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The Reporters' Agreement in Assessing the Quality of Life of Young People with Intellectual Disabilities.

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ABSTRACT

A good evaluation of the quality of life (QoL) of young people with disability is essential to detect, monitor and report their support needs in research, and individual, institutional and policy planning. The aim of this study is to evaluate the reporters' agreement in the assessment of the QoL of young people with Intellectual Disabilities in transition to adulthood. Self and proxy-report version of INICO-FEAPS quality of life scale was used to assess 119 students of a post-compulsory educational program, being the proxy-report informed by one of their relatives. Results show poor intraclass correlations between informants. No discrepancies were found in the global QoL. However, small discrepancies were found for some dimensions. Young people's reports were higher for self-determination, personal development and interpersonal relationships. On the contrary, relatives' reports were higher for rights, material and physical wellbeing. The discrepancies in global QoL assessment were not related to student's severity, IQ, diagnosis or parent's gender. These findings underline the importance of young people participation in the assessment of their QoL as well as the convenience of using both kind of informants when taking appropriate decisions in educational contexts during transition to adulthood.

Keywords: informants, intellectual disability, quality of life, family, young adulthood.

There has been an important international paradigm shift since the nineties in the definition of intellectual disability, led by the adoption of the biopsychosocial model, and guided by the acknowledgement of the disability civil rights (Verdugo, 2018). This model focuses on generating support and overcoming barriers in the relationship between people with disability and their material and social environment to promote their quality of life (QoL) from an inclusive approach (Navas et al., 2012). Consequently, the concept of QoL has become an important framework for developing services, guide supports, evaluate personal needs and results, and inform politics as well as an advocacy tool that highlights the rights and aspirations of people with intellectual disability.

The QoL model developed by Schalock and Verdugo (2002, 2007, 2012) has been the most frequently adopted one in the field of intellectual disabilities (Balboni et al., 2020). It defines QoL as a desired state of subjective and objective personal wellbeing that is shaped multidimensionality, has ethic as well as emic properties, and is influenced by both personal and environmental factors.

The 8 components or domains identified are personal development, self-determination, social participation, interpersonal relationships, social inclusion, rights, emotional well-being, physical well-being, and material well-being. These components were later grouped in three second-order factors, namely independence, social participation, and well-being (Wang et al., 2010). Although the individual shape of QoL has cultural determinants, this model has been empirically validated across different countries and cultures (Jenaro et al., 2005) and has generated an interesting body of research about their determinants at different ecological levels including personal, interpersonal, and social factors (Verdugo, 2018).

A good evaluation of the QoL is essential to detect, monitor and report the support needs in research and individual, institutional and policy planning (Schalock et al., 2018;

Verdugo, 2018). Several instruments have been developed and validated for the evaluation of QoL of people with intellectual disability including the Quality of Life Questionnaire (Schalock & Keith, 1993) or the Personal Outcomes Scale (POS; Van Loon et al., 2008).

The instrument most frequently used in Spanish is the INICO-FEAPS QoL Scale (Verdugo et al., 2013). This instrument has two versions: one in which the person with an intellectual disability informs of QoL in the different dimensions (self-report); and a second one, in which another informant, typically a relative, teacher or professional scores the person's with disability QoL based on his or her opinion (proxy-report).

Despite the existence of these two versions, there are some barriers to use the self-report, disregarding the person's with an intellectual disability perspective (Boluarte & Sánchez, 2018; Clark et al., 2015). A common barrier for the use of self-reported scales is the difficulty that some people with disabilities have to understand the questionnaire or communicate their perspectives, needs and feelings, despite of the adaptations made to improve the cognitive accessibility of the scales (Balboni et al., 2020; Emerson et al., 2013; Nieuwenhuijse et al., 2019). For people with an intellectual disability with a higher level of support and communication needs, some researchers have developed the report on behalf technique, which is different from asking directly for the proxy reporter's own opinion (Balboni et al., 2020).

Another barrier that can hinder the use of the self-report strategy is related to the complication of data collection. In many cases, the research team must inform families, collect the guardian consent when necessary and ask for the person with an intellectual disability consent or assent. Moreover, they should collect the data through an individual or collective but supported interview, providing the necessary adaptations (Fellinger et al., 2020) instead of developing a one shot self-administered postal or online survey for relatives or professionals.

Finally, some practitioners consider that the person with a disability is prone to response bias, such as acquiescence and recency bias, despite their ability to understand the items or communicate their opinion (Finlay & Lyons, 2001). The potential disagreement between self and others perception of QoL may create a dilemma on which information is more accurate and should be used for clinical and educational practices.

In contrast with these barriers, there is a growing interest and commitment in considering the person with intellectual disability's opinion in the evaluation of their QoL (Claes et al., 2010; Emerson et al., 2013). On the one hand, the concept of QoL cannot be entirely measured from the outside (Balboni et al., 2020). QoL in each domain includes the interaction between objective circumstances and the subjective perception, evaluation, and feelings about them. Therefore, the people with disabilities' subjective perspective plays an essential role in the accurate evaluation of their QoL (Emerson et al., 2013).

On the other hand, the QoL concept includes people with intellectual disability's participation in the decisions that affect them. The assessment of their QoL without considering their point of view incur in a contradiction, insofar it weakens the trait it aims to evaluate. Therefore, an active participation of the people with intellectual disability is necessary for researching those aspects with a significant impact on their lives (Pallisera et al., 2017). Since the nineties, a more inclusive research model has been forming (Bigby et al., 2014; Callus, 2017; Walmsley & Johnson, 2003). This model supports that people with intellectual disability can give accurate information on their life conditions and enrich research results (Boluarte & Sanchez, 2018). Within this model, the participation of people with a disability in research, itself can have a positive impact on their QoL.

Therefore, investigating the informant's role in the evaluation of the QoL of people with an intellectual disability is a key issue that has received an increased research interest (Emerson et al., 2013). Literature shows a high agreement between the QoL reports of the

people with intellectual disability and their close informants, despite of the proxy-informant gender or relation with the person with intellectual disability (Claes et al., 2010; McVilly et al., 2000), supporting the interchangeable information they give with that provided by families or professionals.

On the contrary, other studies show important differences between self-perception and others' perception of QoL (Balboni et al., 2013; Clark et al., 2015; Fellingner et al., 2020; Gil-Llario et al., 2016; Simões & Santos, 2016). While in some of them, self-reported QoL was higher than proxy-reported QoL (Balboni et al., 2013; Clark et al., 2015; Fellingner et al., 2020; Schmidt et al., 2010), in others there are lower reports for some domains.

For example, Gil-Llario et al. (2016) studied the agreement between self-report and professional reports of QoL assessed by the Inico-Feaps Scale in a sample of 360 people with intellectual disability and 103 professionals who worked with them. A high level of agreement was found in dimensions such as Material Well-being, Physical Well-being and Civil Rights. On the contrary, there were differences in the dimensions such as Self-determination or Emotional Well-being. These authors interpret these discrepancies based on the type of necessity that each dimension of the QoL represents, according to Maslow's hierarchy of needs. The higher needs in the hierarchy show the greatest differences while there is a greater agreement in the most basic needs. In a similar study, Balboni et al. (2013) found higher self-reports than proxy-reports for all scales excepting for rights, material well-being and self-determination, and they propose as an explanation that these domains involve more objective assessment of conditions of life and less the perception of satisfaction. Clark et al. (2015) reported higher proxy reports in social inclusion and financial resources.

Based on these differences, a combined use of self-report and proxy-report scales has been supported as a mean to have a valid and complete picture of the QoL of people with an

intellectual disability (Balboni et al., 2020; Berástegui & Corral, 2020; Bertelli & Brown, 2006; Claes et al., 2010; Sandercock et al., 2020; Simões & Santos, 2016).

Furthermore, research on the role of the informant has explored whether there are characteristics of the person with disability, such as severity of the disability, IQ scores, diagnosis, or relation with the proxy-reporter that can modulate the degree of agreement between them. Some evidence supports that the severity of the disability can predict a greater disagreement in general (Schmidt et al., 2010) or that a lower IQ score is related with the discrepancy in social inclusion evaluation (Gil-Llario et al., 2016). Some other authors have highlighted that the specific diagnosis can also change the relation between self and proxy report of QoL. For example, Berástegui and Corral (2020) found that QoL scores were greater for young students with Down syndrome as compared to their pairs with other conditions when reported by relatives, but worse when self-reported. On the contrary, people with Autism Spectrum Disorder generally report higher scores than their relatives (proxy-report) (Clark et al., 2015; Kamp-Becker et al., 2010; Shipman et al., 2011), except for financial well-being and social inclusion (Clark et al., 2015) or physical well-being (Shipman et al., 2011).

Some studies have compared the degree of agreement depending on whether the informant is a relative or a professional. Simões and Santos (2016) found that professional reports were closer to self-perspective than family reports. However, it seems that it depends more on the degree of proximity and daily relationship between the informant and the person with a disability than on the professional or familial nature of the relationship. The proximity of the informant increases the degree of agreement, so that family members or professionals who live with the person with disability show higher levels of agreement in their evaluation of his or her QoL (McVilly et al., 2000; Schmidt et al., 2010). In addition, self and other-reports are closer when proxy-informants are asked to estimate the perspective of the person

with intellectual disability and answer in their behalf (Balboni et al., 2013; Kamp-Becker et al., 2010; Simões & Santos, 2016). Concerning parents' reports, main studies rely on mothers' reports, and no evidence has been found of the differences when the family informant is the mother or the father (McVilly et al., 2000).

Transition to adulthood can be a fundamental stage for the person and the family in which to explore their level of agreement in QoL assessment. The transition from high school to adulthood constitutes a challenging stage for most young adults with disabilities and their families (Kim & Turnbull, 2004; Neece et al., 2009; Floyd et al., 2009; Henninger & Taylor, 2014; Leonard et al., 2016). Typical developmental tasks of this stage, such as psychological differentiation, establishing residential and economic independence from the family and forming new attachments may find important barriers and limitations for young people with intellectual disability (Floyd et al., 2009). These challenges coexist with a time of decrease and change in the shape of instruction, services and supports and social connections (Boehlm et al., 2015). The satisfaction with this transition is closely related with the evaluation of individual and family QoL (Boehlm et al., 2015). However, the reporter's agreement has not been specifically studied during this stage of life.

The aim of this study is to explore the level of agreement between young students with intellectual disability and their relatives in the assessment of their QoL during their transition to adulthood. Likewise, we will explore the relationship between this agreement or disagreement and some characteristics of the young people or the reporter previously explored by literature such as severity, IQ, diagnosis or father vs. mother as informants.

MATERIALS AND METHODS

Participants

Participants were 119 young students with an intellectual disability participating in a full-time education program (DEMOS program), between 2012-2020 (Berástegui et al., 2015). The aim of the program is to enhance participation of these students in the university and, therefore, in the community; and training them for future employment. Participants mean age was 21.4 years old ($SD = 2.6$; range = 17-35) and 56.3% of them were female ($n = 67$) and the rest male (43.7%; $n = 52$).

All participants have an intellectual disability certificate issued by the Spanish public administration. The degree of disability issued by the Spanish administration was between 33 and 50% (27.4%), between 50 and 70% (62.9%) or higher than 70% (9.7%). The severity of their disability, as reported by relatives was slight (28.6%), moderate (51.3%), severe (6.7%) or profound (0.8%). Their IQ scores ranged between 41 and 85 ($M = 67.80$; $SD = 9.21$). The majority them have other complementary diagnosis such as such as Down syndrome (17.6%) Pervasive Developmental Disorder (13,4%), Autism Spectrum Disorder (5%) Cerebral Palsy or Damage (4,2%) or Rare Diseases (Noonan, Jubert, Sotos, Williams...) (3,4%).

All of them live in the family home. The proxy-reporters were family members, mainly the students' mothers (61.7%, $n = 66$) or fathers (34.4%, $n = 41$). The rest of them were other cohabitant family members such as siblings, grandparents, or aunts. The yearly income of the family was less than 15,000 euros (5.6%), between 15,000 and 24,000 euros (10.9%), between 25,000 and 49,000 euros (31.9%) and more than 50,000 euros (42.0%).

Variables and Measures

INICO-FEAPS quality of life scale (Verdugo et al., 2013)

This instrument was developed for the multidimensional evaluation of QoL in adults with intellectual disability (Verdugo et al., 2013). For this study, both self-report and proxy-report scales were used. Both scales are composed by 72 items that are organized in eight

subscales, corresponding to the eight core dimensions of QoL: Self-determination, Rights, Emotional Well-being, Social Inclusion, Personal Development, Interpersonal Relationships, Material Well-being and Physical Well-being. Every scale has 9 items, and all items are scored on a 4-option Likert-type scale: 1 (Never), 2 (Sometimes), 3 (Often) and 4 (Always). Higher scores on every scale indicate a better QoL.

The validity and reliability of this instrument are well documented (Verdugo et al., 2013). For this study, the internal consistency scores (alpha-Cronbach) were adequate for the total scale, both for the self-report ($\alpha = .89$) and the proxy-report ($\alpha = .94$) and the consistency for the dimensions was also adequate. Verdugo et al. (2013) offer scale data for self and proxy reports based on a representative sample of 1627 people with IDD (56.1% women) in Spain.

K-BIT (Kaufman & Kaufman, 1997)

The IQ was assessed with the K-Bit IQ score, computed according to Spanish normative scores (Kaufman & Kaufman, 1997). The KBIT is a screening tool rather than a diagnostic one. The KBIT score was collected as a part of the admission process to the program after reaching the age of 18. The result of this test would indicate that some participants are people with borderline intelligence, but their official diagnosis (diagnosed and accredited by the public entity before reaching the age of 18) is intellectual disability, which is what we consider for the program access and also and as a sample inclusion criteria.

Demographic information

Severity of disability was assessed by the proxy reporter, typically the parents, choosing according to their own criteria, between slight, moderate, severe or profound. Demographic data was also collected, including age, complementary diagnosis, and gender and kinship of the proxy-reporter. For results concerning parents gender we only use mothers and fathers reports.

Procedure

The data was gathered between 2012 and 2020 as a part of the admission process to the (name of the program) program. The sociodemographic data, the severity, diagnosis and the proxy-report were reported by the family.

Medical and psycho-pedagogical reports, including the IQ assessment, and a copy of their Disability Certificate issued by the Spanish public administration were provided. In this document, the Spanish public administration accredits that the person has a permanent or temporary physical, intellectual, mental or sensory functional limitation. This certificate is issued after evaluation by an assessment team consisting of a doctor, a psychologist and a social worker. This certificate includes the diagnosis and the disability degree that is expressed as a percentage, according to its impact on daily living activities. In our study we include young people which diagnosis is intellectual disability and their degree of disability 33% or higher.

The self-report was collected at the beginning of the program, in a collective application. A researcher was available to solve any questions and to clarify the meaning of the items when necessary. For students absent during the group application, the questionnaire was applied individually.

The universal ethical principles governing the conduct of research in psychology have been respected, including maintaining confidentiality and obtaining informed consent from participants and their legal guardians when required and the study was approved by the Comillas P. University Ethics Committee.

Data Analyses

The data analyses were performed using SPSS. Cases were eliminated from the original databases when one of the two reports or more than 15% of the items were missing, resulting in a sample of 119 cases. Missing values were replaced with the mean value of the item (0.93% values for the self-report and 0.86% for the proxy-report scales). Raw data were used for all the analysis.

First, the subscale and total scores of self-report and proxy-report were compared with the instrument scales (Verdugo et al., 2013) and a description of the scores of different diagnostic groups were provided. The total QoL score met the normality assumption in both versions and thus a parametric strategy was used for their analysis. On the contrary, the QoL dimensions did not meet the normality assumption and a non-parametric strategy was followed.

Intra-class correlation (two-way random model, total agreement type) were used for the scale and its dimensions. Matched sample analyses were used to examine the differences between each scale: *T*-test for the total score and Wilcoxon's test for the dimensions. A significance level of .05 was used for all analyses. The effect size was calculated using the *z*-value following *r* formula (Fritz et al., 2012), Cohen's guideline for *r* was used, being a small effect size $r = .1$, medium $r = .3$, and large $r = .5$ (Cohen, 1988).

In addition, repeated-measure ANOVA were made to test the impact of different variables on the level of the informant's overall QoL agreement, the effect size was calculated and interpreted using the guideline provided by Sink & Stroh (2006), being a small effect size $\eta^2 = .01$, medium $\eta^2 = .06$, and large $\eta^2 = .14$.

Finally, the multiple linear regression analysis was carried out to test the predictive power of the intellectual disabilities' characteristics (severity, IQ and diagnosis) in the difference between informants.

RESULTS

The descriptive analyses of our sample show above average reports of QoL for both reporters, with mean scores that are located between the 50 and the 75 percentiles of the instrument scale in all subscales (figure 1).

Insert Figure 1

Intra-class correlations between self and proxy scores were poor or non-significant for the total scale and its dimensions (Table 2). No significant differences were found in the overall QoL depending on the informant. Statistical differences between informants were found for the QoL dimensions with the exception of emotional well-being and social inclusion (Table 2). On the one hand, young people with intellectual disability reported higher levels of self-determination, personal growth and interpersonal relations than their relatives did, and these differences were moderate. On the other hand, relatives reported higher levels of rights and physical well-being, being these differences moderate, and moderately higher levels of material well-being.

Insert Table 2

The descriptive statistics of each diagnosis group concerning their gender, age, IQ and their self and proxy reported QOL is reported in Table 3. For the statistical analysis, we compare those with and without Down syndrome diagnosis.

Insert Table 3.

There were no statistical effects of severity of disability, Down Syndrome diagnosis, or parents' gender on the ratings provided by the respondents (Table 3). When comparisons between dimensions were made, it was only found a higher agreement in social inclusion evaluation between informants for young people with Down Syndrome as compared with young people with other conditions ($F = 4.06$; $p = .046$; $\eta^2 = .034$), being this difference small.

Insert Table 3

Multiple linear regression analysis show that the combination of severity of disability, IQ score and Down Syndrome diagnosis cannot predict the difference between informants in total QoL or its dimensions excepting for Social Inclusion dimension. The combination of these three variables explains 5% of the variance of the differences in the assessment of social inclusion ($R^2 = .05$; $F(3, 88) = 2,759$, $p = .047$) although none of them exclusively have significant impact in the prediction: severity of disability ($\beta = -.153$; $p = .138$), IQ score ($\beta = -.160$; $p = .168$) and Down syndrome diagnosis ($\beta = -.150$; $p = .141$). The assumptions regarding linearity, normally distributed residuals, homoscedasticity and absence of multicollinearity were met for this model.

DISCUSSION

The present study examined the level of agreement in the evaluation of the QoL reported by young adults with intellectual disability (self-reported) and those made by their relatives (proxy report). Our sample showed medium to high levels of QoL, both in the parent-report and in the self-report. The parent report scale and subscales averages correspond to higher percentiles of the reference population scale, especially in physical and material well-being and interpersonal relationships. This may be due to sociodemographic biases in our sample that we discuss below.

The total score and its dimensions show poor or non-significant inter-rater reliability, as previous found by Balboni et al. (2013) or Schmidt et al. (2010). Therefore, we cannot consider your reports interchangeable when assessing quality of life. On the other hand, no differences were found in the global evaluation of the QoL of the young person with intellectual disability in accordance with previous literature (Claes et al., 2010; McVilly et al., 2000). In contrast, the reports disagree on some dimensions. The low or moderate magnitude of these differences can be interpreted in favor of general agreement in the assessment of QoL. However, the differences, although small, can inform us about nuances

and key trends for the comprehensive assessment of the QoL of young people with intellectual disabilities.

Young students' evaluation of their QoL was lower in regard with Rights, Physical Well-being and Material Well-being, contrary to Gil-Llario et al.'s (2016) findings. The greatest difference is found in the Rights dimension in which the person with a disability present lower scores than their relatives, though this difference is moderate. Relatives perceive that young people with an intellectual disability have a better understanding of their rights and feel more respected and treated as equals than they self-report. This might be explained because the relatives do not personally experience the same inequalities people with intellectual disabilities do, thus they are partially unaware of this situation, or because the denial of these difficulties.

Young people with disability have a worse perception of their own Physical Well-being, health and lifestyle habits than their relatives have, and the difference is mild, in contrast with previous studies (Balboni et al., 2013; Simões & Santos, 2016) but similar to the findings with samples of people with Autism Spectrum Disorder (Shipman et al., 2011). This can stem from the fact that relatives are more aware of their children medical history, or because the person with disability underestimates their physical abilities. Nevertheless, these two dimensions are the ones with lesser reliability indexes for the self-report ($\alpha=.52$ for physical well-being), so the results might not be accurate. As the differences may be due to the weakness of the measures, conclusions must be taken with caution.

Similarly, students show significantly lower scores in Material Well-being than their relatives and this difference is mild (Clark et al., 2015). Proxy-reporters perceive a higher availability of economic resources to meet their needs than young people with an intellectual disability do. Relatives might respond connected with their own point for view about the accomplishment of family needs. In contrast, young people with disability can be unaware of

family's economy or respond attending to their own personal and limited income, while they remain financially dependent on their parents.

On the contrary, young people reached higher scores than their relatives in their QoL in Self-determination, Personal Growth and Interpersonal Relations domains. Concerning Self-determination, young people with intellectual disability perceive a better QoL in terms the ability of making their own decisions and choosing autonomously than their relatives do, as found in Simões and Santos (2016). This can help us understand why self-determination is one of the lowest scoring dimensions. Although the scores are above the population scale average, it is the dimension that both relatives and students score the lowest. It would seem that in our sample, the achievements in this dimension are high but their aspirations seem to be even more so, especially for relatives. This can make us reflect on the insufficient treatment of self-determination in the Spanish educational system.

Regarding Personal Growth, the young person with intellectual disability perceives having more functional skills, abilities, supports and opportunities than their relatives do, in accordance with previous studies (Balboni et al., 2013; Simões & Santos, 2016). Relatives might underestimate the young people with an intellectual disability, evaluating them as less capable than they perceive themselves. It is important to consider that the person with intellectual disability evaluates their development in the framework of their everyday outcomes in the context of a supported educational program, while relatives might assess this dimension considering the developmental opportunities or outcomes of typical young people, as their other children, or themselves at the same age.

In the Interpersonal Relations dimension, the person with intellectual disability refers to having safer relationships and a better ability to form friendships, than what their relatives perceive, in accordance with previous studies (Balboni et al., 2013; Simões & Santos, 2016). Relatives may try to overprotect their children in their relations, by the means of

undervaluing their social autonomy. Also, relatives are not present during the moments the young people with disability are relating to their equals and thus underestimate the importance of some relations for their children QoL.

To sum up, these three dimensions (Self-Determination, Personal Growth and Interpersonal relationships) might be tainted by the hopes and expectations the relatives might have concerning their children, comparing the person with disability with themselves at a young age, or with siblings they might have. The similarity in the results between our sample and the Italian and Portuguese samples (Balboni et al., 2013; Simões & Santos, 2016) also invites us to explore the cultural dimension of the perception of QoL by the family in the cultures of southern Europe.

These findings contradict those of Gil-Llario et al. (2016), who showed a higher level of agreement in those dimensions which are lower in Maslow's hierarchy of needs (1972). In our sample, disagreement is shown in both higher and lower dimensions of Maslow's hierarchy. Young people with intellectual disability tend to score lower than their relatives in the most basic dimensions (Physical Well-Being, Material Well-being, and rights) and higher in the highest dimensions (Self-determination, Personal Growth and Interpersonal relations).

Finally, there are no significant differences in Social Inclusion and Emotional Well-Being domains between the reporter's, contrary to the finding of Gil-Llario et al. (2016) who found discrepancies in Emotional Well-Being. Cohabitant relatives, especially parents, may be more reliable informants of emotional well-being than professionals, especially in family centered and collectivistic societies as Spanish, but this hypothesis require further replication.

No discrepancies were found in evaluation of QoL when tested for severity or diagnosis, except for some differences in social inclusion. There is a greater agreement in the evaluation of social integration between young people with Down Syndrome and their relatives. This can be due to the effect of the "Down syndrome advantage" phenomenon in

the perception of the well-being of these young people, especially regarding the social dimensions (Berástegui & Corral, 2020). In the same vein, the combination of disability variables (Down Syndrome diagnosis, higher severity and lower IQ scores) can explain a small proportion of the degree of agreement between informants in the evaluation of social integration, in contrast with Gil-Lario et al. (2016). Perhaps this combination draws a picture of lesser social independence, greater social time sharing and thus, greater agreement in the social inclusion domains. Nevertheless, these affirmations should be considered with caution and need further research as most of our sample has a mild to moderate reported severity of disability and the sample has an important heterogeneity concerning diagnosis. Although the dispersion of the disability conditions and etiologies is big, and it is not possible to evaluate effect of individual different diagnoses in our studies, sharing this data can facilitate meta-analytic efforts.

We believe that neither perceived severity of disability nor the specific diagnosis should be a barrier to consider self-report of QoL reliable, at least as long as young people with intellectual disability can receive the necessary support to understand the questions and give the answers. In our sample, despite the availability of supports, we found a relevant number of missing values in the young people with disabilities report. This throws some concern about the group data collection strategy, that may have been a barrier to some subjects' accurate participation. The missing values can be due to a lack of comprehension in the items, the refusal to provide information on some issues in the educational context, despite of the anonymity or the attentional limitations by which some lines might have been skipped. A more sophisticated method for imputation of missing values can eliminate some biases, even when the number of substituted values is very low. An in-depth study of the missing values is also necessary, to provide the accurate supports. Meanwhile, whenever possible, and especially for diagnostic and not just screening purposes, it is recommended to

collect the self-report during an individual interview, as suggested in the manual. In case the accurate support is not enough or cannot be provided, the report on behalf has been raised as a valuable alternative (Balboni et al., 2013; Kamp-Becker et al., 2010; Simões & Santos, 2016).

Although we tend to use mothers as informants, and their presence in the studies is prevalent as is in the present one, no discrepancies were found considering parents' gender as found in McVilly et al. (2000). This result should be replicated with other study designs, able to compare mother's and father's reports of QoL and their agreement for the same children. It would also be interesting to continue the exploration of the different perspectives of QoL depending on the informant, including not only professionals but also siblings, close friends and other informal supports.

This study is focused on young people in transition to adulthood. The specific tasks of this stage such as the psychological differentiation of the family, establishing residential and economic independence and forming new attachments (Floyd et al., 2009; Henninger & Taylor, 2014; Leonard et al., 2016) along with some typical barriers such as the decrease and change in educational opportunities, services and supports and social connections (Boehlm et al., 2015) can have a differential impact on the discrepancies when assessing the QoL. Thus, an in-depth investigation on this question would require a longitudinal approach. Further research can also explore the specificity of this effect for young people with disabilities and their families, since these discrepancies in the evaluation of QoL could occur in typical populations at this particular stage of life. Finally, the cultural dimension of transition to adulthood and disability and its relationship with the QoL assessment should be acknowledged (Schmidt et al., 2010) and can benefit from different samples and countries of study, such as Spain.

It is important to note that this is not a representative sample of young adults with disability. The participation of our sample in an educational program in the university may contribute to several biases concerning their adaptive skills, family resources and educational and social opportunities, which compromise the representativeness of the results. Nevertheless, there is an increasing number of young adults with disabilities in post-obligatory educational programs, which makes this a relevant study sample (Cabezas & Florez, 2015). Thus, these results might be especially useful as a guide on how to interpret the QoL reports in inclusive educational settings for young people with disabilities in transition to adulthood. It would be relevant to continue investigating informant's role on the QoL assessment for young people intellectual disability, with broader and more representative samples exploring, for example, how each dimension contributes to explain the total QoL for each informant.

This study highlights the convenience to gather the information from both informants, to have a more complete view of the QoL of the person with disability (Balboni et al., 2020; Berástegui & Corral, 2020; Bertelli & Brown, 2006; Claes et al., 2010; Simões & Santos, 2016) especially in transition to adulthood. Considering that both informant reports are subjective measures, it cannot be asserted that one reporter is more accurate than the other; on the contrary, they are complementary and both reliable. Nevertheless, different informants can pay attention to different aspects or information about the same dimension, as we have suggested for material well-being, or evaluate the same objective input on a different scale.

Discrepancies between self and proxy-reports have often been considered as a methodological problem leading to sterile discussions about who is “right” or what is the “truth” (Eiser & Varni, 2013). On the contrary, these differences may not be seen as a matter of unreliability but an opportunity in clinical and educational practices. Decisions based on the combination of both perspectives can be more adjusted (Sandercock et al., 2020) and

better respond to the needs of the person with disability and their families. The combined assessment approach can be ideal for the development of person-family interdependent planning in transition to adulthood (Kim & Turnbull, 2004). Furthermore, this can be an interesting tool to improve the communication inside the family, and to acknowledge and discuss the differences in those dimensions in which there are discrepancies, and therefore to improve not only personal but also the whole family QoL. For this purpose, it would be interesting to explore the influence of family communication climate and contents on personal and family QoL development and assessment.

In the ongoing process of transformation regarding the support systems for the people with intellectual disability, it is still necessary to focus on what they – and their families – need to improve their QoL (Verdugo, 2018). Therefore, it is necessary to bear in mind a holistic QoL approach to the personal needs and resources, informed by the person with intellectual disability, their families and professionals, in order to provide individual support and opportunities to achieve the best possible life.

WHAT ADDS

This study explores the informant's agreement in QoL assessment, comparing relative-reports and self-reports in a sample of young students with intellectual disabilities in transition to adulthood attending to a college-based educational program in Spain for the first time in literature. Transition to adulthood can be a fundamental stage for these people and their families in which to explore their level of agreement in QoL assessment. The increasing number of young adults with disabilities in post-obligatory educational settings makes this a relevant study sample. Thus, these results might be especially useful as a guide on how to

interpret the QoL reports in inclusive educational contexts during transition to adulthood. Young people with intellectual disability tend to score lower than their relatives do in the most objective dimensions, which are related to their basic needs (Physical Well-Being, Material Well-being, and rights). On the contrary, they tend to score higher in the mainly subjective dimensions, which are related to the highest needs in the hierarchy (Self-determination, Personal Growth and Interpersonal relations). Nevertheless, the study considers discrepancies not as a methodological problem but an opportunity for improving professional practice, underlying the importance of young people participation in their QoL assessment as well as the convenience of using combined reports for decision-making, planning supports and enhancing family communication and well-being in the transition to adulthood of young people with intellectual disabilities.

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Table 1*Mean differences between informants in QoL dimensions.*

	N	Proxy	Self-Reported	Z	p	r	ICC
	N	M ±SD	M ±SD				
Self-determination	119	26.5 ± 4.0	27.2 ± 4.0	2.44*	.013	.22	.27**
Rights	119	30.9 ± 3.2	28.6 ± 4.0	-4.67**	.001	.43	.12
Emotional Well-being	119	29.4 ± 4.0	29.0 ± 4.4	-0.67	.502	-	.18*
Social Inclusion	119	29.8 ± 3.4	29.1 ± 3.7	-1.55	.121	-	.13
Personal Growth	119	28.4 ± 3.6	29.4 ± 4.1	2.36*	.018	.22	.32**
Interpersonal relation	119	28.1 ± 4.4	29.2 ± 4.4	2.29*	.022	.21	.28**
Material Well-being	119	32.9 ± 2.1	31.9 ± 3.2	-3.05**	.002	.28	.12
Physical Well-being	119	32.6 ± 2.8	31.1 ± 3.4	-4.02**	.001	.37	.22**
QoLTotal	119	235,8±21.0	238,6±18.1	1.29	.198	-	.29**

Note: Single measure ICC is presented *p<.05; **p<.01

Table 2*Descriptive statistics by diagnosis*

	n	%	Gender		Age	IQ	Self QoL	Proxy QoL
			M	F	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Rare disease	4	3.4%	100%	-	20.3 (1.9)	70.8 (4.6)	236.0 (30.8)	247.2 (21.3)
Cerebral palsy or damage	5	4.2%	20%	80%	21.4 (1.7)	69.0 (9.6)	229.9 (15.8)	237.0 (11.6)
Down Syndrome	21	17.6%	33.3%	66.7%	21.9 (2.1)	60.7 (8.6)	236.5 (21.3)	243.3 (13.1)
Autism Spectrum Disorder	6	5%	83.3%	16.7%	21.8 (2.2)	78.8 (5.9)	225.9 (13.4)	235.1 (8.9)
Pervasive Developmental Disorder	16	13.4%	43.8%	56.3%	20.6 (1.7)	72.4 (8.8)	236.3 (22.7)	228.9 (22.2)
Total	119	100	43.7%	56.3%	21.3 (2.6)	69.3 (10.4)	235.8 (21.1)	238.6 (18.1)

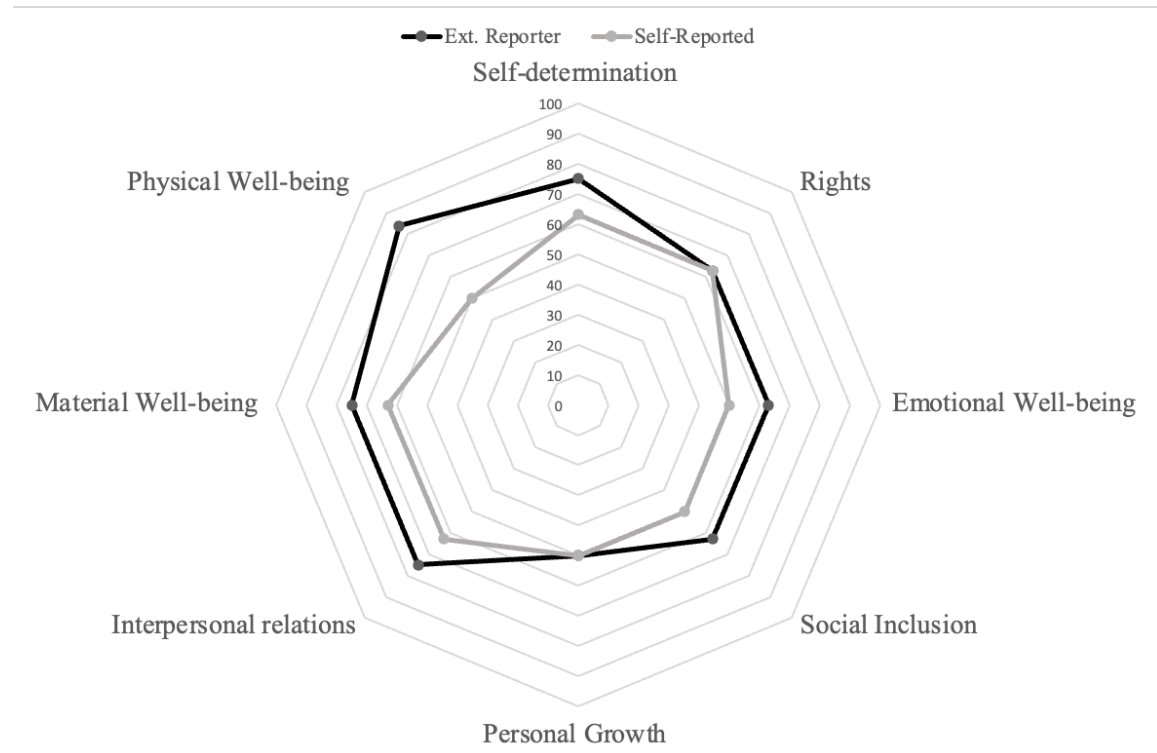
Note: M and SD of QoL typical scores is provided

Table 3*Mean difference in overall QoL between informants * sociodemographic variables.*

		F	p	eta²
Down Syndrome Diagnosis	Informant	4.49	.360	.037
	Informant*DS	2.96	.880	.025
Severity of Disability	Informant	0.59	.469	.006
	Informant*Severity	1.18	.280	.013
Parent Gender	Informant	1.40	.225	.014
	Informant *P. Gender	0.52	.474	.005

Authors Version

Figure 1. *QoL's dimensions percentile according to each reporter.*



Author