

Self-regulation and quality of life in high-functioning young adults with autism

Renee R Dijkhuis^{1,2}, Tim B Ziermans^{1,2}, Sophie Van Rijn^{1,2},
Wouter G Staal^{3,4} and Hanna Swaab^{1,2}

Autism

1–11

© The Author(s) 2016

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/1362361316655525

aut.sagepub.com



Abstract

Background: Autism is generally associated with poor functional outcome but little is known about predictors of quality of life, especially during early adulthood. This study was conducted to assess subjective quality of life during early adulthood in high-functioning autism spectrum disorder and its relation with self-regulating abilities. Individuals with high-functioning autism spectrum disorder who progressed into post-secondary higher education ($N = 75$) were compared to a typical peer control group ($N = 28$) based on behavioral self-report questionnaires. The results indicated that individuals with high-functioning autism spectrum disorder reported significantly lower subjective quality of life than typical controls ($p < 0.001$, effect size (d) = 1.84). In addition, individuals with high-functioning autism spectrum disorder reported more problems with emotion processing ($p < 0.05$, effect size (d) = 0.79) and daily executive functioning ($p < 0.001$, effect size (d) = 1.29) than controls. A higher level of executive functioning problems was related to lower quality of life in the high-functioning autism spectrum disorder group, but no significant relation between level of emotion processing and subjective quality of life became apparent in the regression analysis. Our findings show that even in high-functioning young adults with autism, executive functioning, emotion processing, and subjective quality of life are low compared to typically developing peers. Furthermore, these results emphasize the importance of targeting executive functioning problems in individuals with autism to improve subjective quality of life.

Keywords

autism spectrum disorders, emotion processing, executive functioning, high-functioning, self-regulation, subjective quality of life, young adults

Introduction

Children diagnosed with autism spectrum disorders (ASDs) face uncertain functional outcomes in adulthood (Magiati et al., 2013). About 60%–78% of people with ASD have poor or very poor adjustment in terms of living independently, relationships, and work opportunities in adulthood (Billstedt et al., 2005; Burgess, 2007; Eaves and Ho, 2008). There is some evidence that higher functioning individuals ($IQ > 70$) with ASD have a better outcome (Howlin et al., 2004), although the term “high-functioning autism spectrum disorder” (HFASD) has not been used consistently, and the results have been mixed. Longitudinal studies show that a majority of adults with HFASD has no close friends and a low employment status and that they are relatively dependent on their families (Howlin, 2000).

An important part of outcome is the general well-being of individuals, and this is generally referred to as quality of life (QoL). QoL is defined by the World Health Organization

(WHO, 1995) as the individual’s perception of his or her position in life in the context of the culture and value system and in relation to one’s goals, expectations, standards, and concerns. In a recent meta-analysis by Van Heijst and Geurts (2014), the developmental trajectory of QoL was studied, and it was concluded that people with ASD experience lower QoL compared to typically developing

¹Leiden University, The Netherlands

²Leiden Institute for Brain and Cognition, The Netherlands

³Karakter Universitair Centrum, The Netherlands

⁴Radboud Universitair Medisch Centrum, The Netherlands

Corresponding author:

Renee Dijkhuis, Department of Clinical Child and Adolescent Studies, Leiden University, Wassenaarseweg 52, 2333 AK Leiden, The Netherlands.

Email: r.r.dijkhuis@fsw.leidenuniv.nl

controls across the lifespan. Despite a growing interest, few studies have investigated QoL in the transition phase from adolescence to adulthood. This is remarkable since transitioning to adulthood is particularly challenging for individuals with ASD (Adreon and Durocher, 2007; Kapp et al., 2011). Not only do young adults move out of their parents' homes, but it also becomes increasingly important to develop social relationships and become self-sufficient in everyday life.

Regarding the assessment of QoL, a distinction can be made between objective and subjective QoL. Objective indicators of QoL in HFASD (i.e. residential setting and attainment of a diploma) have been broadly studied, while few studies have considered subjective indicators (i.e. self-reported levels of happiness, pleasure, and fulfillment; Costanza et al., 2007). This is remarkable since knowledge about whether and how happiness in school or self-esteem predicts employability or job satisfaction in the future lives of this intelligent but underemployed group of individuals with autism is very much needed (Levy and Perry, 2011; Shattuck et al., 2012). In a study with 100 families with a young adult relative diagnosed with autism in childhood, about 91% rated the QoL of their relative with autism as good or very good. However, the majority of participants required support in the areas of occupational and recreational activities (Billstedt et al., 2011). While studies like these highlight the importance of assessing objective indicators of QoL in individuals with autism, solely asking objective questions would miss the aim of understanding how the individual evaluates the perceived need. Another reason to ask for subjective experience is the important observation by Renty and Roeyers (2006) that QoL is more strongly linked to the perception of the availability of the support rather than to the effects of the actual supporting behaviors in individuals with HFASD.

In determining subjective QoL, it is important to use self-reports. Although one might argue that people with ASD have difficulties in reporting on their own needs, Shipman et al. (2011) found that the self-reports of QoL in a group of adolescents with HFASD demonstrated internal reliability and concurrent validity with parent proxy reports. Moreover, it was found in this study that self-reported QoL is lower than the population mean for adolescents with HFASD. In a recent study by Barneveld et al. (2014), both objective and subjective QoL in HFASD were measured, and it was found that young adults with HFASD were less satisfied with their work or education, partner relationship, and future perspective than adults with other disorders, such as attention-deficit hyperactivity disorder (ADHD), disruptive behavior disorder, or affective disorders. It was concluded that young adults with HFASD are at relative high risk of poor QoL compared to those with other early onset psychiatric and neurodevelopmental disorders.

A number of studies have attempted to identify predictors of poor outcome or QoL in individuals with ASD. In a recent review by Magiati et al. (2013), it was found that IQ

and verbal abilities are among the strongest predictors of QoL in individuals with ASD: a positive association was reported for childhood IQ with better adaptive functioning and better social outcome in adulthood. Others have suggested that quality of social engagement with peers is a better predictor of adaptive functioning in individuals with ASD than IQ (McGovern and Sigman, 2005). Children with ASD are known to be less accepted by peers and have fewer reciprocal friendships (Chamberlain et al., 2007). This might be explained by difficulties in managing behavior and emotions, and this in turn might be due to poor self-regulation skills (Nadel and Muir, 2005). For positive adjustment and adaptation, one needs optimal self-regulation. Self-regulation refers to the cognitive and behavioral processes through which an individual maintains levels of emotional, motivational, and cognitive arousal that promote positive adjustment and adaptation, as reflected in positive social relationships, productivity, achievement, and a positive sense of self (Blair and Diamond, 2008). Self-regulation difficulties are reported to be present in children with ASD as young as 1 year of age (Gomez and Baird, 2005). Although it is not included in diagnostic criteria, regulatory dysfunctions are often observed in persons with ASD (Barrett et al., 2013). For the effortful regulation of attention and behavior, both executive functioning (EF) and emotion processing are important components (Blair and Diamond, 2008). In a study by Jahromi et al. (2013), it was found that in children with HFASD, EF predicts emotional engagement, and emotion regulation predicts prosocial peer engagement. Moreover, neurobiological studies show that self-regulation in ASD is related to dysfunctions in certain brain circuits that are associated with social-emotional processing (Bachevalier and Loveland, 2006). Given the knowledge that EF and emotion processing are important concepts of self-regulation that influence adaptive behavior in children with ASD, we chose to focus on these control processes.

EF subserves successful self-regulation (Hofmann et al., 2012) and has been studied extensively in ASD, although to a lesser extent in young adults with ASD. EF refers to a broad range of component processes necessary for the control and execution of complex behaviors and includes different metacognitive domains such as planning, inhibition, working memory, and cognitive flexibility (Anderson, 2001; Pellicano, 2012). A growing body of research focuses on EF in ASD, but results have been mixed. Next to large individual differences in EF in ASD (Pellicano, 2010), age differences have been found for specific EFs in ASD (Van den Bergh et al., 2014). Despite the steady accumulation of the literature on EF in ASD, the relation between QoL and EF has thus far only been studied in children with ASD (De Vries and Geurts, 2015). De Vries and Geurts (2015) found that children with ASD showed lower QoL than control children, and this lower QoL was related to higher levels of EF deficits. It is important to assess whether these same relations can be found in

young adulthood given the knowledge that EF deficits in typically developing children can predict lifelong achievement (Diamond, 2013). It has been found that adults with functional problems who show better EF enjoy a better QoL (Brown and Landgraf, 2010).

In addition to EF, awareness of emotions and ability to regulate them is another important element of self-regulation. Emotion regulation can be defined as the automatic or intentional modification of a person's emotional state that promotes adaptive or goal-directed behavior (Hill et al., 2004). Individuals with ASD have been reported to be at high risk of alexithymia (Hill et al., 2004), which is literally translated as "lacking words for feelings." The term "alexithymia" has been conceptualized for reduced emotion awareness as expressed in a reduced ability to identify, experience, verbally describe, and reflect on one's own emotions (Booth-Butterfield and Booth-Butterfield, 1990). In a study by Berthoz and Hill (2005), it was found that adults with ASD expose a cognitive form of alexithymia, meaning that the conscious awareness of emotional arousal appeared intact, while the intensity of emotions accompanying cognitions was low compared to controls. The failure of many individuals with HFASD to use adaptive emotion processing strategies is suggested to originate from deviant emotional reactivity and a lack of emotional insight needed to modify or control the emotion (Mazefsky et al., 2013).

In this study, we aimed to investigate whether young adults with HFASD experience self-perceived problems in specific domains of self-regulation and how these problems may relate to their subjective QoL. To limit the potential confounding effects of verbal skills and IQ on these parameters, a sample of high-functioning subjects with ASD was selected, that is, those who had entered higher education after high school. It was assessed whether young adults with HFASD report more problems in subjective QoL, emotion processing, and EF compared to young adults without HFASD. The second aim of this study was to test whether levels of emotion processing and EF could predict QoL in individuals with HFASD. In addition to lower QoL, we hypothesized that young adults with HFASD would report lower scores on EF and emotion processing than typically developing adults. Finally, it was expected that increased problems with these self-regulation skills would predict lower subjective QoL in young adults with HFASD.

Method

Participants and procedure

The study was approved by the Ethical Board of the Department of Education and Child Studies at Leiden University, the Netherlands. Prior to participation, all participants provided full informed consent. A total of 106 participants (76 HFASD, 30 controls) enrolled in Dutch post-secondary higher education participated in this study.

In the HFASD group, one multivariate outlier in the control group was excluded from analysis due to very high z-scores on all measures (>2.5). Of the remaining participants in the HFASD group, 55% were enrolled in universities and 45% were enrolled in higher vocational education ("HBO" in the Netherlands). Of the participants in the control group, 89% were enrolled in universities and 11% were enrolled in higher vocational education. Participants ranged in age from 18 to 28 years ($M=22.12$, standard deviation (SD)=2.28). Of the students in the HFASD group, 67 were males (89%) and 8 were females (11%). Of the students in the control group, 23 were males (82%) and 5 were females (18%). Young adults with HFASD were recruited through "Stumass," an assisted living program for young adults with HFASD enrolled in higher education where students with HFASD live together with other students in so-called Stumass houses. In these houses, tutors are available for planned and unplanned care during weekdays. The goal of Stumass is to reduce dropout rates in education and increase independence among students with HFASD. Young adults can only enter the Stumass program when they obtain a clinical diagnosis of autism, based on full agreement between two board-certified psychiatrists. These *Diagnostic and Statistical Manual of Mental Disorders* (DSM) diagnoses were retrieved according to the *Diagnostic Statistic Manual* criteria (customary at the time of referral) with semi-structured, DSM-focused interviews, observations, medical records, and structured questionnaires. Criteria for inclusion were (1) age between 18 and 28 years and (2) no axis II DSM diagnosis of mental retardation ($IQ < 70$) in childhood, and for the control group, students from universities and higher vocational education were included unless they reported having received a formal psychiatric diagnosis during their lifetime. All young adults with HFASD attending the Stumass project at that time (about 200 students) were invited to participate in the study, and the students who were willing to participate returned an informed consent to the investigators. The questionnaires were bundled and sent to their houses. The students in the control group were recruited through mouth-to-mouth advertisement in the cities of Leiden and Amsterdam. After signing the informed consent, the questionnaires were sent to their homes with a return folder enclosed. The HFASD individuals participated voluntarily, and control participants received a €10 reward voucher after they had returned the completed questionnaires to the University of Leiden.

Measurements

QoL

Subjective QoL was assessed with a Dutch translation of the Quality of Life Questionnaire (QoL-Q; Schalock and Keith, 1993). According to Renty and Roeyers (2006), the QoL-Q is a reliable and accurate tool for determining

subjective QoL in individuals with ASD. The QoL-Q has good psychometric properties with a test–retest coefficient of 0.87 and Cronbach’s alpha of 0.90 for the total scale (Schalock and Keith, 1993). The questionnaire yields data regarding overall QoL with a composite score of four subscales: satisfaction, competence or productivity, empowerment or independence, and social belonging or community integration. Each subscale contains 10 items, scored on a 3-point Likert-type scale (1 = very satisfied, 2 = somewhat satisfied, and 3 = not satisfied). The competence or productivity subscale was excluded since it consists of questions about the job environment, and most young adults in the HFASD group do not have paid employment. A total score was calculated based on the subscales satisfaction, empowerment or independence, and social belonging or community integration. Higher scores indicate higher subjective QoL.

Additionally, a short 7-item questionnaire, with a composite rating on a 5-point scale (1 = very dissatisfied and 5 = well satisfied) of life satisfaction (QoL_{ls}) was administered. The questions concerned satisfaction about living arrangements, education, physical condition, partner relationship, social relationships, state of mind (general mood), and future perspectives (life prospects). An identical questionnaire has been used by Barneveld et al. (2014) in a large clinical cohort of 408 Dutch participants. We used exactly the same questions but modified the scale of the rating from a 6-point scale to a 5-point scale. The internal consistency (Cronbach’s alpha) of the QoL_{ls} in this study is good, with values of 0.78 for the control group and 0.75 for the autism group.

Current autism traits

ASD symptoms were measured with the Social Responsiveness Scale for Adults (SRS-A; Constantino and Todd, 2005). The SRS consists of 65 questions that map the social shortcomings of the adult. The questionnaire comprises the scales social awareness, social communication, social motivation, and autistic mannerisms and gives a total score. The SRS-A subscale scores give an index of severity of social deficits in the autism spectrum with higher scores indicating more ASD traits. Internal consistency was found to be highly acceptable in a German cohort with Cronbach’s alpha ranging from 0.71 (typically developing participants) to 0.89 (autism participants; Bölte, 2012), and the overall test–retest reliability (Pearson’s *r*) for the SRS-A was found to be 0.64 (Constantino and Todd, 2005).

EF

EF was assessed with the Dutch version of the Behavior Rating Inventory of Executive Function for Adults (BRIEF-A; Roth et al., 2005). Based on the original BRIEF, the BRIEF-A is a self-report developed for adults, and it is composed of 75 items with nine clinical scales that measure

various aspects of EF: Inhibit, Shift, Emotional Control, Self-Monitor, Initiate, Working Memory, Plan/Organize, Task Monitor, and Organization of Materials. Raw scores are calculated for the clinical scales. Higher scores are indicative of greater perceived impairment in EF. The reliability of the BRIEF for children has been estimated with a Cronbach’s alpha for internal consistency ranging from 0.80 to 0.98. Also, reliability based on test–retest is high for both the scales and the indexes (Gioia et al., 2000).

Emotion processing

To assess emotion processing, the Dutch Bermond–Vorst Alexithymia Questionnaire (BVAQ) was administered. Alexithymia refers to a dysfunction in emotional awareness (Morera et al., 2005; Vorst and Bermond, 2001). The questionnaire consists of 40 questions with response possibilities on a 5-point scale from “fully applicable” to “entirely not applicable.” The questions refer to five subscales: the subscales emotionalizing and fantasizing represent an emotional component of alexithymia, and the subscales identifying, analyzing, and verbalizing emotions represent a cognitive component of alexithymia. Higher scores indicate a higher propensity for alexithymia. The reliability of this questionnaire is 0.85, and the questionnaire has proven valid in samples of Dutch students (Vorst and Bermond, 2001).

Statistical analyses

All analyses were carried out in IBM SPSS version 22. Differences in QoL, EF, emotion processing, and current autism traits between the HFASD and control group were tested using analysis of variance (ANOVA) with total scores and multivariate ANOVA with the subscales as the dependent variables and group as between-subjects factor. Hierarchical regression analyses were conducted to examine which independent variables are the best predictors of subjective QoL in the HFASD group. Alpha was set to 0.05, and following Cohen’s (2013) guidelines, effect sizes (ESs) for group differences were defined in terms of small ($d=0.10$), medium ($d=0.30$), and large effects ($d=0.50$).

A series of hierarchical regression analyses were conducted, with the subtotal of the three QoL-Q subscales as the dependent variable. Age and gender were entered in the first step, followed by the centered variables of interest (total EF and emotion processing) in the second step, and to control for autism symptoms, this variable was entered backward in the last step. Autism symptoms appeared to have no significant impact on the model, so it was excluded from both models in the results, and it is not reported in the “Results” section. For emotion processing, a significant positive correlation was found between the emotional component of alexithymia and QoL in the HFASD group. The correlation indicates that more problems with the emotional component of alexithymia relate to higher QoL in this group

Table 1. Group characteristics.

	HFASD (<i>n</i> =75)	TD (<i>n</i> =28)	Group comparison	
			<i>t</i> / χ^2 / <i>F</i>	<i>p</i>
Gender, male, <i>N</i> (% in group)	67 (89)	23 (82)	$\chi^2=0.956$ (1)	0.51
Age, years, <i>M</i> (SD)	21.9 (2.3)	22.7 (2.2)	<i>T</i> =-1.70 (101)	0.09
SRS-A total score, <i>M</i> (SD)	65.2 (21.9)	23.6 (12.6)	<i>F</i> =90.13	<0.001**
Social awareness, <i>M</i> (SD)	18.2 (7.2)	7.0 (3.7)	<i>F</i> =63.69	<0.001**
Social communication, <i>M</i> (SD)	21.6 (7.0)	8.1 (5.3)	<i>F</i> =69.41	<0.001**
Social motivation, <i>M</i> (SD)	13.8 (5.5)	5.1 (3.2)	<i>F</i> =61.51	<0.001**
Autistic mannerisms, <i>M</i> (SD)	11.6 (5.1)	3.5 (3.4)	<i>F</i> =59.80	<0.001**

SRS-A: Social Responsiveness Scale for Adults; HFASD: high-functioning autism spectrum disorder; SD: standard deviation; TS: typically developing. ***p* < 0.001.

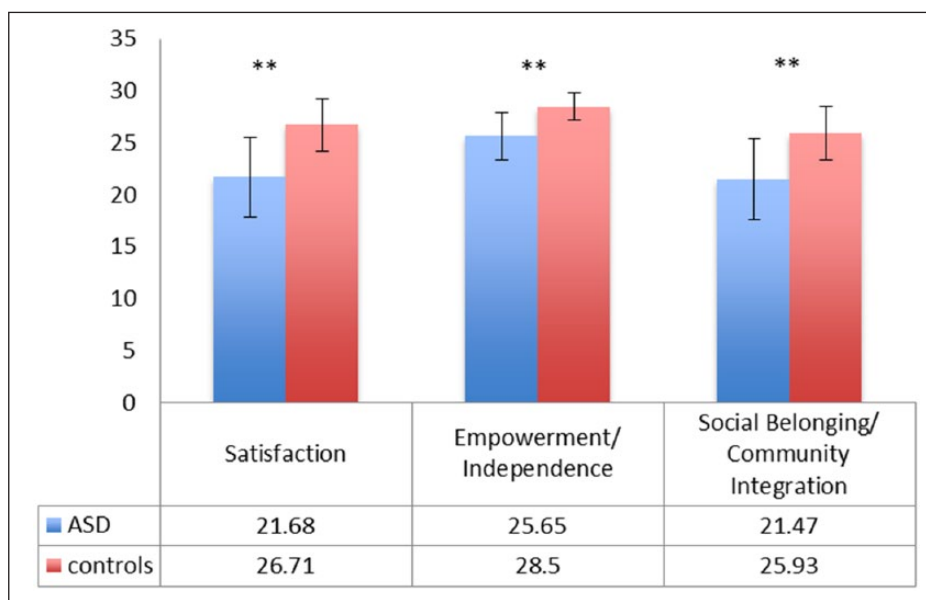


Figure 1. Mean scores on the subscales of the Quality of Life Questionnaire (QoL-Q). Error bars represent standard deviations; higher scores indicate better quality of life.

***p* < 0.001.

(see Supplementary Table 1). However, in the control group, no relation was found between these variables. Moreover, there were no significant group differences for the emotional component of alexithymia, so we decided to leave it out of the regression analysis and to enter only the cognitive component of emotion processing as a predictor of QoL.

Results

Participants

Data were missing in the HFASD group for the QoL-Q (3), the QoL_{is} (3), the BRIEF-A (1), and the BVAQ (4), and no data were missing for the control group. These cases were excluded pairwise from the analysis. Sample characteristics are reported in Table 1. There were no group differences in sex and age. A significant group difference was found in

total autism traits between the HFASD group and the controls ($F=90.13, p < 0.001$), the differences on all subscales of the SRS-A were significant at $p < 0.001$. Individuals in the HFASD group reported significantly more autism symptoms.

QoL

Two outliers (one in the HFASD group and one in the control group) were detected for the QoL variable retrieved from the QoL-Q, both reflecting low QoL. These outliers were retained since the scores were not determined as a result of recording, entry, or order of the questionnaires. Mean scores and SDs on the subtests of the QoL-Q are displayed in Figure 1. A multivariate significant group difference for the subscales of subjective QoL was observed, $F(3, 96)=19.20, p < 0.001$, indicating that young adults

Table 2. QoL_{is} of young adults with HFASD as compared to controls.

	HFASD (N=75)	Controls (N=28)	F	p	d
Living arrangements	4.08 (0.69)	3.89 (1.0)	5.01	0.365	0.22
Education	3.51 (1.06)	4.04 (0.79)	7.82	0.008*	-0.57
Physical condition	3.25 (0.96)	3.68 (0.72)	3.82	0.036*	-0.51
Relationship partner	3.03 (1.11)	3.75 (1.08)	0.081	0.004*	-0.66
Social relationships	3.33 (0.89)	4.36 (0.83)	1.15	<0.001**	-1.20
State of mind	3.57 (0.84)	4.21 (0.74)	1.13	0.001*	-0.81
Future perspective	3.47 (0.90)	4.07 (0.66)	9.59	<0.001**	-0.76

QoL: quality of life; HFASD: high-functioning autism spectrum disorder.

* $p < 0.05$; ** $p < 0.001$.

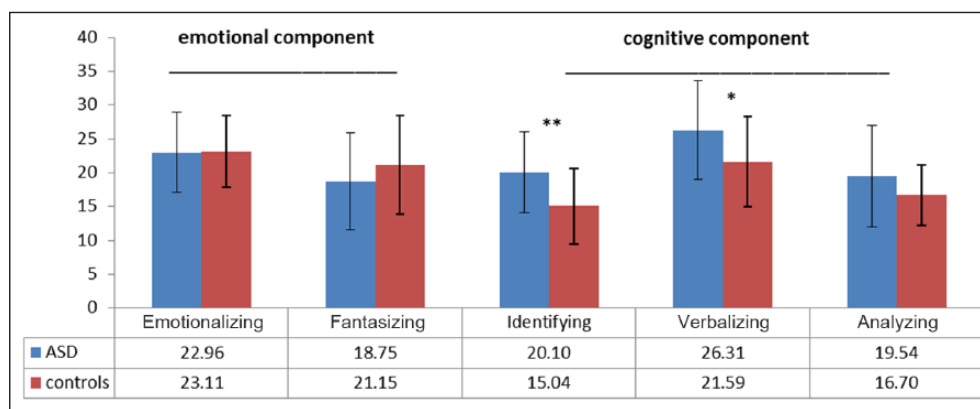


Figure 2. Means scores on the subscales of the BVAQ questionnaire in the HFASD and the control group. Error bars are derived from the individual standard deviations for each group. Higher scores indicate more emotion processing problems.

* $p < 0.05$; ** $p < 0.001$.

with HFASD rate their QoL lower than young adults without HFASD. Subsequent univariate analyses showed differences on all QoL-Q subscales with $p < 0.001$. For total subjective QoL, young adults with HFASD ($M=68.81$, $SD=8.19$) scored significantly lower than controls ($M=81.18$, $SD=4.88$), $F(1, 98)=56.02$, $p < 0.001$, $d=1.84$.

According to the QoL_{is}, HFASD individuals were significantly less satisfied than controls on all measures ($p < 0.05$; d_{range} : -1.20 to -0.51), except for satisfaction of living arrangements ($d=0.22$; Table 2).

Emotion processing

Mean scores and SDs for the HFASD ($n=71$) and the control group ($n=28$) on the subtests of the BVAQ are provided in Figure 2. A significant multivariate effect indicated that young adults with HFASD reported significantly more problems with emotion processing than controls, $F(5, 92)=3.37$, $p < 0.05$. Next, univariate analysis revealed significant group differences only for the subscales verbalizing and identifying at $p < 0.05$. The HFASD group ($M=65.90$, $SD=15.70$) overall reported more problems with the cognitive component of alexithymia than controls ($M=54.07$, $SD=14.34$), $F(1, 99)=11.96$, $p=0.001$,

$d=0.79$, but no significant group differences were found for the emotional component of alexithymia.

EF

Mean scores and SDs for the HFASD ($n=74$) and the control group ($n=28$) on the BRIEF-A subscales are provided in Figure 3. A multivariate significant group difference was found for the different aspects of EF, indicating that young adults with HFASD reported more behavioral EF problems than controls, $F(10, 91)=5.04$, $p < 0.001$. The differences on all BRIEF subscales were significant at $p < 0.05$, except for the subscales “Inhibit” ($p=0.12$) and “Organization of Materials” ($p=0.07$). For total EF, young adults with HFASD ($M=128.51$, $SD=18.65$) scored significantly higher than controls ($M=105.64$, $SD=16.68$), $F(1, 101)=32.30$, $p < 0.001$, $ES (d)=1.29$.

Predictors of QoL in HFASD

The model with BRIEF total score added in the second step was statistically significant in explaining subjective QoL, $F(2, 74)=6.71$; $p < 0.001$, with 22.1% of variance in subjective QoL explained (Table 3). Adding autism

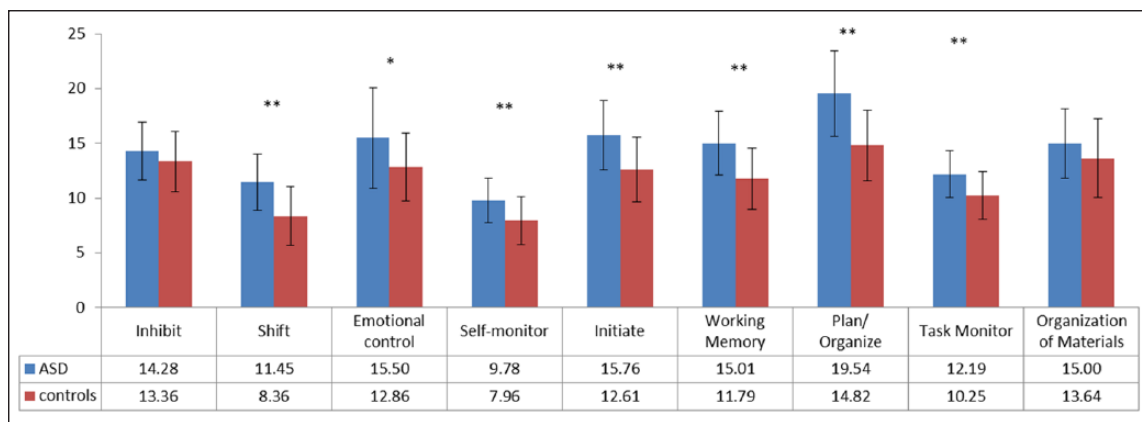


Figure 3. Mean scores (mean) on the subscales of the Behavior Rating Inventory of Executive Function for Adults (BRIEF-A). Error bars represent standard deviations. Higher scores indicate more EF problems. BRIEF T-scores—control group: $M = 51.5$, $SD = 8.2$, and range = 36–64; and ASD group: $M = 62.7$, $SD = 9.1$, and range = 36–83.

* $p < 0.05$; ** $p < 0.001$.

Table 3. Summary of hierarchical regression analysis for variables predicting subjective QoL ($N = 75$).

Predictor variables	Outcome measures				
	R^2	ΔR^2	B	SE B	β
Step 1					
Age	0.13	0.13*	-1.26*	0.39	-0.36
Gender			0.47	2.85	-0.02
Step 2					
Age	0.22	0.13*	-0.92*	0.38	-0.26
Gender			0.97	2.70	0.04
Total EF			-0.14*	0.05	-0.32
Emotion processing ^a			-0.10	0.06	-0.20

QoL: quality of life; SE: standard error; EF: executive functioning; BVAQ: Bermond-Vorst Alexithymia Questionnaire. Age, total EF, and emotion processing were centered at their means. ^aCognitive component of the BVAQ. * $p < 0.05$.

symptoms did not improve the regression models, so it was excluded as a predictor from both models. In the final model, age and EF were statistically significant, with EF recording a higher beta value ($\beta = -0.32$, $p < 0.05$) than age ($\beta = -0.26$, $p < 0.05$). The cognitive component of alexithymia was not a significant predictor ($\beta = -0.20$, $p = 0.07$).

Subsequently, regression analyses were performed to explore individual contributions of subscales of EF. The model with subscales of the BRIEF-A accounted for 38.6% of the variance in subjective QoL (Table 4), $F(11, 74) = 3.60$, $p = 0.001$, with significant independent effects of the subscales Shift ($\beta = -0.43$, $p < 0.05$) and Self-Monitor ($\beta = 0.29$, $p < 0.05$). Plotting of the raw data indicated that for both subscales, more problems were associated with lower QoL.

Table 4. Summary of hierarchical regression analysis for variables predicting subjective QoL ($N = 75$).

Predictor variables	Outcome measures				
	R^2	ΔR^2	B	SE B	β
Step 1					
Age	.13	.13*	-1.26	0.39	-0.36
Gender			.47	2.85	.02
Step 2					
Age	.39	.26*	-0.77*	0.37	-0.22
Gender			-2.80	2.98	-0.11
Inhibit			-0.01	0.40	-0.01
Shift			-1.37*	0.43	-0.43
Emotional Control			-0.24	0.23	-0.13
Self-Monitor			1.14*	0.54	0.29
Initiate			-0.40	0.44	-0.16
Working Memory			-0.25	0.40	-0.09
Plan or Organize			0.07	0.47	0.03
Task Monitor			0.20	0.49	0.05
Organization of Materials			-0.20	0.34	0.03

QoL: quality of life; SE: standard error. Age, Inhibit, Shift, Emotional Control, Self-Monitor, Initiate, Working Memory, Plan or Organize, Task Monitor, and Organization of Materials were centered at their means. * $p < 0.05$.

Discussion

This study investigated QoL, EF, and emotion processing in a sample of young adults with HFASD enrolled in post-secondary higher education. Our findings confirmed that these individuals experience a greatly reduced subjective QoL compared to typically developing peers. They reported to be less content in important qualitative aspects of their lives, such as their physical condition, relationships, and state of mind. In addition, individuals with

HFASD reported more problems in self-regulating skills (i.e. EF and emotion processing). Of these two skills, only EF was a significant predictor of subjective QoL in HFASD, such that more problems in daily EF were related to a lower QoL.

Several conclusions can be drawn from our study. The finding that subjective QoL is lower for young adults with HFASD than for controls is in line with previous claims that QoL in ASD is impaired across the lifespan (Van Heijst and Geurts, 2014). This highlights the fact that ASD is a neurodevelopmental condition with profound effects on QoL, even in those individuals who are high functioning. Furthermore, the findings concerning impaired emotion processing in young adults with HFASD are consistent with earlier studies (Berthoz and Hill, 2005; Hill et al., 2004) suggesting that adults with ASD often show a specific form of alexithymia characterized by impairments in the cognitive rather than the affective domain. This corresponds to Bermond's type II alexithymia: a normal to high degree of conscious awareness of emotional arousal, accompanied by fewer cognitions about the emotional arousal (Vorst and Bermond, 2001). The findings in this study suggest that young adults with HFASD may process emotions in an idiosyncratic manner. This is in line with the suggestion by Hill et al. (2004) that potential problems with mentalizing or an underlying theory of mind deficit may lead individuals with ASD to focus more on external events rather than formulating and thinking about their inner emotional experiences. We believe that these impairments in the cognitive domain of emotion processing may have an important influence on social engagement. Not being able to comment on one's own feelings might lead to less positive social interactions, which in turn prevents learning from social environments due to lack of experience with the social world (Pelphrey et al., 2011). In order to further understand underlying mechanisms of difficulties in social engagement, we think that studying the role of autonomic nervous system in regulation of arousal is a promising direction.

With respect to EF, we found that young adults with HFASD report more difficulties in most aspects of behavioral EF (e.g. planning, working memory, and cognitive flexibility), but no differences were found for inhibition between the autism group and typically developing peers. In earlier studies using procedural EF tasks, such as the Stroop or Go or No Go task, mixed results were found for inhibition in ASD (Hill, 2004), and it appears that response inhibition is intact in HFASD because of the use of compensatory mechanisms (O'Hearn et al., 2008). Jointly, we conclude from these findings that individuals with HFASD appear to experience fewer problems in inhibitory behaviors, relative to other daily EF-related demands.

Regarding the predictive capacity of self-regulation skills for subjective QoL, we found that more problems

with EF, but not poor emotion processing skills, predicted lower subjective QoL in young adults with HFASD. This association between EF and QoL corroborates previous findings in children with ASD (De Vries and Geurts, 2015). By zooming in on different aspects of daily EF, we were able to detect two function-specific correlations with subjective QoL. First, increased problems with flexibility significantly predicted lower subjective QoL. Earlier cognitive behavioral studies with tasks such as the Wisconsin Card Sorting Task to measure flexibility in children with ASD have shown incongruent results, with some reporting deficits in cognitive flexibility (Hill, 2004; Kenworthy et al., 2005). However, these deficits seem primarily task dependent and not related to everyday inflexible behaviors (Geurts et al., 2009). The finding of impaired QoL in relationship to reduced flexibility in this study seems to correspond with the often reported difficulties of young adults with ASD, for example, in school interactions with peers and teachers in dynamic classroom situations. Feeling that you cannot keep up with these requirements in young adulthood may have a significant impact on the experienced self-confidence, feelings of competence, and satisfaction. Second, the other significant aspect of EF as a predictor of QoL in the HFASD group is self-evaluation. This subscale of the BRIEF-A measures awareness of one's own social behavior and the potential effect on other people. From our data, it appears that increased problems with self-evaluation may also relate to lower subjective QoL. Hence, problems with flexibility, behavioral monitoring, and restricted awareness of the consequences of one's own behavior for others lead to lower QoL in young adults with HFASD. The cognitive component of alexithymia did not significantly predict subjective QoL in HFASD, but there was a statistical trend in the expected direction, that is, that fewer cognitions about emotional arousal lead to lower subjective QoL in HFASD. However, according to our results, EF deficits may play a more prominent role in explaining subjective QoL. This is in line with a study done by Jahromi et al. (2013) where the researchers concluded that executive function explained differences in emotion regulation beyond the contribution of other self-regulation components in children with HFASD.

An unexpected finding in this study was the negative relationship between age and subjective QoL in the autism group. In a large study on health-related QoL, Kuhltau et al. (2010) found a negative relationship between age and QoL in children (2- to 17-year-olds) with ASD. In contrast, a recent meta-analysis by Van Heijst and Geurts (2014) reported that age did not have an effect on QoL in ASD. An explanation for this might be that the questionnaire for subjective QoL (QoL-Q) used in this study is different from the World Health Organization Quality of Life (WHOQOL)-BRIEF version used in other studies concerning QoL in young adults with ASD (Jennes-Coussens et al., 2006; Kamio et al., 2012; Kamp-Becker et al.,

2010). The WHOQOL aims to measure health-related QoL and not subjective QoL like the QoL-Q. Additionally, negative relationships with age were also observed in this study for EF and emotion processing. We speculate that these findings may reflect an increasing awareness of subjective (dis-)functioning with age during young adulthood. As such, this study highlights a potential developmental impact of impaired self-regulation due to ASD symptoms and the importance of interventions for children and adolescents with ASD.

Interestingly, young adults with HFASD showed higher satisfaction in living arrangements compared to the control group. An explanation might be that the living circumstances of the Stumass houses provide the young adults with HFASD a safe, controllable environment that makes them value this part of their lives more positive than controls do. The Stumass houses provide tutors to support living needs, and the buildings are chosen or adapted to take into account common autism traits such as oversensitivity and need for functionality. In line with results of earlier research into support for individuals with ASD (Kamp-Becker et al., 2010; Renty and Roeyers, 2006), we emphasize the importance for individuals with ASD to live in an environment where support is readily available.

This study has some important limitations. The use of only self-report may be a double-edged sword. While it provides a unique insight in the personal view of young adults with ASD on their functioning and QoL, it is also known that individuals with ASD have difficulties in verbalizing their own feelings. Specifically, for emotion processing, self-report might not be an optimal way to gather data in an autism sample. Also, the fact that all measures were filled out by the same person increases the chance to find relations between measures. Second, verbal abilities and IQ were not directly assessed in this study. However, students in the Netherlands are only admitted to higher education with a diploma of the highest levels of secondary education or to have completed the first year of mid- to high-level tertiary education. For a student to advance to these levels of education they are required to master high levels of verbal skills and generally assumed to have above-to-high IQ. Another limitation is that only two potential important predictors of QoL or aspects of self-regulation in young adults with HFASD were studied. Other factors such as temperament, presence of comorbidities, or academic success may be equally impaired and influence overall QoL. However, measuring all these factors requires a much larger number of subjects to provide meaningful and replicable results.

To further understand self-regulation in ASD, there are promising new insights from studies investigating underlying neurobiological mechanisms. For example, evidence from pediatric samples suggests that cardiac response and regulation in social-emotional situations in ASD may deviate from children with mental disabilities, psychiatric

disorders, and normal controls (Corona et al., 1998; Porges, 2003; Vaughan Van Hecke et al., 2009). The aberrant physiological reactions in individuals with ASD could lead to inadequate behavioral reactions or coping mechanisms. These and other findings await further replication in high-functioning and adult samples to indicate whether such fundamental disturbances affect self-regulating behavior across the autism spectrum and the lifespan. The current findings provide additional rationale to follow this lead.

To conclude, this study of young adults with HFASD adds to the growing body of evidence that QoL is impaired throughout the entire lifespan in ASD, even in individuals with high IQ and educational attainment. Based on our findings that EF deficits can predict level of subjective QoL, early personalized treatment initiatives are recommended to target EF skills to improve QoL for individuals with HFASD. Neurofeedback treatment has shown improvements in executive control in children with ADHD (Coben et al., 2010) and ASD (Kouijzer et al., 2009). Specifically, for improving cognitive flexibility in individuals with ASD, virtual reality training seems a promising new option (Parsons and Mitchell, 2002). For thinking and talking about emotions, emotion regulation training such as cognitive behavioral therapy (CBT) could be useful (Scarpa and Reyes, 2011). Future clinical initiatives should focus on EF and emotion processing in order to improve QoL in ASD. This may help in the development of specific training in EF and forms of emotion regulation for young adolescents with autism, who have a high level of cognitive functioning.

Acknowledgements

The authors would like to thank Ralph Rippe and Emine Gurbuz for their contributions.

Declaration of conflicting interests

Renee R Dijkhuis is employed as a personal supervisor at Stumass.

Funding

This work was supported by the Stumass Scientific Board Foundation.

References

- Adreon D and Durocher JS (2007) Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders. *Intervention in School and Clinic* 42(5): 271–279.
- Anderson V (2001) Assessing executive functions in children: biological, psychological, and developmental considerations. *Pediatric Rehabilitation* 4(3): 119–136.
- Bachevalier J and Loveland KA (2006) The orbitofrontal-amygdala circuit and self-regulation of social-emotional behavior in autism. *Neuroscience and Biobehavioral Reviews* 30(1): 97–117.

- Barneveld PS, Swaab H, Fagel S, et al. (2014) Quality of life: a case-controlled long-term follow-up study, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood. *Comprehensive Psychiatry* 55(2): 302–310.
- Barrett KC, Fox NA, Morgan GA, et al. (2013) *Handbook of Self-Regulatory Processes in Development: New Directions and International Perspectives*. New York: Psychology Press.
- Berthoz S and Hill EL (2005) The validity of using self-reports to assess emotion regulation abilities in adults with autism spectrum disorder. *European Psychiatry* 20(3): 291–298.
- Billstedt E, Gillberg IC and Gillberg C (2005) Autism after adolescence: population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders* 35(3): 351–360.
- Billstedt E, Gillberg IC and Gillberg C (2011) Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism* 15(1): 7–20.
- Blair C and Diamond A (2008) Biological processes in prevention and intervention: The promotion of self-regulation as a means of preventing school failure. *Development and Psychopathology* 20(3): 899–911.
- Bölte S (2012) Brief report: the Social Responsiveness Scale for adults (SRS-A): Initial results in a German cohort. *Journal of Autism and Developmental Disorders* 42(9): 1998–1999.
- Booth-Butterfield M and Booth-Butterfield S (1990) Conceptualizing affect as information in communication production. *Human Communication Research* 16(4): 451–476.
- Brown TE and Landgraf JM (2010) Improvements in executive function correlate with enhanced performance and functioning and health-related quality of life: Evidence from 2 large, double-blind, randomized, placebo-controlled trials in ADHD. *Postgraduate Medicine* 122(5): 42–51.
- Burgess AF and Gutstein SE (2007) Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health* 12(2): 80–86.
- Chamberlain B, Kasari C and Rotheram-Fuller E (2007) Involvement or isolation? The social networks of children with autism in regular classrooms. *Journal of Autism and Developmental Disorders* 37(2): 230–242.
- Coben R, Linden M and Myers TE (2010) Neurofeedback for autistic spectrum disorder: A review of the literature. *Applied Psychophysiology and Biofeedback* 35(1): 83–105.
- Cohen J (2013) *Statistical Power Analysis for the Behavioral Sciences: Routledge Academic*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Constantino JN and Todd RD (2005) Intergenerational transmission of subthreshold autistic traits in the general population. *Biological Psychiatry* 57(6): 655–660.
- Corona R, Dissanayake C, Arbelle S, et al. (1998) Is affect aversive to young children with autism? Behavioral and cardiac responses to experimenter distress. *Child Development* 69(6): 1494–1502.
- Costanza R, Fisher B, Ali S, et al. (2007) Quality of life: an approach integrating opportunities, human needs, and subjective well-being. *Ecological Economics* 61(2–3): 267–276.
- De Vries M and Geurts H (2015) Influence of autism traits and executive functioning on quality of life in children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders* 45(9): 2734–2743.
- Diamond A (2013) Executive functions. *Annual Review of Psychology* 64: 135–168.
- Eaves LC and Ho HH (2008) Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders* 38(4): 739–747.
- Geurts HM, Corbett B and Solomon M (2009) The paradox of cognitive flexibility in autism. *Trends in Cognitive Sciences* 13(2): 74–82.
- Gioia GA, Isquith PK, Guy SC, et al. (2000) Behavior rating inventory of executive function. *Child Neuropsychology: A Journal on Normal and Abnormal Development in Childhood and Adolescence* 6(3): 235–238.
- Gomez CR and Baird S (2005) Identifying early indicators for autism in self-regulation difficulties. *Focus on Autism and Other Developmental Disabilities* 20(2): 106–116.
- Hill E, Berthoz S and Frith U (2004) Brief report: Cognitive processing of own emotions in individuals with autistic spectrum disorder and their relatives. *Journal of Autism and Developmental Disorders* 34(2): 229–235.
- Hill EL (2004) Executive dysfunction in autism. *Trends in Cognitive Sciences* 8(1): 26–32.
- Hofmann W, Schmeichel BJ and Baddeley AD (2012) Executive functions and self-regulation. *Trends in Cognitive Sciences* 16(3): 174–180.
- Howlin P (2000) Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism* 4(1): 63–83.
- Howlin P, Goode S, Hutton J, et al. (2004) Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry* 45(2): 212–229.
- Jahromi LB, Bryce CI and Swanson J (2013) The importance of self-regulation for the school and peer engagement of children with high-functioning autism. *Research in Autism Spectrum Disorders* 7(2): 235–246.
- Jennes-Coussens M, Magill-Evans J and Koning C (2006) The quality of life of young men with Asperger syndrome: A brief report. *Autism* 10(4): 403–414.
- Kamio Y, Inada N and Koyama T (2012) A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism* 17(1): 15–26.
- Kamp-Becker I, Schröder J, Remschmidt H, et al. (2010) Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. *Psycho-Social Medicine* 7: 1–10.
- Kapp S, Gantman A and Laugeson E (2011) Transition to adulthood for high-functioning individuals with autism spectrum disorders. In: Fernandes FDM and Amato CADLH (eds) *A Comprehensive Book on Autism Spectrum Disorders*. Rev. soc. bras. fonoaudiol. pp. 112–112.
- Kenworthy LE, Black DO, Wallace GL, et al. (2005) Disorganization: the forgotten executive dysfunction in high-functioning autism (HFA) spectrum disorders. *Developmental Neuropsychology* 28(3): 809–827.
- Kouijzer MEJ, de Moor JMH, Gerrits BJL, et al. (2009) Neurofeedback improves executive functioning in children with autism spectrum disorders. *Research in Autism Spectrum Disorders* 3(1): 145–162.

- Kuhlthau K, Orlich F, Hall TA, et al. (2010) Health-related quality of life in children with autism spectrum disorders: Results from the autism treatment network. *Journal of Autism and Developmental Disorders* 40(6): 721–729.
- Levy A and Perry A (2011) Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders* 5(4): 1271–1282.
- McGovern CW and Sigman M (2005) Continuity and change from early childhood to adolescence in autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines* 46(4): 401–408.
- Magiati I, Tay XW and Howlin P (2013) Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review* 34(1): 73–86.
- Mazefsky CA, Herrington J, Siegel M, et al. (2013) The role of emotion regulation in autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry* 52(7): 679–688.
- Morera OF, Culhane SE, Watson PJ, et al. (2005) Assessing the reliability and validity of the Bermond-Vorst Alexithymia questionnaire among U.S. Anglo and U.S. Hispanic samples. *Journal of Psychosomatic Research* 58(3): 289–298.
- Nadel J and Muir D (2005) *Emotional Development: Recent Research Advances*. New York: Oxford University Press.
- O’Hearn K, Asato M, Ordaz S, et al. (2008) Neurodevelopment and executive function in autism. *Development and Psychopathology* 20(4): 1103–1132.
- Parsons S and Mitchell P (2002) The potential of virtual reality in social skills training for people with autistic spectrum disorders. *Journal of Intellectual Disability Research* 46(5): 430–443.
- Pellicano E (2010) Individual differences in executive function and central coherence predict developmental changes in theory of mind in autism. *Developmental Psychology* 46(2): 530–544.
- Pellicano E (2012) The development of executive function in autism. *Autism Research and Treatment*. Epub ahead of print 5 July. DOI: 10.1155/2012/146132.
- Pelphrey KA, Shultz S, Hudac CM, et al. (2011) Research review: constraining heterogeneity: The social brain and its development in autism spectrum disorder. *Journal of Child Psychology and Psychiatry* 52(6): 631–644.
- Porges SW (2003) The polyvagal theory: Phylogenetic contributions to social behavior. *Physiology & Behavior* 79(3): 503–513.
- Renty JO and Roeyers H (2006) Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism* 10(5): 511–524.
- Roth RM, Isquith PK and Gioia GA (2005) *Behavior rating inventory of executive function—Adult Version (BRIEF-A)*. Psychological Assessment Resources.
- Scarpa A and Reyes NM (2011) Improving emotion regulation with CBT in young children with high functioning autism spectrum disorders: A pilot study. *Behavioural and Cognitive Psychotherapy* 39: 495–500.
- Schalock RL and Keith KD (1993) *Quality of Life Questionnaire*. Worthington, OH: IDS Publishers.
- Shattuck PT, Narendorf SC, Cooper B, et al. (2012) Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics* 129(6): 1042–1049.
- Shipman DL, Sheldrick RC and Perrin EC (2011) Quality of life in adolescents with autism spectrum disorders: Reliability and validity of self-reports. *Journal of Developmental and Behavioral Pediatrics* 32(2): 85–89.
- Van Den Bergh SFWM, Scheeren AM, Begeer S, et al. (2014) Age related differences of executive functioning problems in everyday life of children and adolescents in the autism spectrum. *Journal of Autism and Developmental Disorders* 44(8): 1959–1971.
- Van Heijst BF and Geurts HM (2014) Quality of life in autism across the lifespan: A meta-analysis. *Autism* 19(2): 158–167.
- Vaughan Van Hecke A, Lebow J, Bal E, et al. (2009) Electroencephalogram and heart rate regulation to familiar and unfamiliar people in children with autism spectrum disorders. *Child Development* 80(4): 1118–1133.
- Vorst HCM and Bermond B (2001) Validity and reliability of the Bermond–Vorst Alexithymia questionnaire. *Personality and Individual Differences* 30(3): 413–434.
- World Health Organization Quality of Life Assessment Group (WHOQOL) (1995) The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine* 41(10): 1403–1409.