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#### The Swedish Eating Assessment for Autism spectrum disorders (SWEAA)-Validation of a self-report questionnaire targeting eating disturbances within the autism spectrum

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#### Title:

The SWedish Eating Assessment for Autism spectrum disorders (SWEAA) -Validation of a self-report questionnaire targeting eating disturbances within the autism spectrum

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#### 1. Introduction

The autism spectrum disorders (ASD; e.g., autistic disorder, Asperger syndrome, and pervasive developmental disorders not otherwise specified (PDD-NOS)/autistic-like conditions) are characterised by deficits in social interaction, communication, and behavioural flexibility (American Psychiatric Association, 2000) and affect about 1% of the population (Baird et al., 2006; Gillberg, Cederlund, Lamberg, & Zeijlon, 2006). Eating disturbances are notably frequent in children and adolescents with ASD (Råstam, 2008). Eating disturbances recognised in ASD with co-existing intellectual disability (ID) are selective eating, food neophobia, pica, rumination, overeating, and polydipsia (Råstam, 2008). As described by Fodstad and Matson (2008) and reviewed by Råstam (2008), prior research has mainly focused on individuals with a concurrent ID.

Eating disturbances in ASD strongly influence the everyday life of the individual, and may have detrimental effects for the individual (Fodstad & Matson, 2008; Råstam, 2008). The presence of eating disturbances in ASD is clinically acknowledged but rarely investigated. There are different views as to whether persons with ASD are high or low in terms of body mass index (BMI). Researchers have reported extremely low values as well as no significant differences and overweight/obesity for ASD compared with other populations (Bolte, Ozkara, & Poustka, 2002; Chen, Kim, Houtrow, & Newacheck, 2010; Hebebrand et al., 1997).

Eating disorders (ED) and ASD present in children (late childhood regarding ED) as well as in teenagers and adults. The prevalence of ED is 3-5% in the general population (Hoek & Van Hoeken, 2003; Hudson, Hiripi, Harrison, Pope, & Kessler, 2007; Råstam, Gillberg, & Garton, 1989) with a female to male ratio of 10:1 (Hoek & Van Hoeken, 2003). ASDs, on the other hand, with a prevalence of 1% (Billstedt, 2007; Fernell & Gillberg, 2010), are

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overrepresented in males. The female to male ratio of ASD is 1:2-9 (Billstedt, 2007; Fernell & Gillberg, 2010). The detection and diagnosis of ED has traditionally been better in girls/women (Hoek & Van Hoeken, 2003) than in boys/men, while the opposite has been true for ASD (Fombonne, 2009). The prevalence of ED within the autism spectrum is therefore poorly investigated.

ED as possible disorders of a neurodevelopmental origin are fairly new to research. The overlap between ED and ASD is neither well known, nor well researched. Such a connection, first suggested by Gillberg (1985), has become a hot topic in the last few years (Oldershaw, Treasure, Hambrook, Tchanturia, & Schmidt, 2011; Wentz et al., 2005; Zucker et al., 2007). In addition, the same researchers are rarely involved in both fields. Research into the field of ED, specifically anorexia nervosa (AN), has focused on the presence of autistic traits in patients with AN. Today, it is generally accepted that autistic traits in childhood are risk factors for developing AN during the teen years (Wentz, Gillberg, Anckarsäter, Gillberg, & Råstam, 2009).

To our knowledge, there has been no instrument, until now, pertaining to eating disturbances in individuals with ASD and normal intelligence (a full-scale IQ of 70 or higher, hence no diagnosis of ID). This group represents the majority of individuals within the autism spectrum, which underlines the importance of further exploring this area (Fernell & Gillberg, 2010; Fombonne, 2009; Nygren et al., 2012). The purpose of this study was to develop and validate statistically a self-report questionnaire, in order to investigate eating disturbances in young adults with normal intelligence and ASD.

#### 2. Method

#### 2.1. Participants

The questionnaire was addressed to individuals with ASD aged 15 to 25 years. The participants consisted of a clinical group (CLG). The CLG was recruited from the clinical patient base of the Child Neuropsychiatry Clinic (CNC) at the Queen Silvia Children's Hospital in Gothenburg, Sweden. The CLG participants were randomly selected from a list of previous and current patients at the CNC. None of the patients in this group belonged to the first author's age group and were therefore unknown to her. Hence, we believe that the selection was randomly performed even though it was not computer-generated. The first author was instructed to collect one patient born each month, each year (years 1986 - 1995) from the patient base. Each selected individual was checked for diagnosis and intelligence level (individuals with an ID were excluded).

Out of 202 contacted patients, 57 (28%) (males: n=38; females: n=19) of the individuals responded and completed a self-report questionnaire pertaining to eating disturbances, the SWedish Eating Assessment for Autism spectrum disorders, SWEAA (see below) and constituted the CLG. According to the questionnaire, 41 patients (72%) replied that they had Asperger syndrome, four (7%) autistic disorder and 12 (21%) replied PPD-NOS. In total, 60% of the CLG participants reported a psychiatric co-morbid diagnosis; e.g., depression, attention deficit hyperactivity disorder (ADHD) or obsessive compulsive disorder (OCD).

Due to the numerous dropouts in the CLG, a dropout analysis was conducted to investigate possible significant differences between participants and abstainers in the study. The gender distribution in the CLG was the same as among the non-respondents (n=123; 67% male and 33% female), and no significant age difference was found, which ensures the external validity of the study.

A healthy comparison group (COG) consisted of a convenience sample (i.e., subjects recruited among children of colleagues, friends, etc.). In the COG, 31 (males: n=15; females: n=16) out of 56 individuals (55%) responded. The individuals of the COG were matched for age (CLG: mean age 18.7 years, SD 2.94; COG: mean age 19.5 years, SD 2.5) gender, and educational level. No significant differences were found between the CLG and the COG regarding age (p=0.19) or gender. There was a significant difference in educational level between the groups (p<0.0001), with the COG, in general, attending higher educational levels than the CLG. No significant difference was found between the CLG and the COG regarding mean BMI (CLG: mean 23.0 kg/m<sup>2</sup>, SD 4.5; COG: mean 21.7 kg/m<sup>2</sup>, SD 2.2; p=0.52). No significant difference in BMI was found between genders within the CLG or the COG (CLG: male 22.9 kg/m<sup>2</sup>; female 23.2 kg/m<sup>2</sup>; p=0.90; COG: male 21.0 kg/m<sup>2</sup>; female 22.4 kg/m<sup>2</sup>; p=0.12).

A year later, a test-retest analysis was carried out, where 40 participants from the CLG and two new patients recruited from the CNC were approached via telephone or mail and asked to participate in this second part of the validation study. As only a few participants wanted to take part in the test-retest analysis, the two new patients were asked about participation. Twenty-three patients (CLG: n=21; new patients: n=2) submitted the SWEAA on two occasions.

The study was approved by the Regional Ethical Review Board at the University of Gothenburg, Sweden (GU668-10). The individuals participated voluntarily, after giving informed consent. The participants in the initial validation process did not receive any form of compensation; however, individuals participating in the following test-retest received a compensation of 5 Euro.

#### 2.2. Procedure

A questionnaire was initially constructed by two of the authors, both with extensive research and clinical experience in the field of ED and ASD. The items in the questionnaire were based on a thorough literature review by Råstam (2008), combined with the clinical experience from several decades of two of the authors of eating disturbances in ASD. The instrument was developed as a multidimensional self-report questionnaire aimed at assessing eating behaviour in ASD (see Table 1 for the eight subscales and two single items; i.e., the final version of the measure).

The lower age limit of 15 years was chosen as it was intended that the individuals should be able to fill out the questionnaire on their own. The questionnaire contains questions addressed to persons of at least teen age; i.e., traditional ED questions pertaining to dieting, bingeing and purging behaviour, and questions about medicines and somatic and psychiatric diagnoses that may affect eating habits, appetite and weight. The age limit of 15 years was also chosen over a lower limit, as this patient group is expected to have a lower maturity level than normally developing children of the same age. However, there are no established scientific criteria supporting this choice.

The SWEAA can be seen in its final version in appendix A. The initial version of the SWEAA consisted of 81 items, divided into five subscales (deleted items can be seen in full in appendix B). The subscales referred to areas such as social situation at mealtimes, perception and behaviour, and routines regarding food and mealtimes.

The SWEAA was designed as a web-based self-report measure, with an expected completion time of 15 minutes. To ensure patient anonymity, the first author coded the individuals using

two letters and three digits. The list was only accessed by the authors and stored in a locked cupboard at the clinic. An information letter explaining the study and the anonymity of the respondents was formulated. The letter included the web address to the questionnaire, as well as the specific identification code for each participant. Each name was coded with a corresponding letter-digit code. The self-report method was chosen based on its convenience and practical advantages. The questionnaire was designed to be web-based, allowing for the respondents to submit their answers at any computer with internet connection by using the letter-digit code provided. With reference to the core psychopathology of ASD and the target age group in this study, 15-25 years, a web-based version was the primary choice. Self-report measures are used in ASD; e.g., the Autism Spectrum Quotient (AQ), developed by Baron-Cohen and co-workers (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001); however, this does not target eating and mealtime problems in this diagnostic group. The obvious downside of this approach, and also the major disadvantage of any self-report measure, is that no one is available to explain or help the respondent in any way (Brace, 2008). In an attempt to remedy this shortcoming, a pilot study including five participants was carried out prior to the general distribution, where difficult wording, ambiguous phrasing or vague questions were identified and changed.

Following recommendations by Comrey (1988), a quantitative answer scale with five numerical responses; i.e., a five-point Likert scale with a semi-neutral mid-point alternative, was chosen for the response options (never, seldom, sometimes, usually, always). The mid-point alternative was phrased "sometimes," rather than an undecided or indifferent option, as most items consider habits rather than absolute facts.

The focus of the validation process was to determine which items were appropriate to include in the questionnaire; i.e., which items possess internal consistency and are clinically relevant in terms of content validity. Another aim was to divide the items into internally valid subscales. Alongside this, the validation process intended to ensure reliability and face validity, as well as several aspects of construct validity. Content validity was achieved through clinical expertise, as the authors constructed the items of the initial questionnaire. A test-retest reliability was carried out when the questionnaire had been modified, and the questionnaire was then administrated on two occasions with a mean interval of 34 days.

An additional three subscales (not included in the validation process) were added, with items regarding specific issues within the autism symptomatology, special diets, medication and somatic and psychiatric co-morbidity. The five autism-specific items were adapted, with permission, from the already existing and validated AQ (Baron-Cohen et al., 2001). These items were added to provide additional information and add another dimension to the results. With this addition it is possible to analyse potential connections between core problems in ASD and how they might relate to different eating disturbances. It is not known today whether the severity of illness produces different levels of eating and mealtime problems. Against this background, ASD-specific questions and background variables were included, although they are not of relevance to the validity. These items were not included in the validation process as they came from a separate questionnaire. They were, however, statistically evaluated with regard to their ability to discriminate between controls and patients, hence being the items best suited for inclusion in the SWEAA. Items were chosen from the AQ to cover areas of social interaction, communication, behaviour, and attention to detail.

#### 2.3. Statistical analysis

All Statistical analyses were performed using the SAS software, version 9.2, or SPSS for Windows, version 16.0.

#### 2.3.1. Internal validation, construction of items and subscales

Exploratory factor analysis was performed in order to examine the factor structure for the present data. The scree plot was used to determine the number of non-trivial factors. The factor patterns were rotated with Varimax Rotation. Factor loadings >0.4 were considered to be of large or moderate importance and therefore considered significant (Fayers & Machin, 2001). The factor analysis, together with the internal consistency in terms of Cronbach's alpha, formed the basis on which subscales and their corresponding items were constructed. Based on this, the items were carefully evaluated and deleted if considered not to contribute to the instrument, kept in the original subscale if appropriate, or moved to another subscale and the items excluded one at a time to determine whether exclusion of the item would increase Cronbach's alpha. Together with an evaluation based on the clinical experience of the authors, ensuring content validity, the items were finally placed in the most appropriate subscales.

Cronbach's alpha was also used to measure the internal consistency (reliability) of the subscales. Within each subscale, item-internal consistency (item-convergent validity) was analysed using Pearson correlations between each item and its own scale and corrected for overlap (scale – actual item). Each item was also correlated with each of the other subscales in order to show that each item in a subscale has a higher correlation with its own subscale compared to any of the other subscales (item-discriminant validity). For each subscale, the

number and percentage of scaling success and scaling error were calculated. Descriptive statistics for both the CLG and the COG, for all subscales, were given as the mean with a 95% confidence interval (CI), the standard deviation (SD), the 25<sup>th</sup> percentile, the median, the 75<sup>th</sup> percentile, and the minimum, maximum and percentage of floor and ceiling responses.

### 2.3.2. External validation

The second step of the statistical process focused on the external validity of the questionnaire. For comparison between two groups ("Known-groups validity"), the Mann-Whitney U test was used for continuous variables, the Mantel-Haenszel Chi<sup>2</sup> test for ordered categorical variables, and Fisher's exact test for dichotomous variables. Effect Sizes (ES) were calculated as the difference between the mean of the CLG and the mean of the COG divided by the standard deviation (SD) of the COG for each subscale<sup>1</sup>.

As no other comparable instrument exists it was not possible to assess the concurrent validity of the questionnaire in this study.

#### 2.3.3. Further analyses

Additional and further analyses included comparisons between the CLG and the COG and allowed an evaluation of the clinical implications of the SWEAA. Stepwise logistic regression was used in order to determine which items and subscales discriminate best between the CLG and the COG. Significant items on the 0.01 level and significant subscales

<sup>&</sup>lt;sup>1</sup> Except for the single item *Pica* where  $SD_{CLG}$  was used because of the 0 value of the COG.

on the 0.05 level were entered into stepwise logistic regression analyses in order to determine the significantly independent predictors for ASD. The ASD-specific questions were evaluated based on their ability to differentiate between the CLG and the COG, hence being the items best suited for use in the SWEAA. BMI was calculated and compared for both groups.

#### 2.3.4. Test-retest reliability

As a final step, a test-retest was performed to assess the reliability of the SWEAA over time. The test-retest analysis will measure the repeatability and the reproducibility of the test. If the results of the test change within a short period of time, when the patient is in a stable condition, the test is not useful and has no practical value. Hence, test-retest is an important part of any validation of a new instrument. For each subscale, the test-retest analyses determined the distribution of differences between the two test occasions, the within-individual standard deviation and the intra-class correlation coefficient (ICC). The Wilcoxon Signed rank test was performed to detect systematic differences between test and retest (p values). Differences were calculated as second value minus first value. The ICC was calculated according to Shrout and Fleiss (1979), with single rating with visit as a random effect.

#### 3. Results

#### 3.1. Step 1: Internal validation, construction of items and subscales

Regarding the factor analysis, the Scree plot suggested a breakpoint of five to eight subscales for the questionnaire. During the process, all these alternatives were carefully evaluated and considered when deciding on items and their location in the subscales. The alternative with eight subscales plus two single items was chosen. Items concerning 'Simultaneous capacity'; i.e. "I find it difficult to do two things simultaneously during a meal, i.e. chewing and cutting the food," and 'Pica'; i.e., "I eat things that others consider inedible (e.g. mortar or soil)," were transferred into single-item subscales. With regard to clinical pertinence and importance, those items were kept, although they did not fit statistically into any of the subscales. The five items adopted from the AQ questionnaire were statistically evaluated with regard to their ability to differentiate between the CLG and the COG. The results suggest that three items (K1, K4 and K5) differentiated well and significantly between groups in this sample, and two (K2 and K3) did not. This was, however, reviewed and on the basis of previous research and validation of the AQ, the items were kept.

The final version of the SWEAA measure consisted of 60 items comprising eight subscales, two single items, five ASD-specific items and the demographic and medical background variables. Eleven items (B6, B7, F1, F3, F4, F5, F7, F8, F9, H1, H2) are scored in the opposite direction, as is one (K1) of the AQ items. The final structure of the SWEAA can be seen below (Table 1).

#### ---Table 1 about here---

Item-internal consistency showed good results with all correlations above 0.40 for six of the subscales and above 0.30 for all subscales (Table 2). Cronbach's alpha for each subscale showed good internal consistency, above 0.80 for six of the subscales and above 0.70 for all subscales (Table 2).

Scaling success and scaling error are illustrated in Table 2. The scaling success varied between 86% and 100%. No scaling errors were found for any subscale. One item, "I prefer certain food, depending on the colour of the food," from the *Eating behaviour* subscale, was

shown to be a "probable scaling error," due to the higher correlation with other subscales than with its own subscale. It was not, however, a case of "a definite scaling error," as the correlation with other subscales was not significantly higher than with its own subscale. The item-discriminant validity showed acceptable values (Table 2).

#### --- Table 2 about here ---

The mean of the items for each subscale was calculated (response alternatives numbered as follows; 1: never, 2: seldom, 3: sometimes, 4: usually, 5: always). The mean was then transformed into a scale from 0 to 100, where 0 is equivalent to the lowest and 100 the highest possible answer on all items. Most modern questionnaires, such as The Short Form Health Survey (SF-36) (Ware & Sherbourne, 1992) use this type of scaling as it creates an easily interpreted scale. The lowest scores were attained for Pica, where the majority of participants answered "never" or "seldom". The remaining subscales showed high levels of dispersion, including answers at the high end of the scale ("often" and "always"). The *Social situation at mealtime* subscale had the highest scores, with all the participants in the CLG indicating answers corresponding to deviant eating behaviour; i.e., no one responded with the lowest (least deviant) option in this group.

### 3.2. Step 2: External validation

Known-groups validity is presented together with the effect sizes (ES) (Table 3). Significant differences were attained for the *Mealtime surroundings*, *Social situation at mealtime* and *Simultaneous capacity* subscales. The subscales on which significant differences were found between the CLG and the COG were accompanied by ES ranging from 0.6 - 2.7. Table 3 also shows descriptive statistics in terms of the  $25^{\text{th}}$  and  $75^{\text{th}}$  percentile, and floor and ceiling values for the CLG and the COG.

#### ---Table 3 about here---

In the CLG, significant negative correlations were found for BMI and the subscales *Eating behaviour* ( $r_s$ =-0.35, p=0.01) and BMI and *Social situation at mealtime* ( $r_s$ =-0.39, p=0.004); i.e., the higher the scores on these subscales, the lower the BMI.

3.3. Step 3: Further analyses, group comparisons and clinical implications

The following items differed significantly (p<0.01) between the CLG and the COG: "*I find it difficult to do two things simultaneously during a meal, e.g. chewing and cutting the food*" (p=0.0055), "*I adapt my behaviour to others who sit around the table (e.g. table manners, conversation*)" (p=0.0025), "*I like company around a meal*" (p=0.0005), "*I talk during the meal*" (p=0.0012), "*I say if I think the food is good (when I am invited for a meal*)" (p=0.0006), "*I thank people for the food (when I have been invited for a meal*)" (p=0.0019), "*I leave the table as soon as the food is eaten*" (p<0.0001), "*I have good table manners*" (p=0.0027). The results from the stepwise logistic regression, where these variables were entered, are presented in Table 4.

### ---Table 4 about here---

#### 3.4. Step 4: Test-retest

The mean time between the two occasions for the test-retest was 34.0 days (median: 28 days, SD: 16.7 days). The test-retest reliability over a four-week period, in terms of the distribution of differences between the occasions, the within-individual SD and the ICC, and systematic changes are presented for the subscales in Table 5.

---Table 5 about here---

The mean ICC for all subscales was 0.860, which is considered good agreement (Altman, 1991).

For the two single items, *Simultaneous Capacity* and *Pica*, the weighted kappa was 0.763 and 0.657, respectively, and the percentage agreement was 87% and 96%.

Due to the variance in days between the two occasions, correlations were made between the number of days and the difference in response. A longer time between occasions could not explain the somewhat large individual SD; for example, for the *Purchase of food* subscale.

#### 4. Discussion

The present study aimed to develop and statistically validate an instrument for the investigation of eating and mealtime problems in individuals with ASD and normal intelligence. The final version of the measure, the SWEAA, indicates in many aspects acceptable to high levels of validity and reliability. An extensive validity and reliability test with numerous analyses has been carried out. The internal consistency results have shown high values, indicating coherent subscales. The instrument has also shown the ability to differentiate between the CLG and the COG in areas closely linked to autism spectrum symptomatology; e.g., Social situation at mealtime. The test-retest analysis indicates a well-functioning instrument over time for the majority of the subscales.

#### 4.1. Internal validity

During the development of the questionnaire the aim was to create subscales with as high internal consistency as possible using Cronbach's alpha and clinical evaluation. The instrument has indicated good reliability, in terms of internal consistency (Field, 2009; Kline, 2000; Nunnally & Bernstein, 1994). Using factor analysis, the initial version of the

questionnaire was shortened from 81 to 60 items, which is considered an appropriate number (Rubenowitz, 1983).

Regarding convergent validity, the values represented subscales with well-correlated items, resulting in content validity (de Lauzon et al., 2004; Nunnally & Bernstein, 1994). Values of item-discriminant validity should be lower than item-internal consistency, which means that every item is significantly better correlated with its own subscale than with any of the other subscales. This was found for all subscales in the questionnaire and content validity in terms of discriminatory validity was thus achieved. To further confirm the construct validity of each subscale, inter-item correlations were made. These values showed a moderate to strong relationship within subscales between items (de Lauzon et al., 2004; Jayasekara, Rajapaksa, & Bredart, 2008).

All individuals in the CLG indicated problems on each item of the *Social situation at mealtime* scale (i.e., never rated "never correct" or, for reversed items, "always correct"). With regard to the core psychopathology of ASD, this was expected, as difficulty of social interaction is a key feature (Wing, 1981a). For the *Pica* subscale, on the other hand, 96.5% of the CLG participants reported that they never engage in eating inedible things. This finding was likely due to pica being more common in patients with concurrent ID (Provost, Crowe, Osbourn, McClain, & Skipper, 2010; Råstam, 2008).

The two items from the AQ questionnaire that did not differentiate significantly between the groups in this study were kept due to clinical relevance and results from other research reports (Kloosterman, Keefer, Kelley, Summerfeldt, & Parker, 2011) where those specific items were found to possess acceptable levels of validity to be kept in the AQ.

#### 4.2. External validity

A significant difference between the CLG and the COG was noticed for the subscales *Mealtime surroundings, Social situation at mealtime* and *Simultaneous capacity*, suggesting these three subscales to be the main discriminators between ASD and non-ASD. When looking at the ability to detect differences between groups (Fayers & Machin, 2001), the overall results showed greater variation and a larger number of response alternatives associated with deviant responses for the CLG compared to the COG, thus confirming a higher presence of eating disturbances within the autism spectrum.

For *Social situation at mealtime* and *Simultaneous capacity*, the ES indicated a very high effect for those subscales. High values were also attained for several of the other subscales, indicating a difference between the CLG and the COG regarding most subscales. The *Social situation at mealtime* subscale attained a low p value alongside a high ES, hence underlining the importance of this area and the strong relationship with ASD. The questionnaire's ability to detect those differences is aligned with the core psychopathology of ASD (Lord, Rutter, DiLavore, & Risi, 2008; Råstam, 2008; Schreck, Williams, & Smith, 2004). The statistical analyses suggest certain areas of particular difficulty to individuals with ASD, which gives an indication of what eating and mealtime problems are most likely to occur for individuals in this group.

The single item, Simultaneous capacity, and the subscale, Social situation at mealtime, were determined through logistic regression analyses, as possessing, indeed, the strongest discriminatory power and the greatest sensitivity in distinguishing between a healthy comparison group and those with ASD. The individual items selected through logistic regression analysis both belonged to the *Social situation at mealtime* subscale. This also

indicates the impact of social skills on mealtime situations in individuals with ASD. The SWEAA is able to discriminate well between comparison cases and ASD in areas closely linked to the ASD core psychopathology, hence possessing known-groups validity.

#### 4.3. Test-retest

The test-retest analysis showed good reliability, except for the subscale *Hunger/Satiety*. A possible explanation of the poor results for the *Hunger/Satiety* subscale was the fact that the items in this subscale were somewhat vague and may, for the ASD patient group, refer to the current state and not the state of hunger or satiety in general. The *Hunger/Satiety* subscale was kept due to face validity. The test-retest was only carried out on a limited number of persons, which also contributed to the retention of the subscale, hence allowing for future modifications when tested on larger groups. Although the test-retest revealed a difference between occasions for *Social situation at mealtime*, this subscale was considered suitable for the SWEAA as it had acceptable within-individual SD values and only a small difference in points between occasions.

#### 4.4. Comorbidity - ED and NPD

Research into the field of ED has recently reported on the presence of autistic traits in a subgroup of individuals with AN. It is generally accepted today that autistic traits during childhood is a risk factor for developing AN during adolescence (Wentz et al., 2009). With regard to the discussion of an overlap between ASD and ED, a near-significant difference was found in responses between the CLG and the COG for the subscale *Other behaviour associated with disturbed eating*, which includes items targeting behaviour common in ED (i.e., purging, dieting, fasting). Overall, however, the eating and mealtime problems most strongly represented by those with ASD were related to social situations, simultaneous

capacity and eating behaviour (e.g., selective eating). The affirmation of selective eating as one of the problem areas detected by SWEAA confirms this as a problem also for those with ASD and normal IQ. Selective eating may have severe implications, both for the individual in terms of health but also for the caregiver burden. However, the near-significance found for *Other behaviour associated with disturbed eating*, on a group level, indicates that individuals with ASD have these eating disturbances to a greater extent than healthy comparison cases, although perhaps not to the level seen in ED.

#### 4.5. Limitations and methodological reflections

The majority of the CLG participants in this study were males. This is in concordance with the sex ratio in epidemiological ASD research (Anello et al., 2009). The majority of CLG responses were from participants with Asperger syndrome. This can be explained by the fact that one of the inclusion criteria for participation in the study was an IQ level within the normal range and individuals with Asperger syndrome often have IQ above 70 (Gillberg & Gillberg, 1989; Wing, 1981b). Despite the large number of participants who were contacted, the response frequency was only 28%, which may have biased the results. Difficulty of planning and taking initiatives are impairments commonly found among those with ASD (Geurts, Verte, Oosterlaan, Roeyers, & Sergeant, 2004); hence, only the motivated participants and those with lesser deficits in this area may be inclined to respond. In the present study, the sample size was small and clinic-based. As with any study relying on voluntary participation, it was not possible to control for who actually decided to submit the questionnaire. Did it appeal to those with or without certain problems? Were, for example, those with depression more inclined to respond than those without? Results from the drop-out analysis in this study and the literature on comorbidity (Anckarsäter et al., 2006; Stewart,

Barnard, Pearson, Hasan, & O'Brien, 2006) indicate no reasons to suspect biased results because of age, gender or comorbid depression and/or ADHD.

Another limitation of the study was the fact that IQ levels in the CLG were not measured in the study but taken from medical records. The participants were included if their IQ was above the limit for normal intelligence (IQ 70 or above). All participants in the CLG had been classified as having normal intelligence based upon psychometric assessments (the Wechsler scales) at the CNC. All subjects in the CLG had been diagnosed with ASD according to the DSM-IV criteria but the severity of the ASD was not assessed in the present study. There was a significant difference in educational level between the groups (p<0.0001), with the COG, in general, attending higher educational levels than the CLG. IQ was not assessed in the COG, which is a shortcoming of the present study. One may surmise that the higher educational level mirrors a higher mean IQ in the COG compared with the CLG but it may also reflect the disability that characterises the CLG. Future research needs to explore a possible relationship between IQ and eating disturbances in ASD.

A possible limitation regarding the test-retest analysis was that most of the participants had completed the SWEAA on a previous occasion more than a year before the test-retest period. However, the test-retest reliability was assessed more than a year after the initial validation, with a mean interval of 34 days. Remembering the entire questionnaire is therefore no believed to be an issue that would effect the results of the test-retest.

#### 5. Conclusion

The SWEAA is the first instrument pertaining to eating and mealtime problems in individuals with ASD without an ID. The fact that SWEAA has been developed and validated is of great importance, as the majority of ASD patients have normal intelligence. This initial validity and reliability testing of SWEAA has showed promising results. It is, however, important and desirable that the SWEAA be further used to assure its validity. Eating disturbances are a common but overlooked problem in ASD. With SWEAA it is possible to detect and explore the scope of this problem, both in a research context and clinically. Individuals with ASD, their caregivers and relatives have the possibility to gain knowledge and a larger understanding of one of the most common behavioural problems in ASD, as well as of the extent and frequency of the problem. The SWEAA instrument will also give knowledge and insight to researchers and clinicians about the nature of eating disturbances present in this diagnosis group. In addition, SWEAA also raises the awareness about eating disturbances in order to create possibilities for developing treatment strategies and the clinical care of these patients. The authors gratefully acknowledge the young adults who participated. Independent statistical analysis was performed by Nils-Gunnar Pehrsson. This work was supported by the Wilhelm and Martina Lundgren Foundation. Parts of the manuscript have been presented at Eating Disorders 2011, London, UK, 2011, and the Eating Disorders Research Society's 17<sup>th</sup> Annual Meeting, Edinburgh, UK, 2011.

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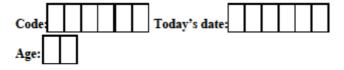
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# 8. Appendices

Appendix A: The SWedish Eating Assessment for Autism spectrum disorders (SWEAA) p. 26-31.

Appendix B: Deleted items p.32.

Appendix A: The SWedish Eating Assessment for Autism spectrum disorders (SWEAA)



Tick one option per line:

Girl/woman Boy/man I live alone I live together with other people

I go to: \_\_junior high school \_\_\_high school \_\_\_folk high school \_\_\_ college/university \_\_\_do not study

Tick one or multiple options:

I have completed: I middle school junior high school high school folk high school college/university

#### Tick the option that is most appropriate:

A	never correct	seldom correct	sometimes correct	usually correct	always correct
<ol> <li>I am plagued by food smells, e.g. I must leave the room or the meal due to the smell</li> </ol>					
2. I am over sensitive to certain flavours					
3. I find it difficult to tell what the food tastes like					
4. I am sensitive to the food's special texture					
<ol> <li>I prefer that the food has a smooth texture, as e.g. puree</li> </ol>					
<ol><li>I find it difficult to eat dishes where several ingredients are mixed, e.g. stews</li></ol>					
7. I am disturbed by the sound of when I chew certain food, e.g. Swedish cracker					
8. I am disturbed by the sounds others make when eating					
9. I am disturbed by other people talking while I am eating					
10. It is important that the food is sorted on the plate					
<ol> <li>I eat the food on the plate in a certain order (e.g. first meat, then potatoes)</li> </ol>					

В	never correct	seldom correct	sometimes correct	usually correct	always correct
1. I find it difficult to chew					
2. I am drooling during the meal					
<ol> <li>I get food around the mouth while I am eating</li> </ol>					
4. I find it difficult to swallow					
5. I spill when I eat					
6. I have good table manners					
7. I drink out of a glass without spilling					
с					
<ol> <li>I buy groceries from a special supermarket/business chain</li> </ol>					
2. My food must be of a certain brand					
3. If I buy food with someone else, I want to check what goods are purchased					
D					
<ol> <li>I prefer certain food depending on the colour of the food</li> </ol>					
2. I eat the same food every day					
3. I avoid trying new food/new dishes					
4. I only eat a limited menu, maximum of 10 dishes					
5. I eat smaller amounts of food than others					
6. I drink excessive fluids					
E					
<ol> <li>I require the glass, plate and cutlery to be placed in a certain way, different from standard table setting</li> </ol>					
2. I find it difficult to change seats at the dinner table					
3. I have certain rituals around meal					

	never correct	seldom correct	sometimes correct	usually correct	always correct
4. I get outbursts at the dinner table					
5. I whine at the dinner table					
<ol> <li>I find it difficult to eat at school/ workplace/activity centre or similar</li> </ol>					
7. I find it difficult to eat with relatives					
8. I find it difficult to eat with friends					
9. I find it difficult to eat in the café					
10. I find it difficult to eat in a restaurant					
<ol> <li>I find it difficult to eat when I am abroad</li> </ol>					
F					
1. I eat together with the one/ones I live with					
2. I eat in my bedroom					
<ol> <li>I adapt my behaviour to others who sit around the table (e.g. table manners, conversation)</li> </ol>					
4. I like company around a meal					
5. I talk during the meal					
<ol><li>I look down at my food most of the time during the meal</li></ol>					
<ol><li>I say if I think the food is good (when I am invited for a meal)</li></ol>					
8. I thank people for the food (when I have been invited for a meal)					
9. I eat with a knife and fork					
10. I leave the table as soon as the food is eaten					

G	never correct	seldom correct	sometimes correct	usually correct	always correct
1. I induce vomiting after meals					
2. I use diuretics					
3. I use diet pills					
4. I diet even if other people think I am too thin					
5. I fast					
<ol> <li>I am replacing meals with nutritional drinks/powder</li> </ol>					
7. It is important that one person (the same person) prepares my food					
8. I refuse to eat					
Н					
l. I feel when I am hungry					
2. I feel when I am full					
Ι					
<ol> <li>I find it difficult to do two things simultaneously during a meal, e.g. chewing and cutting the food</li> </ol>					
J					
<ol> <li>I eat things that others consider inedible (e.g. mortar or soil)</li> </ol>					
K					
1. I prefer to do things with others rather than on my own					
2. I prefer to do things the same way over and over again					
3. I tend to notice details that others do not					
<ol> <li>I frequently find that I don't know how to keep a conversation going</li> </ol>					
<ol> <li>I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.)</li> </ol>					

L L1. I am on a diet because of the following illness:	Yes	No	
a) Diabetes type I			
b) Diabetes type II			
c) Gluten intolerance			
d) Lactose intolerance			
e) Other food intolerance			
f) Other, what:			
L2. I am on a diet because I am:	Yes	No	
a) Overweight			
b) Underweight			
L3. I avoid eating:	Yes	No	
a) Dairy products			
b) Beef and pork (e.g. steaks,			
hamburgers or pork chops)			
c) Poultry (e.g. chicken)	_	_	
d) Fish and seafood			
e) Vegetables			
f) Fruit			
g) Other, what:			
M M1. I have received any of the following diagnoses	Yes	No	
a) ADHD			
b) Asperger's syndrome			

c) Autism/autistic syndrome

		Yes	No	
d) Autistic like condition/ atypical a	atism			
e) Tourette's syndrome				
f) Obsessive compulsive disorder (O	CD)			
g) Anorexia nervosa				
h) Bulimia nervosa				
i) Other eating disorder e.g. binge eating disorder				
j) Depression				
k) Other psychiatric disorder, what:				
l) Hyperthyroidism				
m) Diabetes type I				
n) Diabetes type II				
o) Gluten intolerance				
p) Lactose intolerance				
q) Other food intolerance, what:				
r) Bowel disease, what:				
M2. I am treated with any of the fo	ollowing medications	Yes	No	
a) Growth hormone				
b) "Precocious puberty prevention" Decapeptyl, Suprefact, Procren)	(e.g.			
<ul> <li>c) "Antidepressants" (e.g. Fluoxetin Prozac, Sertralin, Zoloft, Citalopram Cipramil)</li> </ul>				
d) "ADHD-medication" (e.g. Conce Ritalin or Strattera)	rta,			
e) Neuroleptics (e.g. Risperidon, Ris Olanzapin, Zyprexa, Seroquel, Abili				
f) Other, what:				

A2. I have reduced sensitivity to food smells.

A8. I eat food so hot that I burn myself.

A9. I do not reheat food that is intended to be eaten hot.

A19. I find it hard to suck through a straw.

B5. I eat raw meat.

B6. I eat frozen food without defrosting it first.

C8. I have cravings for sugar.

C9. I have cravings for carbohydrates (e.g. pasta, bread, potatoes).

C10. I use salt more than others.

C11. I season my food more than others.

C13. I ruminate on food (=regurgitate and re-chew food).

C15. I drink too little.

D5. I eat at the dining table.

D6. I eat in front of the TV.

D17. I utter unacceptable sounds at the dining table (e.g. burps, loud yawning or sneezing).

D21. I eat exceptionally fast.

D22. I eat exceptionally slow.

E1. I am constipated.

E2. I work out more than 1 hour per day.

E4. I use laxatives.

E5. I use clysters.

E8. I binge eat (i.e. during an episode I consume an amount of food that is most definitely larger than what most people would eat in that time frame or under those circumstances, and I feel I lose control over how much I eat during that episode).

# **Table 1**. Subscales and single items, according to the SWEAA after validation

Subscales
A. Perception
<b>B</b> . Motor control
C. Purchase of food
<b>D</b> . Eating behaviour
E. Mealtime surroundings
<b>F</b> . Social situation at mealtime
G. Other behaviour associated
with disturbed eating
H. Hunger/Satiety
Single items
I. Simultaneous capacity
J. Pica

Subscale	Items per scale	Item- Convergent validity	Item- Discriminant validity	Scaling success	Scaling error	Reliability (Cronbach's α)
Α	11	0.37	0.01	68/77 (88%)	0/77 (0%)	0.87
В	7	0.44	0.01	46/49 (94%)	0/49 (0%)	0.81
С	3	0.62	0.02	21/21 (100%)	0/21 (0%)	0.81
D	6	0.34	0.05	36/42 (86%)	0/42 (0%)	0.76
Е	11	0.47	0.05	71/77 (92%)	0/77 (0%)	0.92
F	10	0.44	0.01	69/70 (99%)	0/70 (0%)	0.87
G	8	0.41	0.01	56/56 (100%)	0/56 (0%)	0.88
Н	2	0.57	0.01	14/14 (100%)	0/14 (0%)	0.73

**Table 2.** Item scaling tests: item-internal consistency, item-discriminant and convergent validity and reliability

Item-Convergent validity: Item-Internal Consistency, correlation between each item and its scale corrected for overlap

Item-discriminant validity: correlations between the items within the subscale and with other subscales

Scaling success: number of convergent correlations (with own subscale) significantly higher than discriminant correlations (other subscales) / the total number of correlations (in brackets, scaling success rate as a percentage)

Scaling error: number of correlations significantly higher with other subscale than with own subscale (in brackets, scaling error rate as a percentage).

- A Perception
- B Motor control
- C Purchase of food
- D Eating behaviour
- E Mealtime surroundings
- F Social situation at mealtime
- G Other behaviours associated with disturbed eating
- H Hunger/satiety

Variable	Clinical group	Comparison group	P value	Effect
	(n=57)	(n=31)		Size
Perception	22.2 (18.2)	13.9 (9.6)		
	20.5 (0.0; 61.4)	11.4 (0; 36.4)	0.079	0.86
	n=57	n=31		
	25 <sup>th</sup> : 6.82, 75 <sup>th</sup> : 38.6	25 <sup>th</sup> : 6.82, 75 <sup>th</sup> : 18.2		
	Floor n (%): 7 (12.3%)	Floor n (%): 3 (9.7%)		
	Ceiling n (%): 0 (0%)	Ceiling n (%): 0 (0%)		
Motor control	12.1 (12.7)	8.53 (8.13)		
	7.1 (0; 67.9)	7.14 (0; 32.1)	0.29	0.44
	n=57	n=31		
	25 <sup>th</sup> : 3.57, 75 <sup>th</sup> : 17.9	25 <sup>th</sup> : 3.57, 75 <sup>th</sup> : 14.3		
	Floor n (%): 12 (21.1%)	Floor n (%): 6 (19.4%)		
	Ceiling n (%): 0 (0%)	Ceiling n (%): 0 (0%)		
Purchase of	20.2 (25.1)	18.8 (18.5)		
food	8.3 (0; 100)	16.7 (0; 58.3)	0.75	0.08
	n=56	n=31		
	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 33.3	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 25.0		
	Floor n (%): 23 (41.1%)	Floor n (%): 10 (32.3%)		
	Ceiling n (%):1 (1.79%)	Ceiling n (%): 0 (0%)		
Eating	19.3 (19.0)	13.3 (11.3)		
behaviour	12.5 (0; 80.0)	12.5 (0; 54.2)	0.38	0.32
	n=57	n=31		

 Table 3. Comparisons between the clinical group and the comparison group

	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 29.2	25 <sup>th</sup> : 8.33, 75 <sup>th</sup> : 16.7		
	Floor n (%): 16 (28.1%)	Floor n (%): 3 (9.7%)		
	Ceiling n (%): 0 (0%)	Ceiling n (%): 0 (0%)		
Mealtime	15.2 (18.1)	6.52 (8.08)		
surroundings	11.4 (0; 88.6)	4.55 (0; 36.4)	0.017*	0.60
	n=57	n=31		
	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 22.7	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 11.4		
	Floor n (%): 15 (26.3%)	Floor n (%): 10 (32.3%)		
	Ceiling n (%): 0 (0%)	Ceiling n (%): 0 (0%)		
Social situation	29.8 (18.1)	15.1 (9.5)		
at mealtime	25.0 (2.5; 92.5)	15.0 (0; 45)	<0.001***	1.55
	n=57	n=31		
	25 <sup>th</sup> : 17.5, 75 <sup>th</sup> : 40.0	25 <sup>th</sup> : 7.50, 75 <sup>th</sup> : 22.5		
	Floor n (%): 0 (0%)	Floor n (%): 1 (3.2%)		
	Ceiling n (%): 0 (0%)	Ceiling n (%): 0 (0%)		
Other	4.45 (9.79)	1.79 (3.81)		
behaviour associated with	0 (0; 68.8)	0 (0; 17.9)	0.053	0.70
disturbed eating	n=57	n=31		
	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 6.25	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 3.13		
	Floor n (%): 30 (52.6%)	Floor n (%): 23 (74.2%)		
	Ceiling n (%): 0 (0%)	Ceiling n (%): 0 (0%)		
Hunger/satiety	24.6 (24.2)	17.3 (20.6)		

	25.0 (0; 87.5)	12.5 (0; 100)	0.17	0.35
	n=57	n=31		
	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 37.5	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 25.0		
	Floor n (%): 17 (29.8%)	Floor n (%): 11 (35.5%)		
	Ceiling n (%): 0 (0%)	Ceiling n (%): 1 (3.2%)		
Pica	0.88 (4.64)	0 (0)		
	0 (0; 25.0)	0 (0; 0)	0.30	0.19
	n=57	n=31		
	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 0.0	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 0.0		
	Floor n (%): 55 (96.5%)	Floor n (%): 31 (100%)		
	Ceiling n (%): 0 (0%)	Ceiling n (%): 0 (0%)		
Simultaneous	12.9 (21.8)	0.81 (4.49)		
capacity	0 (0; 100)	0 (0; 25)	< 0.001***	2.70
	n=56	n=31		
	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 25	25 <sup>th</sup> : 0.0, 75 <sup>th</sup> : 0.0		
	Floor n (%): 36 (64.3%)	Floor n (%): 30 (96.8%)		
	Ceiling n (%): 1	Ceiling n (%): 0 (0%)		
	(1.79%)			
Mean (SD) / Media	an (Min; Max) / n= / Q1, Q	3 / Floor /Ceiling are prese	ented for the	
subscales.				

25<sup>th</sup>: percentile 25, 75<sup>th</sup>: percentile 75

\*=p<0.05, \*\*\*=p<0.001

	Adjusted Odds Ratio	Adjusted P value
	(95% CI)	
Intercept items		<0.0001
I 1. Simultaneous capacity	16.7 (1.89-147)	0.01
<b>F</b> 7. I say if I think the food	3.29 (1.41-7.64)	0.006
is good (when I am invited		
for a meal)		0.000
<b>F 10.</b> I leave the table as soon as the food is eaten	2.00 (1.20-3.35)	0.008
Intercept subscales		0.007
<b>F.</b> Social situation at	1.08 (1.03-1.14)	0.002
mealtime		
I. Simultaneous capacity	1.11 (1.02-1.20)	0.02

**Table 4**. Independent predictors from individual items and subscales to differentiate the clinical group from the comparison group

Area under the ROC curve: 0.862 for individual items

Area under the ROC curve: 0.824 for subscales

CI = Confidence Interval

	First	Second		Р	Within-	
Subscale	Measurement	Measurement	Difference	Value	ind. SD	ICC
Perception	22.7 (19.8)	21.3 (18.3)	-1.4 (6.4)	0.193	4.6	0.943
	15.9 (0.0; 75.0)	13.6 (0.0; 72.7)	-2.3 (-11.4; 13.6)			
Motor control	9.6 (13.5)	8.9 (13.3)	-0.7 (3.5)	0.484	2.5	0.967
	7.1 (0.0; 64.3)	7.1 (0.0; 64.3)	0.0 (-10.1; 3.6)			
Purchase of food	28.6 (29.1)	29.7 (29.3)	1.1 (19.8)	0.776	13.7	0.776
	8.3 (0.0; 91.7)	25.0 (0.0; 91.7)	0.0 (-50.0; 50.0)			
Eating behaviour	19.2 (21.7)	19.6 (19.8)	0.4 (8.2)	0.654	5.6	0.926
	8.3 (0.0; 70.8)	16.7 (0.0; 70.8)	0.0 (-16.7; 16.7)			
Mealtime	16.1 (23.7)	14.9 (22.4)	-1.3 (8.1)	0.203	5.7	0.939
surroundings	6.8 (0.0; 75.0)	4.5 (0.0; 77.3)	0.0 (-20.5; 20.5)			
Social situation at	30.0 (20.2)	24.5 (19.5)	-5.5 (8.1)	0.002	6.8	0.885
mealtime	25.0 (7.5; 90.0)	20.0 (0.0; 80.0)	-2.5 (-20.0; 7.5)			
Other behaviour	4.5 (8.3)	4.8 (8.0)	0.3 (3.0)	0.540	2.1	0.936
associated with	0.0 (0.0; 37.5)	0.0 (0.0; 34.4)	0.0 (-3.1; 6.3)			
disturbed eating						
Hunger/Satiety	13.6 (16.8)	25.0 (25.3)	11.4 (19.9)	0.007	16.0	0.508
	12.5 (0.0; 50.0)	25.0 (0.0; 100.0)	0.0 (-12.5; 75.0)			

**Table 5.** Test-retest analyses, distribution of differences, within-individual SD, test for systematic differences and intra-class correlation coefficient

n=23 for all categories

## SD: Standard Deviation

Data are presented as mean (SD) / median (min; max).

Within-ind SD: within-individual standard deviation.

ICC: intra-class correlation coefficient.

The ICC values correspond to 2.1