevertheless, the fact that people with IDs rate themselves more positively than others do, although they may face difficult living conditions, constitutes an apparent paradox that has been explained in a variety of ways. Thus, Claes *et al.* (2009) propose that staff overestimate the needs of their clients due to “job-identity” issues or the obligation of justifying their role. For their part, people with IDs may underreport needs due to overestimation of individual abilities (Claes *et al.*, 2009), positively biased self-cognitions that try to maintain at least moderate life satisfaction (Cummins and Nistico, 2002), lack of an idea that potential help might be available (McCausland *et al.*, 2010) or a long-standing process of adjustment to disability (Schützwohl *et al.*, 2018). In our view, all of these explanations are plausible and not mutually exclusive. In addition, we submit that another explanation is credible, i.e. self-ratings have been found to be susceptible to inaccurate responses, faking and social desirability, and people with IDs have been recognized as vulnerable to this kind of bias (Finlay and Lyons, 2001).

Regarding the convergences and divergences between sources of information, they constitute a complex and not easily explainable pattern. However, there are some dimensions inherent to the needs assessed that may explain similarities and differences. Firstly, the prominence of needs as illustrated in the good agreement of self and staff reports regarding literacy, handling of money and information about rights. Other needs that figure amongst those most reported by both sources (e.g. cognitive rehabilitation; eyesight; information on services; major mental health problems; occupation at holidays) also registered fair intraclass correlation coefficients. Secondly, older adults with IDs and staff have access to different information regarding the needs. For example, the needs related to accommodation, individualized support and technical aids registered poor agreement, probably due to this fact. People

with IDs know their living contexts well, and this may explain why they rated the needs regarding future and temporary accommodation higher than staff. On the contrary, staff knows more about technical aids and individualized support, and thus may consider that they are more important than people with IDs. Thirdly, some needs have a more subjective dimension, since they assess preferences, social relationships or appreciation of physical health. In these circumstances, the agreement between older adults with IDs and staff is poor, as shown in sport and self-expression activities, in friends and in general physical health. A similar trend has been reported by other research with IDs (Balboni *et al.*, 2013, Schützwohl *et al.*, 2018), inclusively in physical health (Schmidt *et al.*, 2010). Fourthly, social desirability also played its role since older people with IDs showed a tendency to choose a more positive response alternative in items regarding sensitive topics, such as other mental health problems, risk of exploitation, financial needs or substance misuse. In these circumstances staff ratings were usually higher than the ones of people with IDs.

Notwithstanding some divergences, the IIN showed mostly excellent or good agreement between informants regarding factors and good or fair agreement regarding items.

Regarding limitations, the sample of this study is not very large, and the mean chronological age of the adults with IDs could be higher. The sample also includes adults living in different residential settings (family houses and group homes) and both needs (e.g. accommodation, health) and inter-respondent agreement may be influenced by the type of residence. In addition, needs were assessed just one time, and they may change over time.

Conclusions

Needs of older people with IDs should be assessed regularly and services developed accordingly. In order to achieve this goal, it is essential to have needs assessment instruments, and in this regard, the IIN can play an important role since it has shown adequate psychometric characteristics (including inter-respondent agreement) and it is easy to apply.

The sources of information identifying needs should be diverse and should include the person with IDs, staff members and other caretakers. However, it is not always possible to obtain self-reports from people with IDs, as illustrated by the fact that this research only comprised adults with mild or moderate IDs able to understand and answer the IIN. As noted by Fujiura and the RRTC Expert Panel on Health Measurement (2012), the extraordinary heterogeneity of individuals with IDs means that there will always be individuals able to answer an interview protocol, those too

cognitively impaired to respond and those between the extremes.

In this study, there was mainly good or fair agreement between people with IDs and staff members. This means that agreement is reachable when staff and older adults with IDs have close contact and the assessment instrument addresses the specificities of the IDs.

Nevertheless, agreement was also influenced by several dimensions of the needs assessed. The inter-respondent agreement was greater when needs were considered important by both sources, and this assures us that the essential needs will not be missed out, even when only one respondent is available. The inter-respondent agreement was lesser when the respondents had access to different information, thus stressing the relevance of both sources. The agreement was also lesser when subjective appraisal was required or when sensitive topics were inquired, therefore indicating that in some circumstances, respectively, people with IDs or a proxy might be preferable.

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