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# Quality of life of high-functioning children and youth with autism spectrum disorder and typically developing peers: Self- and proxy-reports

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**Abstract**

Studies have shown parents to report lower quality of life for their children with autism spectrum disorder than children's self-report scores and the same applies for data on typically developing children. Our objectives were to: (1) explore how high-functioning children with autism spectrum disorder rate their quality of life compared with paired controls without autism spectrum disorder; (2) explore how parents of high-functioning children with autism spectrum disorder rate their children's quality of life compared with parents of paired controls; and (3) compare child self-reports of quality of life with their parent's proxy-reports for both groups of children. Data were collected with the Icelandic self- and proxy-reported versions of the KIDSCREEN-27. Reports of 96 children with autism spectrum disorder, 211 controls and their parents were included in the analyses. Compared with controls, children with autism spectrum disorder had lower means on all quality of life dimensions. Parents of children with autism spectrum disorder evaluated their children's quality of life lower on all dimensions than did parents of controls. On four out of five dimensions, children with autism spectrum disorder reported better quality of life than did their parents. Despite differences in ratings children with autism spectrum disorder and their parents agreed on the most problematic dimensions, namely, *social support and peers* and *physical well-being*. Our results highlight the importance of seeking the viewpoints of both children and their parents.

**Keywords**

autism, child self-reports, KIDSCREEN-27, parent's proxy-reports, quality of life

## Introduction

Quality of life (QoL) is a multidimensional concept that reflects on the individual's perception of his or her life and daily participation (Berntsson and Köhler, 2001; Felce and Perry, 1995). QoL is closely related to children's rights and comprises health, well-being, living conditions, family relations, play, social life, education and leisure. Since the publication of the UN Convention on the Rights of the Child (UNICEF, 1989), the importance of eliciting children's views on QoL and all other matters affecting them have been increasingly stressed. There is evidence to support that children as young as 8 years are able to interpret basic concepts in relation to questionnaires and rating scales (Cremeens et al., 2006; KIDSCREEN Group Europe, 2006).

Autism spectrum disorder (ASD) is a group of neurodevelopmental conditions, which have in common impairments in social-communication, repetitive behaviours or restricted interests, as well as sensory issues (American Psychiatric Association, 2013). Despite the wealth of research that has been carried out in the field of autism, few studies have focused on the views of children themselves. For some time it was assumed that due to their limited capacity for self-reflection, individuals with ASD were unable to report reliably on their own experiences, moods and feelings (Barnhill et al., 2000; Capps et al., 1992; Frith et al., 1994; Mazefsky et al.,

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2011). Now scholars increasingly emphasize the importance of seeking the views of these children and youth, and more research is currently directed at their experiences within specific domains, such as communication, friendship and emotions (Bauminger and Kasari, 2000; Calder et al., 2012; Humphrey and Lewis, 2008; Knott et al., 2006).

Recent findings indicate that self-reports of high-functioning children with ASD about their emotions (Hobson et al., 2006) and QoL (Burgess and Turkstra, 2010; Shipman et al., 2011) are valid and reliable. Shipman et al. (2011) used the Pediatric Quality of Life InventoryTM (PedsQL) to explore QoL of 39 adolescents with ASD compared with normative data of same-age adolescents. Overall, the adolescents with ASD experienced lower QoL than adolescents in the general population. Their parent's proxy-reports were even lower as parents considered lack of social and emotional functioning as severely limiting their children's QoL. Another study compared the QoL of high-functioning children with ASD with that of typically developing children as well as the relationship between parent and child viewpoints on the children's QoL (Potvin et al., 2013). The parents and their children with ASD reported significantly poorer QoL than the parents of typically developing children.

These former studies showing parents of children with ASD to report significantly lower QoL scores for their child than the children's self-report scores have, for the most part, had relatively low numbers of participants ($n = 10-39$) (Clark et al., 2015; Potvin et al., 2013; Shipman et al., 2011; Tavernor et al., 2013) and the child–parent scores have not been paired. Also, few studies have compared self-reported QoL of children with ASD with that of children without ASD as a control group; instead normative data have been used. Although one recent study had a comparison group of typically developing children, these were selected by convenience (Potvin et al., 2013).

Most studies of QoL of high-functioning children with ASD have utilized the PedsQL (Varni et al., 1999). It has been pointed out that the majority of items in the PedsQL are framed in a rather concrete context, focusing on what a child can do rather than how he or she feels (Upton et al., 2008). In contrast, many of the items in the KIDSCREEN (Ravens-Sieberer et al., 2007, 2014) are more subjective in nature, which may better allow for reflecting emotions and feelings of involvement, which is more in line of our understanding of QoL.

In view of the above, the objectives of this study were to explore the self- and proxy-reports of QoL of children with ASD with a larger sample than has been used previously and compare with a randomly selected and paired control group of peers, using the KIDSCREEN-27. Our research questions were as follows:

1. How do high-functioning children with ASD rate their QoL compared with paired controls without ASD?
2. How do parents of high-functioning children with ASD rate their children's QoL compared with parents of paired controls without ASD?
3. How do child self-reports of QoL compare with their parent's proxy-reports for both groups of children?

## Methods

### Participants

Eligible for participation were all children diagnosed with high-functioning ASD aged 8–17 years and listed in the clinical registry of the State Diagnostic and Counselling Centre (SDCC). The SDCC is a tertiary institution specializing in children with neurodevelopmental disorders, and as such the only one in Iceland. Its role in diagnosing ASD has been described elsewhere (Saemundsen et al., 2013). 'High-functioning' means $IQ \geqslant 80$, a criterion that is likely to increase a child's capacity to read and respond to a questionnaire. Altogether 303 children (258 boys and 45 girls), and their parents were invited to participate in the study. The children were then paired to a control group ($n = 1.199$) from the national registry by gender, residence, year and month of birth.

The response rate was 36% ($n = 109$) for children with ASD and 21% ($n = 251$) for controls. Some parents did not complete proxy-reports, hence, when paired to their parents a total of 96 children with ASD and 211 controls were included in the analyses. Nevertheless, the numbers of dyads differ in different types of analyses due to missing values (see results). Table 1 shows the sample characteristics of the participating children.

The majority of parent respondents in both groups were mothers (89.6% for the ASD group, and 86.3% for controls). Their mean age was 43.4 (standard deviation (SD) = 6.9)/43.4 years (SD = 5.9). The majority of respondents in both groups held a university degree, 59.4% for ASD group and 69.2% for controls (not a significant difference: $\chi^2(1, n = 307) = 2.419$; $p = 0.120$).

Most missing values were in the dimension of *autonomy and parent relations* for children and parents in both groups (10.4% each for children and parent in the ASD group, and 7.6% for children and 8.1% for parents in the control group). Typically questions about finances were left unanswered. The second highest rates of missing values were in the *social support and peers* dimension for the ASD group (7.3% for children and 5.2% for parents) and for parents in the control group (6.6%). In other dimensions, missing data were below 4.2%. No patterns were found between missing values and the child's age, gender, residence or type of school setting.

**Table 1.** Characteristics of the participating children.

| | ASD, *n* (%) | Controls, *n* (%) |
|---|---|---|
| Gender | | |
| Boy | 84 (87.5) | 175 (82.9) |
| Girl | 12 (12.5) | 36 (17.1) |
| Age range (years) | | |
| 8–11 | 42 (43.8) | 94 (44.5) |
| 12–17 | 54 (56.3) | 117 (55.5) |
| Residence | | |
| Capital region | 60 (62.5) | 133 (63) |
| Small towns and rural areas | 36 (37.5) | 78 (37) |
| Type of school setting[a] | | |
| Mainstream | 87 (90.6) | 207 (98.1) |
| Special education class | 9 (9.4) | 3 (1.9) |

ASD: autism spectrum disorder.

[a] A significant difference between ASD and control group: $\chi^2(1, n=306)=9.033$; $p=0.03$.

## Procedure

A cross-sectional descriptive comparative design was used. Introductory letters to all families in the SDCC registry and controls from the national registry were sent by regular mail in an envelope addressed to parents. The letters also contained a link to the study website and a keyword that enabled prospective participants to answer the measure electronically. Approximately 10 days later all parents received a phone call as a reminder. This also gave them an opportunity to ask questions and seek more information about the study. Additional reminders were sent a week later to both groups by email. If the parents responded to the questionnaire and delivered the introductory letter to their child this was considered as consent for their and the child's participation in the study. This arrangement was described in the introductory letters to parents and children.

For this study an electronic version of the KIDSCREEN-27 (KIDSCREEN Group Europe, 2006) was developed that allowed questions to be presented one at a time. To further increase accessibility and minimize effects of language skills, children in both groups had the option of listening to pre-recorded questions. All parents completed the proxy version of the KIDSCREEN-27 and were given the instructions, 'Please answer the following questions to the best of your knowledge, ensuring that the answers you give reflect the perspective of your child'.

Participation was anonymous, ensuring that no personal information was attached to the electronic questionnaire. A professional with long experience working with children with ASD and their families at the SDCC was responsible for all communication with the ASD group while professionals at the University of Akureyri Research Centre contacted the control group.

Data were gathered from September to December 2013. In 92% of cases, children and their parents answered the questionnaire within the same week. The study was approved by the National Bioethics Committee (VSN-13-081).

## Measure

Data were collected with the Icelandic parallel self- and proxy-reported versions of the KIDSCREEN-27 which we considered more suitable for the ASD group than the longer KIDSCREEN-52. This internationally validated measure is applicable for children of ages 8–18 years and includes five QoL dimensions: *physical well-being* (five items), *psychological well-being* (seven items), *autonomy and parent relations* (seven items), *social support and peers* (four items) and *school environment* (four items). Either the frequency of behaviour/feelings (how often) or the intensity of an attitude (not at all to extremely) is assessed. A 5-point Likert response scale is used and the recall period is 1 week (Ravens-Sieberer et al., 2007). Scores are computed for each dimension and are transformed into *t*-values with a mean of 50 and a standard deviation of 10; higher scores indicate higher QoL and well-being. The measure has been shown to have good psychometric properties (Ravens-Sieberer et al., 2007). The translation process of the Icelandic version of the KIDSCREEN-27, which included cognitive interviews with children with ASD and their parents, has been described elsewhere (Egilson et al., 2013).

## Analyses

Internal consistency (Cronbach's alpha) for both proxy- and self-ratings for this study was in the range of 0.790–0.893 for self-report measures and 0.705–0.916 for the proxy version (Ólafsdóttir et al., 2014), so they met or exceeded the threshold of 0.70 that is required for group comparisons (Nunnally and Bernstein, 1994). Demographic characteristics were assessed using chi-square tests. Dependent *t*-tests were conducted to compare the means of the self- and proxy-reported QoL scores (95% significance level) and effect sizes (eta ($\eta^2$) or partial eta ($\eta^2 p$) squared statistics) were calculated and classified as a small effect: $\eta^2=0.01$; moderate effect: $\eta^2=0.06$; or large effect: $\eta^2=0.14$ (Cohen, 1988). Mixed between-within subjects, analysis of variance (ANOVA) was used to relate QoL to characteristics of the child and his or her environment (age, gender, parental education, residence and type of school setting). Intraclass correlation coefficients (ICCs) of absolute agreement were used to estimate the convergence between the reports of children and parents in both groups (McGraw and Wong, 1996). The strength of agreement was categorized into three levels: poor agreement: ICC $<$ 0.5; moderate agreement: ICC = 0.50–0.79; and strong agreement: ICC $>$ 0.80 (Sturms et al., 2003). Consistent with guidelines from the KIDSCREEN manual, the children were divided into younger (8–11 years) and older (12–17 years) age groups. Additionally, in keeping with the guidelines, a dimension score was not calculated if more than one question remained unanswered.

## Results

QoL scores based on self- and parent's proxy-reports on the KIDSCREEN-27 are shown in Figure 1 and in Tables 2 and 3.

### Comparison of QoL ratings of children with and without ASD and their parents

Table 2 provides means, paired-sample *t*-tests and effect sizes for children with ASD and their paired controls, as well as for parents of children with ASD and parents of paired controls.

The mean self-report QoL scores of children with ASD fell between 45 and 50 or within half a standard deviation from the average of the normal distribution on all QoL dimensions except for *social support and peers*. On *physical well-being* the children's QoL was close to being less than average. The control children evaluated their QoL within the average range on all QoL dimensions. Compared with their paired controls, children with ASD considered their QoL significantly lower on all five KIDSCREEN-27 dimensions. Most differences were found in the dimensions of *physical well-being* and *social support and peers* with large effect sizes.

Parents of children with ASD also rated the QoL of their child significantly lower on all dimensions compared with parents of the controls. Most differences were found in *social support and peers*, *physical well-being* and *psychological well-being* with high effect sizes.

### Comparison of children's and their parents' ratings

Table 3 shows ICCs, mean differences, and effect sizes for the scores of children with ASD and their parent's proxy-reports, as well as for the controls and control-proxy-reports.

*Agreement between QoL scores of children with ASD and their parents.* The agreement between the ratings of the children and their parents on all QoL dimensions was moderate. Nevertheless, the children's mean scores were significantly higher than those of their parents in *physical well-being, psychological well-being, social support and peers* and *school environment*. Large effect sizes were found in these four dimensions. No difference was found between the ratings of children with ASD and their parents on *autonomy and parent relations*.

*Interaction effects.* On three QoL dimensions, significant interaction effects for age were detected; *psychological well-being* ($F(1, 90)=7.223$, $p=0.009$, $\eta^2p=0.074$), *autonomy and parent relations* ($F(1, 77)=7.148$, $p=0.009$, $\eta^2p=0.085$) and *social support and peers* ($F(1, 84)=4.286$, $p=0.041$, $\eta^2p=0.049$). More differences were found between the older age group (12–17 years) and their parents on these dimensions. A significant interaction effect regarding residence was detected in *psychological well-being* ($F(1, 90)=6.651$, $p=0.012$, $\eta^2p=0.069$), with more differences between children and their parents in the national capital region than in small towns and rural areas.

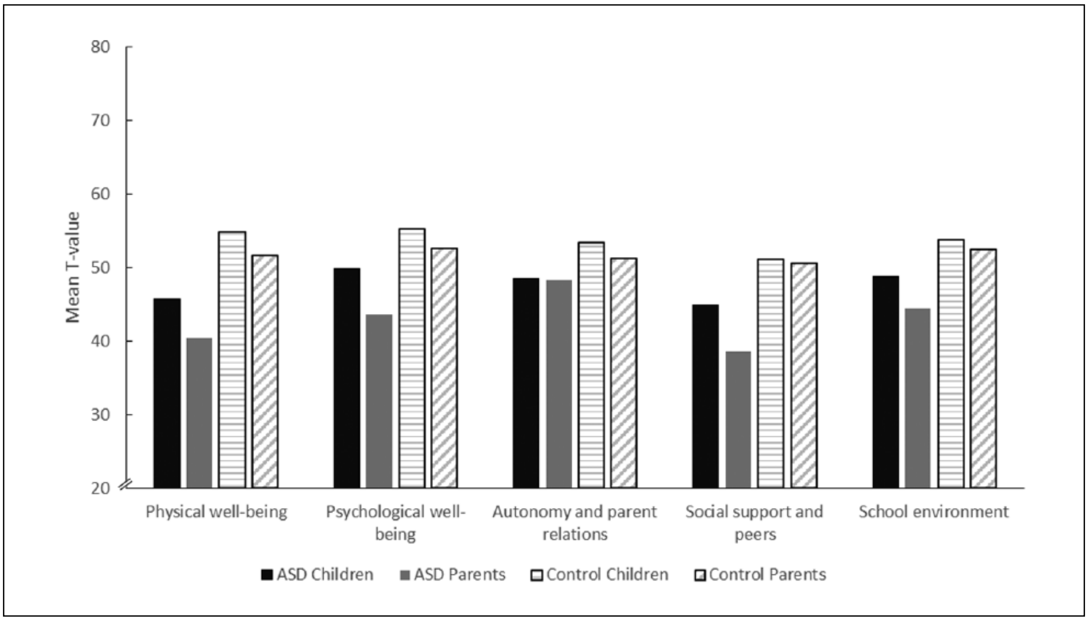

**Figure 1.** QoL scores based on self- and parent's proxy-reports in both groups of children.

**Table 2.** Comparison of QoL ratings of children with and without ASD and their parents: paired-sample *t*-tests.

| | *n*[a] | Mean (SD) | | Paired-sample *t*-tests | | Effect sizes |
|---|---|---|---|---|---|---|
| | | Children with ASD | Controls | *t* | *p* | $\eta^{2,\text{b}}$ |
| Child rating | | | | | | |
| Physical well-being | 62 | 46.02 (11.13) | 53.85 (10.48) | −4.486 | <0.001 | 0.248 |
| Psychological well-being | 62 | 49.36 (11.24) | 54.69 (10.02) | −2.989 | 0.004 | 0.128 |
| Autonomy and parent relations | 53 | 49.23 (7.92) | 53.78 (9.91) | −3.016 | 0.004 | 0.149 |
| Social support and peers | 55 | 44.86 (10.38) | 51.82 (8.71) | −4.091 | <0.001 | 0.236 |
| School environment | 60 | 48.42 (10.68) | 53.07 (10.99) | −2.562 | 0.013 | 0.100 |
| Parent rating | | | | | | |
| Physical well-being | 74 | 40.85 (9.33) | 50.86 (9.85) | −7.273 | <0.001 | 0.420 |
| Psychological well-being | 72 | 42.86 (11.42) | 52.33 (10.79) | −5.469 | <0.001 | 0.296 |
| Autonomy and parent relations | 60 | 47.00 (8.48) | 51.48 (9.44) | −3.104 | 0.003 | 0.140 |
| Social support and peers | 70 | 37.09 (12.73) | 50.03 (10.87) | −7.644 | <0.001 | 0.459 |
| School environment | 72 | 44.04 (8.61) | 49.61 (10.53) | −3.699 | <0.001 | 0.162 |

SD: standard deviation; ASD: autism spectrum disorder.

[a] A total of 62 children dyads and 78 parent dyads were included in the analyses. The final numbers of dyads vary between dimensions due to unanswered questions.

[b] Interpretation of $\eta^2$: 0.01 = small effect; 0.06 = medium effect; 0.14 = large effect.

**Table 3.** Comparison of children's and their parent's ratings: ICCs and paired-sample *t*-tests.

| | *n*[a] | ICC[b] | Mean (SD) | | Paired-sample *t*-tests | | Effect sizes |
|---|---|---|---|---|---|---|---|
| | | | Child rating | Parent rating | *t* | *p* | $\eta^{2,\text{c}}$ |
| Children with ASD | | | | | | | |
| Physical well-being | 92 | 0.73 | 45.69 (10.75) | 40.37 (9.98) | 5.873 | <0.001 | 0.275 |
| Psychological well-being | 92 | 0.62 | 49.88 (10.87) | 43.61 (11.73) | 5.410 | <0.001 | 0.243 |
| Autonomy and parent relations | 79 | 0.55 | 48.46 (8.47) | 48.36 (8.07) | 0.103 | 0.918 | 0.001 |
| Social support and peers | 86 | 0.59 | 44.84 (9.90) | 38.49 (13.02) | 4.984 | <0.001 | 0.226 |
| School environment | 90 | 0.63 | 48.71 (10.12) | 44.49 (8.53) | 4.296 | <0.001 | 0.172 |
| Controls | | | | | | | |
| Physical well-being | 209 | 0.74 | 54.84 (10.53) | 51.62 (9.70) | 5.228 | <0.001 | 0.116 |
| Psychological well-being | 198 | 0.63 | 55.18 (9.94) | 52.63 (10.07) | 3.507 | <0.001 | 0.059 |
| Autonomy and parent relations | 184 | 0.67 | 53.33 (10.25) | 51.21 (9.35) | 2.984 | 0.003 | 0.046 |
| Social support and peers | 195 | 0.49 | 51.10 (8.22) | 50.60 (9.70) | 0.670 | 0.504 | 0.002 |
| School environment | 200 | 0.72 | 53.80 (9.99) | 52.46 (9.68) | 2.054 | 0.041 | 0.021 |

SD: standard deviation; ICC: intraclass correlation coefficient; ASD: autism spectrum disorder.

[a] A total of 96 ASD dyads and 211 control dyads were included in the analyses. The final numbers of child–parent dyads vary between dimensions due to unanswered questions.

[b] Interpretation of ICC: $< 0.5$ = poor agreement; 0.50−0.79 = moderate agreement; $>0.80$ strong agreement.

[c] Interpretation of $\eta^2$: 0.01 = small effect; 0.06 = medium effect; 0.14 = large effect.

*Agreement between QoL scores of control children and their parents.* The agreement between the ratings of the children and their parents on all QoL dimensions was moderate except for *social support and peers* where it was poor. The control's mean scores were significantly higher than those of their parents in *physical well-being, psychological well-being, autonomy and parent relations* and *school environment.* The size of the effect was small except for *physical well-being*, with a medium effect. No difference was found between the controls and their parents on *social support and peers*.

*Interaction effects.* In four QoL dimensions, small but significant interaction effects for gender were found; *physical well-being* ($F(1, 207)=8.155$, $p=0.005$, $\eta^2p=0.038$), *psychological well-being* ($F(1, 196)=10.049$, $p=0.002$, $\eta^2p=0.049$) and *autonomy and parent relations* ($F(1, 182)=4.815$, $p=0.029$, $\eta^2p=0.026$), with more differences among boys and their parents than for girls. Also in *school environment* ($F(1, 198)=7.346$, $p=0.007$, $\eta^2p=0.036$), with more differences among girls and their parents. A small but significant interaction effect regarding residence was found in *autonomy and parent relations* ($F$(1,

182) = 6.765, $p = 0.010$, $\eta^2p = 0.036$) with greater difference between scores of children and parents in the capital region than in other areas.

## Discussion

We studied QoL of high-functioning children and youth with ASD as rated by themselves and by their parents, as compared to typically developing children. When compared to self-ratings of their paired controls, children with ASD had significantly lower means on all QoL dimensions. The largest differences were found in *social support and peers* and in *physical well-being*, although on all QoL dimensions differences were found.

The parents of children with ASD also evaluated their children's QoL significantly lower on all dimensions than did parents of the controls. Large effect sizes between the proxy-answers of the two groups of parents were obtained on all dimensions, in particular for *physical well-being* and *social support and peers*. Thus, despite a similar pattern in scores, such as in reflecting positive and problematic QoL dimensions, there was greater discordance between the views of the two parent groups on their children's QoL than among the children themselves.

On four out of five dimensions, children with ASD reported, on average, significantly better QoL than did their parents, except in *autonomy and parent relations*. Despite these differences in ratings, the children with ASD and their parents seemed to agree about which areas were most problematic, as evident in the lowest mean scores and high effect sizes for the QoL dimensions of *social support and peers* and *physical well-being*. Interestingly, the control children also reported significantly better QoL scores than their parents on four out of five QoL dimensions, but with smaller effect sizes. This is an important finding which makes the difference between children with ASD and their parents less outstanding.

Difficulties in social functioning and relations among children with ASD have been reported in various studies (Clark et al., 2015; Knott et al., 2006; Kuhlthau et al., 2010; Tavernor et al., 2013). Studies also report that children with ASD have fewer friends and more difficulties with friendship than children in general (Bauminger and Kasari, 2000; Bauminger and Shulman, 2003; Calder et al., 2012; Kuo et al., 2011). Interestingly, in our study children with ASD as well as the controls had their highest means in the dimension of *psychological well-being* (seven questions about positive emotions and satisfaction with life as well as the absence of feelings of loneliness and sadness) (KIDSCREEN Group Europe, 2006). So despite their difficulties in the social domain, the children with ASD did not seem to consider that these issues affected their emotional well-being very much. This indicates that even though children with ASD may often be alone, they do not necessarily consider themselves as being lonely. Their parents, on the other hand, were clearly concerned about their child's emotions and satisfaction with life, as evident in their low ratings. This finding may also reflect different preferences of children with ASD and children in general such as placing more importance on activities performed in solitude or together with parents.

Physical challenges have not been considered as important an issue for children with ASD as their difficulties in social relationships. The low scores for *physical well-being* among children and their parents correspond nevertheless with studies reporting that children with ASD participate in fewer types of physical activities and spend less time performing them than typically developing children do (Bandini et al., 2013), and that children with Asperger syndrome have significantly poorer physical fitness than peers (Borremans et al., 2010). In this context it should be acknowledged that many organized physical activities such as sports teams and classes include social demands or a set of rules that may be challenging for children with ASD (Potvin et al., 2013). The five questions in this KIDSCREEN-27 dimension focus on the child's physical activity, energy and fitness, as well as the extent to which she or he feels unwell and complains of poor health (KIDSCREEN Group Europe, 2006). Since both children with ASD and their parents consider this area as problematic, more importance may need to be placed on the children's physical health and their opportunities to participate in physically demanding activities in order to promote their overall QoL. It must be ensured that the children get adequate amounts of physical activity to meet overall health recommendations (World Health Organization, 2010).

*Autonomy and parent relations* was the only dimension for which there was no difference between the mean scores of children with ASD and their parent's proxy-answers, meaning that the children and their parents generally agreed on the quality of their interactions, the child's level of autonomy and the quality of his or her financial resources. Larger effect sizes were found between children with ASD and their parent's proxies than for the controls and their parent's proxies on all dimensions except for *autonomy and parent relations*. Nevertheless, even though the means of children with ASD and their parents were practically the same on *autonomy and parent relations*, the correlations between their answers were only moderate, reflecting individual variations.

Overall agreement between the answers of both groups of children and their parent's proxies was moderate. Our correlations are similar to or slightly higher than those reported in the manual (KIDSCREEN Group Europe, 2006) but slightly lower than those reported by Dey et al. (2013), who used KIDSCREEN-27 with children with mental health issues and controls. In contrast Clark et al. (2015) found low correlations between the reports of adolescents with ASD and their parents, indicating discordance in their QoL ratings as measured by the KIDSCREEN-52. Similarly a study which used the PedsQL to evaluate differences between child and parent ratings for high-functioning children with ASD and controls also found low correlations between these two types of reports (Potvin et al., 2013).

Although more differences were obtained between the ASD group and their parent's proxies in this study than among the controls and their proxies, on no dimension in either group did parents, on average, rate their children's QoL higher than did the children themselves. For the ASD group, this is consistent with studies that have shown parents to report QoL scores for their child that are lower than self-report scores, when the child has some kind of impairment (Dey et al., 2013; Sheldrick et al., 2011; Upton et al., 2008; White-Koning et al., 2007).

Our results and those of others who have found parents to rate QoL of their children with ASD considerably lower than the children do themselves (Bastiaansen et al., 2004; Potvin et al., 2013; Sheldrick et al., 2011) seem to reflect different perspectives, reasoning and response styles between the children and their parents, and not merely inaccuracy or bias. Thus, children with ASD and their parents appear to have different preferences and also focus on different aspects of QoL when answering the questions (Davis et al., 2007; Dey et al., 2013; Potvin et al., 2013; Tavernor et al., 2013). Parents' concerns for their child's future prospects as well as their own experience of burden may also affect their answers, even if they are asked to answer just as their child would. The discordance between the answers of the children and their parents highlights the fact that parents' views cannot replace the views of their children. Instead the viewpoints of both parties should be sought whenever possible (De Los Reyes and Kazdin, 2005; Hemmingsson et al., submitted; Potvin et al., 2013).

According to the Attribution Bias Context model by De Los Reyes and Kazdin (2005), parents are more likely, as observers, to attribute their child's behaviour to his or her disposition and also tend to see the behaviour as more problematic than do the children themselves. In contrast, children are more likely, as actors, to attribute various challenges they experience to external causes. Individuals with ASD may see autism as a fundamental and valued aspect of their self-image as described by Grandin (1995): 'If I could snap my fingers and be nonautistic, I would not – because then I wouldn't be me. Autism is part of who I am' (p. 60). Increasingly, studies report the positive aspects some children and youth with ASD experience with having ASD (Mogensen and Mason, 2015; Molloy and Vasil, 2004).

Many of the items of the KIDSCREEN are rather subjective in nature (asking about happiness, joy, cheerfulness, sadness, being loved and respected). The moderate correlations between the ratings of children with ASD and their parents in this study suggest nevertheless that the KIDSCREEN-27 seems to be well suited for children with ASD. Tavernor et al. (2013) argued for the need for a condition-specific measure for ASD. We on the other hand fear that condition-specific measures may focus too much on impairment effects and not acknowledge the relational or environmental impacts on QoL, such as the importance of positive attitudes, understanding and necessary supports in accommodating the needs of children with ASD. Also, use of such measures would hamper comparison to typically developing children (Ravens-Sieberer et al., 2005) as we have done in this study. Nevertheless, careful attention must be taken in the choice of QoL measures and how they are translated and adapted to different languages and cultural contexts in order to correctly reflect the views of children with ASD. In our on-going qualitative follow-up study with children with ASD, we continue to further explore such validity issues within the Icelandic context.

In our study, more differences were found between the older age group of children with ASD and their parents on *psychological well-being*, *autonomy and parent relations* and *social support and peers*, which may indicate that parents have less insight into their child's emotions and social interactions as the child grows older. Interestingly, child age did not affect the ratings of parents and children in the control group. Differences relating to residence were detected in some QoL dimensions of both groups and indicate that parents in small towns and rural areas may have a better overview on their child's interactions and feelings, and thus have better opportunities to reflect their children's point of view.

## Strengths and limitations

This study had a higher number of participants than previous studies focusing on the QoL of children with ASD. An additional strength of the study is the fact that our control group was not a convenience sample but carefully paired to the children with ASD according to gender, date of birth and residence. Pairing the children's and their parents' proxy-answers enabled us also to study their concordance (through both means and correlations), whereas occasionally parents' self-reports and not their proxy-reports have been used and compared. While many studies use the Pearson product-moment correlation coefficient for examining agreement, we used the ICC, which reflects the ratio between subject variability and total variability. We stressed accessibility issues such as providing the option of listening to pre-recorded questions to children in both groups. Also, an experienced professional was in contact with the ASD group and provided extra information about the study whenever necessary.

Limitations to this study are first and foremost the low response rate in both groups although a large number of Icelandic high-functioning children with ASD participated in the study. Mothers constituted a great majority of respondents with overrepresentation of parents with university degrees, although the latter factor was not found to be associated with differences between child and proxy ratings. Overall, families with higher education seem to be more willing to participate in studies (Rodriguez et al., 2006). No information was gathered about other factors that are known to influence QoL, such as the social-economic status, financial resources and marital status of the participating families or services received other than special education services. These factors might bias the findings if not equal in both groups. Moreover, since we did not gather information about the children's reading abilities, adaptive skills or possible co-morbidities, like depression and anxiety, we do not know whether or how these factors influenced responses to the questionnaires.

## Conclusion

Despite lower scores for children with ASD than for their controls, it should be acknowledged that the children themselves were quite positive about many aspects of their lives. The results revealed their overall positive emotions and satisfaction with life, contentment with their relationships with their parents and autonomy, as well as with their schools. In order to increase QoL of children with ASD, special attention should be given to factors related to their social participation and well-being in different contexts. These findings can be useful for guiding and planning services for children with ASD and their families, and highlight the importance of including the views of the children in all clinical work. Since more individuals with high-functioning ASD are being identified, it is of utmost importance to focus carefully on the needs of this group (Lai et al., 2014; Saemundsen et al., 2013).

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