Does quality of life differ for children with autism spectrum disorder and intellectual disability compared to peers without autism? Abstract

The main goal was to test if children with intellectual disability (ID) and autism spectrum disorder (ASD) show lower quality of life (QOL) in comparison to those with ID but not ASD. The KidsLife Scale was applied to 1,060 children with ID, 25% of whom also had ASD, aged 4-21 years old. Those with ASD showed lower scores in several QOL domains but, when the effect of other variables was controlled, lower scores were only kept for interpersonal relationships, social inclusion, and physical wellbeing. However, they obtained slightly higher scores for material wellbeing. Level of ID and support needs were the covariables with the greatest influence in most domains, while gender was only significant for social inclusion (girls scored lower than boys).

Keywords. Quality of life; autism spectrum disorder; intellectual disability; support needs; gender; children.

Does quality of life differ for children with autism spectrum disorder and intellectual disability compared to peers without autism?

The concept of quality of life (QOL) has had a great influence on both research and the more applied fields of disability, particularly in the intellectual and developmental disabilities (IDD) field (Brown et al. 2009; Cummins 2005; Felce and Perry 1995; Schalock et al. 2002, 2016; Schalock and Verdugo 2012; Verdugo et al. 2012). Currently, QOL has become a reference framework for the provision of individualized supports and person-centered planning (Buntinx and Schalock 2010; Claes et al. 2012) as well as a basic principle guiding professional practices and social policies (Gómez et al. 2013; Schalock et al. 2008, 2017; van Loon et al. 2013).

There are numerous existing theoretical frameworks and definitions concerning QOL. The one proposed by Schalock and Verdugo (2002, 2012) has great acceptance in the field of disability given the amount of empirical evidence on its validity (Gómez et al. 2010; Jenaro et al. 2005; Schalock et al. 2005; Wang et al. 2010) and because it is the most widely used by professionals in organizations providing services and support in various countries (Buntinx and Schalock 2010; Carbo-Carreté et al. 2015; Claes et al. 2010; Gómez et al. 2015, 2016a; Lombardi et al. 2016; Moran et al. 2015; Schalock et al. 2016; Simões and Santos 2016; Verdugo et al. 2010, 2014). According to this model, QOL is a multidimensional phenomenon composed of eight core domains—emotional wellbeing, physical wellbeing, material wellbeing, social inclusion, interpersonal relationships, self-determination, rights, and personal development—that are influenced by personal and environmental variables. These eight core domains are the same for all people but are assessed on the basis of culturally sensitive indicators. The indicators' measurement results in personal outcomes that can be used for developing person-centered planning and guiding the provision of individualized supports (Schalock et al. 2011). In this regard, supports are defined as resources and strategies that aim to promote personal wellbeing and functioning (Thompson et al. 2009).

Faced with these developments in the research of QOL in general and in the field of disability in particular, one of the groups that have benefited less in terms of the development in the operationalization and implementation of the QOL construct has been people with autism spectrum disorder (ASD) (Plimley 2007). The few existing studies agree that ASD is a predictor variable for the worst scores in QOL over the life cycle (Biggs and Carter 2016; Saldaña et al. 2009; van Heijst and Geurts 2015). Focusing on the early stages of life, it seems that children and adolescents with ASD show lower levels of QOL than their peers without this condition (de Vries and Geurts 2015; Ikeda et al. 2014; Kamp-Becker et al. 2011; Kose et al. 2013; Lee et al. 2008; Shipman et al. 2011; Tavernor et al. 2013) and even those with chronic diseases (Kuhlthau et al. 2010).

These lower results in QOL appear regardless of possible moderating variables such as IQ level (Lord and Bailey 2002; McGovern and Sigman 2005; Stabilise et al. 2004), the severity of symptoms (Billstedt et al. 2005; Chiang and Wineman 2014; Szatmari et al. 2003) or the support needs (Renty and Roeyers 2006). Regarding the IQ level, it is noteworthy that ASD and intellectual disability (ID) covary at very high rates (La Malfa et al. 2004; Matson and Shoemaker 2009). When both diagnoses are made, recent studies agree that young people with ASD and ID show the worst QOL-related personal outcomes compared to peers presenting ID in the absence of ASD (Bradley et al. 2004; Matson et al. 2009; Viecili and Weiss 2015). According to Centers for Disease Control (2012), approximately 38% of people with ASD have a comorbid diagnosis of ID, and 23.5% of people with ID present ASD. Although ASD is diagnosed more frequently in males—one woman with ASD for every four males (Lee et al. 2008)—women with ASD often present higher levels of ID and lower levels of functioning (Amiet et al. 2008; Halladay et al. 2015; Kirkovski et al. 2013; Rubenstein et al. 2015). The prevalence of ID rises to 46% in females with ASD compared to 37% in males (Centers for Disease Control 2012). Therefore, among people with ASD, females and those showing higher levels of ID, lower levels of human functioning or, therefore, more support needs are those who could be at risk for low levels of QOL (Biggs and Carter 2016; Note et al. 2007).

In this sense, a new line of research has recently arisen that recommends investigating the important role played by variables such as gender, level of ID, and supports needs in this relationship (Chiang and Wineman 2014; Felce et al. 2011; Totsika et al. 2010; Volkmar et al. 2014). Unlike the traditional perspective that predicts worse QOL outcomes for people with ASD, several authors such as Totsika et al. (2010) argue that there are no differences in QOL among people with only ID versus those with ID and ASD if the differences between them related to their level of disability are controlled. More specifically, the findings in the Totsika et al. study suggested that the presence of ASD was not associated with differential outcomes in QOL among 282 adults over 49 years old with ID, of whom 87 were also diagnosed with ASD. The differences that were initially present became non-significant once the level of ID (based on adaptive behavior) was controlled. These results suggested that the lower scores observed in adults were due to a

higher prevalence among adults with ASD of severe or profound ID. Similar results were also reported by Felce et al. (2011) and La Malfa et al. (2004).

In accordance with the latter studies, the main goal of this research consists in testing whether differences in QOL of children with ID are associated, not with the presence of ASD per se, but due to their differential distribution of higher levels of ID and support needs by diagnostic groups and gender (i.e., higher levels of ID and support needs in the female and ASD groups). To test this hypothesis, it is necessary to confirm, firstly, that the QOL model operates similarly in children with only ID and children with ID and ASD (in other words, confirming the eight-domain model fit to data for both populations) and, secondly, that the measurement is not biased against any of the two groups—in other words, if strong measurement invariance between the compared groups is not guaranteed, the population heterogeneity estimators are at risk of being biased, given the potential influence of differential item functioning (Brown, 2006). If measurement invariance holds, the observed heterogeneity may be interpreted as being due to genuine differences in the latent trait, rather than as a result of measurement artifacts. Finally, if children with ID and ASD differ (i.e., score lower or higher) in any of the eight QOL domains with respect to their peers with ID but not ASD, it is necessary to test whether those differences persist once the effect of gender, level of ID, and level of support needs has been controlled. Given the established diagnostic criteria for ASD, once the effect of these variables is controlled, only differences in the domains of interpersonal relationships and social inclusion are expected, showing children in the ASD group as having the worst results due to their limitations in communication and social interactions (Biggs and Carter 2016; Clark et al. 2015; Deckers et al. 2014; Ikeda 2014, 2016; Kamp-Becker et al. 2011; Taheri-azar et al. 2016; Tureck and Matson 2012).

Methods

Participants

The participants were 1,060 people with ID receiving support and services in organizations and educational centers in Spain. Their ages were between 4 and 21 years (Me = 14; M = 13.6; SD = 5.0). Almost two-thirds (n = 681; 64.2%) were male, and one-fourth (n = 273; 25.8%) had a comorbid diagnosis of ASD according to official records at the schools and organizations in which participants were recruited. The distribution by gender and age met the equiprobability assumption ($\chi^2 = 22.17$; p = .178). The distribution of the sample by levels of ID (in terms of IQ) was mostly (73.7%), concentrated in the intermediate range

(moderate = 42.3%; severe = 31.4%); the lower levels (profound = 10.2%) and above (mild = 16.1%) were less represented. Regarding the support levels, more than half required extensive (27.7%) or generalized (34.2%) support, one-fourth (25%) needed intermittent support, and only 13% needed limited support. It should be noted that the vast majority came from special education schools (71.4%) and that only one-third attended ordinary education centers (21.4%) or received a combined mode (7.2%).

The assessments were made by 569 external observers or respondents, such as teachers, professionals, and direct care staff (50.3%), or relatives and legal guardians (49.7%). The majority (83.3%) of the respondents were women. The average age of all respondents was 42 years (SD = 9.4). The average time that they knew the people evaluated was approximately 6 years (SD = 5.1), though it ranged from 6 months to 21 years. Almost all had contact with the person evaluated daily or several times a week (90.2%).

Materials

The Spanish version of the KidsLife Scale (Gómez et al. 2016b) was applied to assess QOL according to the eight-domain model proposed by Schalock and Verdugo. The KidsLifeScale was originally developed and validated in Spanish, showing adequate reliability through Cronbach's alpha, ordinal alpha, theta, and omega coefficients. All of the internal consistency coefficients were adequate for the eight domains, varying between .812 for rights and .949 for personal development (Gómez et al. 2016b). Also, evidences of validity of content (Gómez et al. 2014) and evidences based on the internal structure of the scale through Confirmatory Factor Analyses confirming the intercorrelated eight-domain model are available: RMSEA < .060; CFI and TLI above .98 and SRMR < .50 (Gómez et al. 2016).

The KidsLife Scale is a report completed by external observers (e.g., support professionals, teachers, family members) that comprises 96 items, third-person formulated, which evaluate personal outcomes in each of the eight domains of QOL (i.e., social inclusion, self-determination, emotional wellbeing, physical wellbeing, material wellbeing, rights, personal development, and interpersonal relationships). Each domain has a total of 12 items whose answer format is a four-option frequency scale (never, sometimes, often, and always). The answers are scored between 1 and 4. The scale provides a total score for each domain (the greater the score, the greater the QOL).

Despite being a very recently developed scale, it is currently being translated into various languages and adapted for implementation in various countries (Argentina, Azerbaijan, Chile, Colombia, the United States, Italy, India, Iceland, Mexico, Norway, Peru, the United Kingdom, Sweden, and Turkey). The Spanish version of the KidsLife Scale can be freely downloaded at

http://sid.usal.es/idocs/F8FDO27258Herramientas_10_2016.pdf. An English version can be found in Appendix A.

In addition to the KidsLife Scale, an ad-hoc survey was used to collect sociodemographic data on the person evaluated (date of birth, date of application, diagnoses, type of schooling, ID level, and level of support needs), on the respondent or external observer (relationship with the person evaluated, time that they have known the person, and frequency of contact), and on the center or organization where they receive supports (full name, location, and contact data).

Procedure

The data collection was performed in a first phase by identifying schools and organizations providing services to people with ID or ASD in Spain's 17 counties. Then, they were sent an e-mail explaining the goals and characteristics of the study and requesting their participation. In parallel, the study was advertised in courses, seminars, and conferences held in the field of disability, on the websites of the Institute on Community Integration (INICO, University of Salamanca) and *Plena Inclusion* (Full Inclusion), which represents people with ID in Spain and consists of nearly 900 entities, as well as on social networks (i.e., Facebook, Twitter). The centers that expressed interest in participating in the study (n = 108) completed a brief online survey to provide their contact data for the entity and the name of the person responsible for coordinating the study in it.

The participants at each center were selected by the coordinator appointed by every entity responsible based on the selection criteria. On the one hand, the selection criteria for those evaluated were having ID, being between 4 and 21 years old, and receiving services or support in educational, social, or healthcare centers. To ensure that among those with ID there would be a significant number of people with an ASD diagnosis (at least one-fourth of the sample), it was emphasized that not only children with ID should be assessed but also those with ID and other comorbid disorders such as ASD. In this way, the recruitment method was exactly the same for all participants. In order to avoid biased results, the only exclusion criterion was that the assessed person could not be employed or performing any type of labor activity, given that the KidsLife Scale includes items related to education settings but not concerning employment contexts. In this regard, it must be made clear that, although 18 is the age of majority in Spain, most of the childhood supports stop at 21, and many young people with ID stay in educational settings until they turn 22. On the other hand, the selection criteria for external observers who completed the KidsLife Scale were knowing the person evaluated for at least six months, and having opportunities to observe the person for long periods of time in various contexts.

The scales were completed online. Each person evaluated was provided with an identifying code to safeguard the identity of the participants and ensure the confidentiality of the data. The informed consent of the participants or their legal guardians was obtained, and the principles of the Declaration of Helsinki regarding human-based research were met. The project received the approval of the Ethics Committee of the University Oviedo. The research team was available to the respondents via email, phone, and face-to-face as necessary. Once the evaluation work in each entity was completed, the research team returned a report with the results obtained by their participants.

Data analysis

All analyses were conducted with MPlus v. 7.3 (Muthén and Muthén 2014). The data were analyzed in three stages: (a) the fit of the optimal confirmatory factor model; (b) investigation of measurement invariance between people with and without ASD; and (c) investigation of the structural parameters invariance and comparison of latent means in each QOL domain, controlling the effect of covariates of gender, level of ID, and level of support needs. All the models included a multilevel component (TYPE = COMPLEX within MPlus), in order to account for the non-independence of the observations made by the same informant.

Phase I: Fit of the base model. Prior to the study of the invariance of QOL among children with and without ASD, three confirmatory factor analysis (CFA) models were estimated in both groups separately: (a) a none-dimensional model (M1), which hypothesized that all indicators of QOL were explained by a single factor; (b) a first-order model (M2),composed of eight correlated domains, that replicated the theoretical structure of the scale; and (c) a completely orthogonal bifactor model (M3), which hypothesized that QOL is organized in a general factor and eight specific domains. Given the high number of items in each dimension,

we used the same parcels as those used by the authors of the validation study of the instrument (for more information, see Gómez et al. 2016). The final model (M2) was estimated again for the entire sample. Based on the standardized factorial loadings, we assessed (a) the convergent validity of the factors through the average variance extracted (AVE; Forner and Larcker 1998; AVE values > .50 suggest an adequate convergent validity of the factor); (b) the discriminant validity of the factors, by comparing the AVE values and the square of the highest correlation between factors (Forner and Larcker 1981; the AVE value must be greater); and (c) the composite reliability (CR).

Phase II: Measurement invariance. The measurement invariance of M2 between people with and without ASD was estimated by two CFA models nested in two levels (Meredith 1993): configural invariance (CI, M4) and strong/scalar invariance (SI, M5). Each of these models tests different assumptions about the equivalence of parameters between compared groups. CI assumes that, in both groups, the model presents the same number of domains and the same configuration of factor loadings; that is, in both groups we are measuring a qualitatively similar construct. For its part, SI requires that both factor loadings as well as the intercepts be equivalent between groups. Meeting SI means that the differences between groups in the latent means are due to differences in the trait, and are not dependent on the scale; therefore, the scores are not biased against any of the compared groups. Consequently, if SI is met, then the changes observed in the factor scores can be interpreted as depending on the change in the latent construct of interest (Marsh et al. 2010) and not on spurious sources, such as the mere fact of belonging to a group or category. SI is the minimum level of invariance necessary to interpret differences between groups (Wu, Li, and Zumbo 2007).

Phase III: Structural parameters invariance. Once the measurement invariance was guaranteed, two new models were estimated to assess the equivalence of the structural parameters: invariance of variances and covariances (V-CvI, M6) and latent means invariance (LMI, M7). V-CvI tests the assumptions that, in the compared groups, the latent scores have the same degree of dispersion and the latent variables present the same degree of relationship between them. In the case of LMI, we contrast the hypothesis that the groups do not differ in terms of the levels presented in the latent variables (i.e., if LMI yields a fit similar to the scalar model, it is possible to conclude that there are no differences in means between groups, or that the differences are irrelevant). Because the results revealed substantial differences between children with and without ASD, we analyzed whether the main effect of ASD in the latent means of QOL could have been affected by the

effect of non-modeled covariates. To that end, we estimated two multiple indicators–multiple causes models (MIMIC; Jöreskog and Goldberger 1975): M8, in which the only predictor of QOL was the presence of ASD (the regression weights of sex, level of ID, and support needs were fixed at zero, reflecting the null hypothesis that these covariates have no impact either on the QOL factors or on the relationship between the presence of ASD and QOL), and M9, in which the effect of the rest the covariates was freely estimated. Thus, in M9, each of the eight QOL factors was regressed to four predictors constructed from the observable variables: presence/absence of ASD, gender, level of ID, and level of support needs (Figure 1). In this model, each regression path of the QOL domains in the dichotomous variable presence/absence of ASD (encoded as 0 and 1, respectively) can be interpreted as the difference in latent means expressed in standard deviations from a group on the other (Brown, 2006), controlling the effect of the rest of the rest of the covariates.

< Figure 1 >

All models were estimated by maximum likelihood robust (MLR; Muthen and Muthen 2014). The goodness of fit was evaluated by the Comparative Fit Index (*CFI*), the Tucker-Lewis Index (*TLI*), the Root Mean Square Error of Approximation (*RMSEA*), and the Standardized Root Mean Square Residual (*SRMR*). *CFI* and *TLI* values higher than .90 and *RMSEA* and *SRMR* values below .08 were considered adequate (Hu and Bentler 1999). To compare the fit of the nested models in the analysis of invariance, the recommendations of Chen (2007) and Cheung and Rensvold (2002) were followed, according to which increases below .01 in *CFI* and *TLI*, and decreases below .015 in *RMSEA* suggest that there are no relevant changes in the fit of a model with respect to the previous, less restrictive model. Furthermore, in the case of nested models, decision-making was supported through the estimation of Bayesian Information Criterion (*BIC*), the Akaike Information Criterion (*AIC*), and the ratio of the chi-square (χ^2) to the degrees of freedom (*df*). For the three indexes, the model with the lowest value is preferred.

Results

Phase I: Fit of the base model.

As shown in Table 1, although the one-dimensional model (M1) yielded fit indexes that were unacceptable in both groups, the model with eight correlated dimensions (M2) and the bifactor model (M3) obtained fit indexes within that were acceptable. Given the small differences in fit between M2 and M3, and because the specification of M2 corresponds to the theoretical structure of the scale (Gómez et al. 2016b), it was decided to retain the model of eight correlated factors for subsequent analysis.

< Table 1>

Then, the parameters of the M2 model were estimated using the whole sample (Table 2). The factor loadings were generally high (*range* .65 to .92, M = .81, SD = .06), with reasonably low standard errors (*range*: .009 to .030). The correlations between factors were of a magnitude between low and moderately high (*range*: .28 to .78, M = .58, SD = .11). The domains reached sufficient convergent validity, and their *AVE* values were for all cases above .50 (between .57 and .78). The discriminant validity of the factors was guaranteed, given that only one *AVE* value was lower than the square of the highest correlation (.59). Finally, all factors presented acceptable composite reliability indexes (*CR* between .79 and .91).

< Table 2>

Phase II: Measure invariance of QOL among children with and without ASD.

After verifying the sufficient fit of the configural model (M4; *RMSEA* = .063, *CFI* =.937, *TLI* =.923; see Table 1), all factor loadings and parcel intercepts were restricted to equality. The deterioration in the fit indexes of the scalar model (M5) with respect to the configured model remained at acceptable levels (ΔCFI =.004; ΔTLI =.001; $\Delta RMSEA$ = .000). Meanwhile, the ratio of χ^2/df was similar, and the *BIC* was lower for the scalar model (but not the *AIC*, which was slightly higher; ΔAIC =.43). Therefore, no evidence of absence of complete strong invariance was obtained; thus, there is no evidence of measurement bias against any of the groups compared.

Phase III: Invariance of structural parameters and the effect of covariates.

The invariance of variances and covariances model (M6) did not yield worse fit indexes than the configural model ($\Delta CFI = .009$, $\Delta TLI = .000$, $\Delta RMSEA = .000$); thus, the dispersion in the latent variables and

the magnitude of their relations was equivalent between the groups. Then, on the basis of M6, the latent means were restricted to equality in the eight QOL domains (M7). A substantial gap in *CFI* ($\Delta CFI = .019$) was observed, but not in *RMSEA* or *TLI* ($\Delta RMSEA = .04$, $\Delta TLI = .009$). After consulting the rest of the indexes, it was noted that M7 fit worse than M4, considering the values of the *BIC*, *AIC*, and χ^2/df . Meanwhile, substantial modification indexes were observed (*M.I.* > 4.0) for five of the eight restricted means. The previous results lead us to reject the invariance of latent means model, which suggests that, in some QOL domains, there are significant differences between children with and without ASD.

Next, two MIMIC models were fit: one model in which the only predictor of the QOL domains was the presence of ASD (M8) and another model that includes the effect of the covariates of gender, level of ID, and level of support needs (M9). In both cases, the fit was acceptable (Table 1).

< Figure 2>

As shown in Table 3 and Figure 2, in M8, the QOL levels of the group of children with ASD was significantly lower than those without ASD in five of the eight domains: the latent means of children with ASD were -.46 *SD* in interpersonal relationships, -.41 *SD* for physical well-being, -.39 *SD* for social inclusion, -.23 *SD* for rights, and -.17 *SD* for self-determination. According to Cohen (1988), these differences represented an effect size that was between moderate (SI, PW, and IR) and small (SD and RI).

In model M9, the effect of the three covariates (gender, level of ID, and level of support needs) was freely estimated. M9 showed substantially better fit than M8 ($\Delta RMSEA = -060$, $\Delta CFI = .022$, $\Delta TLI = .020$, $\Delta SRMR = -0.47$; Satorra-Bentler scaled χ^2 difference = 403.3 (24), p < .000), so we decided to retain the model and proceed to their interpretation. As Table 3 and Figure 2 show, the inclusion of the new covariates altered some of the mean differences observed in M8. As mentioned, in M8 the presence of ASD produced significant and small differences in self-determination and rights. However, in M9, both differences lost their statistical significance, which was assumed by degree of disability and of support needs. On the other hand, once the effect of the covariables was controlled, the presence of ASD had the most impact in interpersonal relationships (-.36 dt), physical well-being (-.42 dt), and social inclusion (-.35 dt).

Discussion

Contrary to what is traditionally argued in the scientific literature on ASD, we agree with Felce et al. (2011), La Malfa et al. (2004), and Totsika et al. (2010), and we hypothesized that the frequently lower QOL scores shown by children with ASD do not strictly relate to the ASD condition but rather to other associated variables that must be controlled, such as the level of ID, the level of support needs, or gender (Biggs and Carter 2016; Bradley et al. 2004; Matson et al. 2009; Note et al. 2007; Viecili and Weiss 2015), except for the most social domains of QOL (social inclusion and interpersonal relationships) for which it is logical to expect the worst scores for those with an ASD diagnosis (Biggs and Carter 2016; Clark et al. 2015; Kamp-Becker et al. 2011; Taheri-azar et al. 2016). More specifically, in this study we have focused on three goals: firstly, confirming if QOL is a construct that operates similarly in children with ID and with out ASD; secondly, verifying if children with ID and ASD obtain worse scores in any QOL than their peers without ASD; and thirdly, testing if the worst scores of children with ASD only remain in interpersonal relations and social inclusion, once the effect of gender, the level of ID, and the level of support needs is controlled.

Regarding the first question, the results showed that the measure of QOL, through the KidsLife Scale, is valid for children with ID, whether or not they have ASD, given that it was invariant between the two groups. This finding shows that the instrument measures the same construct and is not biased towards any of the groups compared. Consequently, the scale allows us to compare children with and without ASD fairly. Evidences related to the validity of the internal structure of the scale on the evaluation of the eight QOL domains through confirmatory factor analyses have been provided in this study for people with ASD, as it was made for people with ID in the original study (Gómez et al. 2016b).

Regarding the second issue (whether lower QOL scores are obtained by children with ASD and ID compared to those without ASD), the results showed that the latent means regarding QOL differed between the two groups, with the former having a significantly lower level of QOL in five of the eight domains (self-determination, rights, physical wellbeing, interpersonal relationships, and social inclusion). These results would be in line with traditional studies that predict worse results for children with ASD (de Vries and Geurts

2015; Ikeda et al. 2014; Kamp-Becker et al. 2011; Kose et al. 2013; Lee et al. 2008; Shipman et al. 2011; Tavernor et al. 2013).

However, the third goal of this study made it possible to show that such differences do not always persist if the effects of other variables with a known impact on QOL are isolated. Indeed, the presence of ASD loses its explanatory power when the effect of other variables is controlled. In this way, once the effect of the covariables was controlled, the differences in self-determination and rights disappeared (these were explained by the degree of disability and the support needs). Only moderate negative differences remained, as expected, in social inclusion and interpersonal relationships (Biggs and Carter 2016; Clark et al. 2015; Kamp-Becker et al. 2011; Taheri-azar et al. 2016). More surprising was the fact that significantly lower scores on physical wellbeing persisted and significantly higher scores in material wellbeing were obtained (although the size of the latter difference was small). Several explanations may be pointed out with respect to these unexpected results. First, individuals with ASD frequently have worse health conditions and more health-related conditions compared to their peers with only ID, which can lead to greater needs in the area of physical wellbeing. The worst results in physical wellbeing are consistent with previous studies that show that children with ASD have worse physical health (e.g., greater prevalence of sleep problems as well as gastrointestinal, respiratory, and skin problems, in addition to more allergies) than children without disabilities (Kose et al. 2013; Kuhlthau et al. 2013). It may be interpreted that healthcare remains a pending issue, with numerous difficulties, for children with ASD and ID in our country, and they have not only worse health conditions but also greater barriers to access to sanitary services and adequate sanitary supports. On the other hand, the better results in material wellbeing may be because children with ASD receive systematically better technical assistance and environmental adaptations than children without ASD, because the former often receive much more attention regarding the adaptation of spaces, materials, and resources to facilitate the predictability of their environments and adapt to their cognitive abilities and their preferred forms of perceiving and processing information (e.g., pictograms, calendars, visual keys). A second explanation may focus on the fact that the difference actually concerns a non-modeled interaction between material wellbeing and some other covariate, such as the higher socioeconomic level of children with ASD or the fact that they receive more aids, resources, and social benefits. In future investigations, it should be determined whether these results are replicable and, if such differences are repeated, the effect of other covariates should be explored.

On the other hand, our results provide evidence concerning the important role that variables such as gender, but especially the level of ID and support needs, play in QOL scores. To the best of our knowledge, no previous study has examined the relationship between the level of support needs and QOL in children with ASD (Chiang and Wineman 2014). These variables explain their significantly lower scores in most domains, except in the case of physical wellbeing (whose differences are explained by the presence/absence of ASD) and emotional wellbeing (in which none of the variables showed a significant influence). In the case of social inclusion, the presence of ASD, a higher level of ID, and being female were related to significantly lower results. Perhaps the possible different manifestation of ASD in girls, whose diagnosis is typically delayed and masked (van Wijngaarden-Cremers et al. 2014), or the possible differences in social and cultural expectations for boys and girls (Halladay et al. 2015) may be the causes of these greater difficulties in social inclusion. Although it is necessary to continue investigating why it is more difficult for girls with ASD to achieve good results in social inclusion, it should be stressed that the levels of ID and support needs are what seem to determine QOL, more than the condition of ASD itself.

Like most research, this study is not free of limitations. First, despite being a very broad sample, it was non-probabilistic. Second, there is a limitation in the sample in terms of the presence (25%) and absence (75%) of ASD; however, this distribution resembles the most recently identified and less conservative prevalence of 18-23.5% (Centers for Disease Control 2008; Roeyers and Thys 2012; Tonnsen et al. 2016). Third, the high number of items in each domain (*n* = 12) and the desire to replicate the structure indicated in the original study of the KidsLife Scale led us to use parcels with the inconvenience that may result from this approach (on the formation and justification of the parcels, see the original study by Gomez et al. 2016). Fourth, it should be noted that the fit of M9 was similar to M8, except in TLI, in which a significant deterioration was observed. Because TLI is a fit index penalized for the decrease in parsimony, the reduction in the fit was most likely due to the inclusion of the gender variable, whose paths did not contribute to the prediction of the criteria, despite introducing eight new parameters. However, given that other indexes (particularly RMSEA) also penalized for the same reasons were not affected, we decided to retain this model. Finally, it should be noted that, QOL has been assessed not through self-reports but through reports from external observers who knew the children well. Nowadays, the KidsLife Scale is the only QOL instrument in Spanish addressed to people with ID and ASD in infancy and adolescence with adequate evidence of

reliability and validity. In this way, there is an urgent need for developing tools that will allow for the gathering of children's own perspective.

Despite these limitations, this study contributes to illuminating the complex relationships that can be established between the different domains that compose QOL and the individual variables that can have an impact on it (Gómez et al. 2016a; Schalock et al. 2016). Future research should be directed at improving the social inclusion and interpersonal relationships of children with ASD, and enhancing QOL-related personal outcomes for those with higher levels of ID and greater support needs.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent was obtained from all individual participants included in the study.

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APPENDIX A. English version of the KidsLife Scale

SOCIAL INCLUSION

- 1. He/she enjoys holidays in inclusive environments.
- 2. He/she is integrated with his/her class peers.
- He/she participates in activities in his/her community with persons outside his/her support group.
- He/she participates in inclusive activities that are commensurate with his/her physical and cognitive abilities.
- 5. He/she participates in inclusive activities that are in line with his/her interests.
- 6. He/she participates in family celebrations.
- 7. He/she participates in natural groups from his/her community.
- 8. He/she carries out leisure activities with same age peers.
- 9. He/she receives supports and interventions in natural environments.
- 10. Specific measures are taken to strengthen his/her participation in the community.
- 11. He/she has opportunities to go to other environments, different from the place where he/she lives.
- 12. He/she uses community environments.

EMOTIONAL WELLBEING

- 25. In the service he/she receives appropriate signs of affection, emotional support, and physical contact when needed.
- 26. He/she receives praise and compliments when he/she does something good.
- 27. Persons providing him/her supports pay attention to his/her facial expressions, look, direction of eye gaze, tone/volume of voice, muscular tension, body position, movements, and physiological reactions.
- Persons providing him/her supports know his/her individual expressions of emotional wellbeing.
- Persons providing him/her supports know his/her individual expressions of emotional distress.
- Persons providing him/her supports schedule activities based on his/her expressions of satisfaction with them.
- 31. Specific measures are taken to make his/her environment recognizable and predictable.
- 32. Information is given to him/her in advance of the daily activities and events in an understandable way.
- 33. He/she is informed in advance about changes in the staff that provides supports to him/her.
- 34. Persons providing him/her supports apply Positive Behavior Supports to establish, maintain, and reduce behaviors.
- 35. Persons providing him/her supports know how to deal with a crisis (e.g., assault, self-injury).
- 36. When unexpected events occur, persons providing him/her supports help him/her understand the situation.

SELF-DETERMINATION

- 13. Specific measures are taken to allow him/her to influence his/her environment.
- 14. He/she chooses how to spend his/her free time.
- 15. He/she chooses who he she/spends his/her free time with.
- 16. When opportunities are provided he/she chooses the meal or part of the meal.
- 17. He/she decorates his/her bedroom to his/her liking.
- 18. He/she refuses what he/she does not like with gestures, sounds, or words.
- 19. He/she has opportunities to refuse to do things that are unrelated to his/her health issues.
- 20. He/she asks for help from other persons when he/she needs.
- 21. His/her opinion in taken into account when changes are made.
- 22. Supports are provided to him/her that take into account his/her needs, wishes, and preferences.
- 23. He/she participates in the development of his/her individual support plan.
- 24. His/her decisions are respected.

PHYSICAL WELLBEING

- 37. He /she has the recommended quantity of food and liquids to maintain good health.
- He/she has an adequate hygiene (e.g., teeth, hair, nails, body) and personal image (e.g., age-adequate clothing style, situation-specific clothing).
- 39. He/she receives specific supports when he/she wants change any aspect of his/her appearance.
- 40. He/she carries out physical activities and exercise that are adequate to his/her characteristics and needs.
- 41. He/she receives supports from the health professionals that he/she needs.
- 42. Specific measures are taken to prevent or treat physical disabilities (e.g., spasticity, stiffness, malformations).
- 43. Special attention is provided to the diagnoses and treatment of sensory disabilities that he/she might have.
- 44. Specific measures are taken to prevent or treat pain.
- 45. He/she receives supports to guarantee an adequate postural comfort.
- 46. The use or need of medication is supervised periodically (e.g., doses, frequency, benefits, side effects).
- 47. He/she has a preventive health care plan (periodic analytics, check-up with specialists).
- 48. He/she receives immediate attention when feels sick.

MATERIAL WELLBEING

- 49. He/she has the appropriate assistive devices to maximize his/her autonomy.
- 50. The assistive devices that he/she needs have been individually adapted.
- 51. He/she has his/her own things to entertain himself/herself.
- 52. He/she has physical space where his/her personal belongings are within reach.
- 53. He/she has the material goods that he/she needs.
- 54. He/she likes the things he/she has.
- 55. He/she has clothing that is age-appropriate and matches his/her preferences.
- 56. The place where he/she lives has furniture that is adequate to his/her physical characteristics.
- Specific measures are taken to adapt the environment where he/she lives to his/her wishes and preferences.
- He/she has free access to his/her bedroom, bathroom, and other places in which his/her daily routines take place.
- 59. He/she has newest technologies to increase or facilitate his/her communication.
- 60. In the educational service teaching materials are adapted to his/her needs.

PERSONAL DEVELOPMENT

- 73. Specific measures are taken to maintain his/her abilities and skills.
- 74. He/she learns things that help him/her be more independent.
- 75. Activities that promote his/her independence are prioritized.
- 76. Activities of daily living are taught to him/her (e.g., eating, self-care, meal preparation).
- 77. Instrumental activities of daily living are taught to him/her (use of transports, preparing meals, shopping).
- 78. The activities he/she does enable him/her to learn new skills.
- 79. Instructions and modeling are provided so that he/she learns new skills.
- 80. He/she has opportunities to show his/her skills.
- 81. His/her development in different areas is stimulated (e.g., cognitive, social, sensory, emotional, motor).
- 82. The tasks that are proposed to him/her are fitted to his abilities and preferences.
- 83. Persons providing him/her supports help him/her plan activities that he/she wants to do.
- 84. His/her strengths are taken into account when new goals are established.

RIGHTS

- 61. Persons providing him/her supports have specific training on ethics and respect for rights of persons with disabilities.
- 62. Persons providing him/her supports treat him/her with respect.
- 63. Specific measures are taken to respect his/her privacy.
- 64. The confidentiality of his/her individual assessments is adequately protected.
- 65. His/her belongings and right to property are respected.
- 66. He/she has a room with intimacy if he/she wants.
- 67. His/her rights are respected and defended.
- 68. He/she is provided with the needed supports to understand and exercise his/her rights.
- 69. He/she is treated with respect in his/her environment.
- 70. He/she is properly informed about relevant decisions that are taken in his/her name.
- 71. The authorization of his/her legal guardian for the use of seclusion and restraints is available in case of use.
- 72. He/she participates in activities with the same opportunities available to others.

INTERPERSONAL RELATIONSHIPS

- Activities to facilitate personal interactions with peers are offered.
- 86. He/she has relationships with same age peers at the school.
- 87. He/she has opportunities to initiate friendships if he/she wants.
- 88. He/she has opportunities to be alone with his/her friends and acquaintances.
- 89. Specific measures are taken to maintain and extend his/her social networks.
- 90. The meaning of his/her gestures, sounds, and behaviors is assessed.
- 91. Specific measures are taken to improve his/her communication skills.
- 92. Persons providing him/her supports understand the communication system that he/she uses.
- 93. The best ways to communicate information to him/her (i.e., visual, tactile, auditory, olfactory, taste) are identified.
- 94. Enough time is provided for him/her to answer questions.
- 95. Persons providing him/her supports check to make sure if he/she understands them correctly.
- 96. He/she uses a communication system that is understandable in different contexts.