Running Head: SELF-CONCEPT OF INDIVIDUALS WITH PRADER-WILLI SYNDROME

Psychopathological Beginnings for Populations with Intellectual Disabilities: Investigating the Self-Concept of Individuals with Prader-Willi Syndrome

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Abstract

Individuals with Prader-Willi syndrome (PWS) are at risk for psychopathology due to their maladaptive behavior profile. This study investigated the self-concept of these individuals to better understand the origin and manifestation of their psychopathology. In this cross-sectional study, 128 individuals with PWS were administered semi-projective and behavioral measures to gain an introspective analysis of their self-concept. Results showed a positive correlation between age and negative statements about the physical self, and positive statements about the non-physical self. There was a negative correlation between BMI and negative self statements, where individuals with a normal weight had the highest average frequency of negative statements about the non-physical self. Thus, demographic features of individuals with PWS may predict aspects of their self-concept, which could have implications for prevention and treatment of psychopathology.

Introduction

The initial goal of this thesis was to better comprehend the cognitive and social issues behind the highly prevalent rates of co-morbid psychopathological disorders and intellectual disabilities (Dykens, 2000), and ultimately focus on a modified intervention plan for individuals with intellectual disabilities. However, upon further scrutiny of the present literature and current research, it became clear that to provide effective treatment for the psychopathological disorders of individuals with developmental disabilities, one must better understand the psychological development of these individuals, specifically in terms of their self-esteem and self-awareness. This study explores the *self-concept* of individuals with Prader-Willi Syndrome, through self-reflective measures, for the purpose of investigating the relationship between having an intellectual disability and later developing a co-morbid psychopathological disorder. Based on previous literature demonstrating the etiological differences in later behavioral and psychological patterns of individuals with Prader-Willi Syndrome, it was predicted that individuals with Prader-Willi Syndrome will differ in self-concept according to their genetic subtype, as well as other demographic factors.

Prader-Willi Syndrome

Prader-Willi Syndrome (PWS) is an intellectual disability (ID) resulting from a genetic mutation on chromosome 15. PWS typically occurs in one out of 12,000-15,000 individuals, with prevalence rates equal across both race and gender; yet it is of particular interest in this study for its behavioral phenotype (Dykens, 2000). Common characteristics of PWS include hypotonia, hypogonadism, hyperphagia, cognitive impairment, and behavior difficulties including underactivity, compulsions, stubbornness, and aggressive behavior (Dykens, 2000). As a result of these food-related (especially the excessive appetite, which manifests from hyperphagia) and behavioral problems, individuals with PWS are at a very high risk for morbid obesity (Dykens, 2000; Plesa-Skwerer et al., 2004). Individuals with PWS can weigh

more than 200% of their BMI-appropriate body weight; in fact, PWS is the most commonly known genetic cause of obesity (Napolitano et al., 2010). However, their strengths are equally important. Persons with PWS typically have IQs between 50 and 69, within the higher range for individuals with intellectual disabilities. They also show unique strengths in visual-motor tasks, such as jigsaw puzzles. In other words, individuals with PWS tend to struggle with behavior difficulties and social competency, while maintaining a higher cognitive ability relative to other individuals with intellectual disabilities (Rosner et al., 2004).

The genetic abnormality causing PWS can vary: most have a de novo paternal deletion along chromosome 15q11-13. There are two subtypes of the chromosomal abnormality involving paternal deletion, where Type I deletion encompasses a larger area of chromosome 15 than does Type II deletion (Napolitano et al., 2010). Approximately 30% have a maternal uniparental disomy of chromosome 15 (UPD), or an "imprinting center mutation" (Napolitano et al., 2010; Dykens, 2000).

Psychopathological Disorders and Developmental Disabilities

Psychopathology encompasses a spectrum of mental illnesses and disorders, from psychiatric diseases including mood disorders and psychoses to disruptive and maladaptive behavior, such as attention deficit hyperactivity disorder, anxiety, and self-injurious behavior. Individuals with developmental and intellectual disabilities often possess aberrant behaviors and personalities, poor communication and assertiveness skills, and a greater likelihood of experiencing peer rejection and failure, all of which heighten their risk of developing a psychopathological disorder (Dykens, 2000). An individual having an intellectual disability *and* a psychopathological disorder is classified as having a 'dual-diagnosis;' however, this term fails to capture both the complexity and magnitude of contributing factors, including personality profiles, social stigmatization, genetic etiology, neurological deficits and other bio-psychological features (Tremblay et al., 2010). Ultimately, about 40% of individuals with an

ID suffer from emotional and behavioral issues (Hodapp & Dykens, 2009), with prevalence rates varying, based on population-based and epidemiological samples, from 10% to 70% (Dykens, 2000).

One reason for this variability in prevalence studies is the sample diversity, which varies by IQ level, age, and cause of disability. In addition, the measures of psychopathology, which have been modified over time by instrument and diagnostic criteria, present another source of variability in prevalence studies for co-morbid psychopathology and ID. Furthermore, there exists a considerable amount of overlap between symptoms of an ID and traits of a psychopathological disorder (Dykens, 2000; Tremblay et al., 2010). Indeed, one of the most challenging issues with treating individuals with IDs who also suffer from a psychopathological disorder is *distinguishing* the disability from the mental illness (Tremblay et al., 2010). For instance, both clinicians and researchers have had difficulty assessing the boundary between anxiety disorders and the autism spectrum disorders or Williams syndrome, due to the symptom intersect of the disability and psychopathological criteria (Leyfer et al., 2006; Reaven, 2009; White et al., 2009; Rosbrook & Whittingham, 2010; White et al., 2009).

Numerous studies have examined PWS in terms of its genetic variability to uncover causal links between the behavioral phenotype of PWS and subsequent psychopathological disorders. One study, by Soni et al. (2007), found that the psychiatric illness of an individual with PWS could be described as an affective disorder. Those who had the maternal uniparental disomy (UPD) genetic subtype of chromosome 15 experienced the greatest severity of psychopathological symptoms, as compared to those with the deletion subtype. The severity reflected a greater risk of recurrence, more psychotic episodes, higher incidence and a possibly poorer response to medication with more side-effects (Soni et al., 2007). Similar studies have found analogous results, indicating that genetics may play a significant role in the prevalence of a psychiatric illness with PWS (Soni et al., 2008; Dykens & Roof, 2008; Dimitropoulos & Schultz, 2007).

Additional research further supports the idea that PWS is both a unique and complex disability in terms of psychopathology. One study examining the behavioral and emotional difficulties of children and adolescents with PWS revealed that, in comparison to other intellectual disabilities, the PWS population had the highest levels of psychopathology in terms of externalizing, internalizing, attention/delinquency, conduct, anxiety, and acute problem behaviors (Reddy & Pfeiffer, 2007). In a more recent study, researchers found significant differences in behavioral phenotype according to genetic subtype when age became a factor. For individuals with Type 1 deletion, the severity of their behavioral problems, including hyperphagia and externalizing behaviors, decreased. For those with UPD, behavioral issues, including noncompliance, obsessions, and psychotic episodes, increased in severity (Roof, Kulbaba, Deisenroth, & Dykens, 2011). Regardless of how these problem behaviors appear in individuals with PWS, they result in social difficulties, including struggles with being disliked and teased by peers (Rosner et al., 2004).

Individuals with PWS are at a particular risk for psychopathology because of the psychological and behavioral traits of their maladaptive profile, including hyperphagia, non-food obsessions and compulsions, skin-picking, temper tantrums, perseveration, stubbornness, and underactivity (Dykens, 2000). Though some scientists have certainly examined this co-morbidity, they have neglected to explore the psycho-social development and well-being of people with IDs, as possible correlates or predictors of psychopathology.

Self-Concept

The purpose of this study was to investigate specific psychological features of individuals with PWS, and ultimately to better understand their emotional well-being. One way to measure well-being is to assess the individual's development of 'self,' which progresses over time through social experience and cognitive growth (Donohue, 2008). As human beings, the development of 'self' evolves in terms of

complexity in both content and structure. The idea of 'self' is constructed through the beliefs one holds about oneself and the responses of others, otherwise defined as the 'self-concept' (Burack et al., 1998). One's self-concept is composed of self-assessments regarding attributes such as personality, skills and abilities, occupations and hobbies, and physical characteristics. Ultimately, the self-concept represents the awareness one has of the self and others, combined with the confidence one has in his or her own worth and abilities (i.e. self-awareness and self-esteem).

Typically, the development of self-concept begins with self-recognition in infancy, as demonstrated by the "rouge task" where infants (around 15 months of age) are able to recognize a mark on their nose in front of a mirror. Because this task is correlated more strongly with mental age than chronological age, self-recognition is generally delayed in children with developmental disabilities (Donohue, 2008). During preschool, typically developing children begin to acquire self-descriptions and make self-evaluations. According to Evans (1998), with age and experience, typically developing children begin to make accurate self-assessments that evolve into the 'self-esteem', and later 'self-concept.' In contrast to typically developing children, individuals with an ID tend to possess a less differentiated self-concept, as well as an inability to discriminate self-descriptions across domains (i.e. social, cognitive, and physical qualities) (Burack et al., 1998). Furthermore, many researchers have discovered that individuals with an ID are more vulnerable to developing a poor self-concept and self-esteem. These negative self-evaluations are attributed to their perceptions of their academic and social inabilities, as well as the stigmatization surrounding their ID (Napolitano et al., 2010).

Yet, mental age or intellectual impairment alone does not fully explain this atypical development of self-concept; and in fact, Festinger's social comparison theory claims that individuals who lack the cognitive ability to self-evaluate through rank and achievement are able to assess their status based on social relationships (Donohue, 2008). Thus, the emergence of self-concept relies strongly on the

individual's "social interaction[s] and development of overall sense of whether one is rejected or accepted by others" (Burack et al., 1998).

Self-Concept and Prader-Willi Syndrome

Unraveling the development of self-concept for individuals with PWS would be especially critical for understanding how individuals with IDs judge themselves, because these individuals typically have higher IQs than other individuals with IDs, but are weaker in social competency (Plesa-Skwerer et al., 2004; Rosner et al., 2004). Furthermore, due to food-seeking behaviors and hyperphagia, which can cause obesity and other health-related problems, individuals with PWS become increasingly vulnerable to acquiring a negative self-concept (Dykens et al., 2007; Napolitano et al., 2010). In fact, previous studies have already established the high risk for poor self-regard for typically developing, obese youth, especially concerning their perception of their physical appearance and their social functioning (Griffiths, Parsons, & Hill, 2010). Unfortunately, there is a higher incidence of obesity in children with IDs than children in the general population; while at the same time, there are few studies examining IDs and co-morbid obesity (Holcomb, Pufpaff, & McIntosh, 2009). The self-esteem and awareness issues that come with obesity and behavioral and social difficulties are vital to fully comprehending the self-concept of individuals with PWS.

The shortage of research examining the self-concept and well-being of individuals with IDs can be attributed to the difficulty in studying this population and the lack of necessary support required in this field of research (Hodapp & Dykens, 2009), especially in the area of positive psychology (Dykens, 2006). Fortunately, studies are beginning to emerge which focus on measurement and etiology of well-being in those with an ID. For instance, Dykens et al. (2007) utilized semi-projective tools, which assess self-perceptions through structured and open-ended tasks that allow for a wide range of responses and adaptations, to measure self-awareness in individuals with IDs, specifically PWS and Down Syndrome.

Through the "Sentence Completion and Three Wishes" tasks (or Brief Incomplete Sentences Task), these researchers were able to measure the self-perceptions of individuals with PWS and Down syndrome in areas such as global self-appraisals and social relationships (Dykens et al., 2007).

Based on previous research, the semi-projective tools should provide the greatest degree of insight into the self-concept of individuals with Prader-Willi Syndrome. In this study, introspective measures, including the Brief Incomplete Sentences and Body Image Task, as well as informant measures, including Child Behavior Checklist (CBCL) were utilized to evaluate the self-concept of approximately 130 individuals with PWS. If an accurate self-concept can be measured, then these individuals may differentiate, in terms of their self-concept (i.e. some having a more positive or negative self-regard), by gender, age, and genetic subtype of PWS. In particular, we hypothesized that subjects with PWS who have the maternal uniparental disomy genetic abnormality (UPD) would report more negative self-evaluations than individuals with the deletion subtype (Type 1 and 2).

Methods

Participants

This study was composed of 128 individuals clinically diagnosed with Prader-Willi Syndrome, all of who have been previously assessed by other research projects at Vanderbilt University. The participants ranged in age from 5 to 66 years (M=12.9, SD=10.9), 50% were female, and most had deletion subtypes. All data were previously collected for an ongoing study at Vanderbilt University's Kennedy Center. This was a retrospective study, using measures and procedures that were previously approved by the IRB.

Measures

This study utilized standardized and semi-projective measures, including demographic and introspective questionnaires as well as behavior surveys. Specifically, this study used participants'

responses on the Brief Incomplete Sentences Task and the Body Image Task. Parent reports on the Child Behavior Checklist (CBCL) were also utilized. These tools helped to reveal the self-esteem and self-awareness of the sample, as well as take into account the different backgrounds for each participant (i.e. genetic subtype, IQ, gender, age, socio-economic status).

For the purpose of this study, assessments measuring self-concept were scrutinized, including the Brief Incomplete Sentences Task and the Body Image Task. The Brief Incomplete Sentences Task was a one-page introspective survey that asked the participant to complete sentences based on the self-reflective projections (see Appendices). Examples include, "I am…", "I would like most to…", "People think that I…", and "I am best when…" Nine items, similar to these, were said aloud by the researcher in a closed room to the participant so that he could answer how he would finish the sentence. The final question on the survey asked the participant to provide three magic wishes that he would wish to come true. If the participant struggled to respond, the researcher would provide probes to help (e.g. "I would like most to…" became, "Well, what would you like most to…?"). The Body Image Task was another one-page introspective measure that displayed six silhouettes (3 males and 3 females), and asked two questions of the participant: "Which one of these pictures looks most like you…weight and size?" and "Which one is the weight and size that you would like to be?" (see Appendices). Participants would then choose among three silhouettes, depending on their gender, of varying weights and sizes. The researcher would also help to prompt the participant if he was having difficulty answering the question (e.g. "Well, which one do you wish you looked like?"). Body Dissatisfaction was then coded as the difference between these two responses.

The other measure tapped emotional and behavioral problems; specifically, the Child Behavior Checklist (CBCL) was administered to the participants' parents or guardians to complete at home. Raw scores were used in data analyses of the CBCL. In particular, three sub-domains of the CBCL were

scrutinized, including the "internalizing" and "externalizing" subscales and the total CBCL score (see Appendices). Though the assessment days were long, every member of the lab was encouraging, supportive, and patient with the participants; they would receive several breaks, including one for lunch. The lab paid for traveling and living expenses, and the participant would also receive a gift card at the end of the assessment.

Design

This study was a between-subjects and cross-sectional design. All data were gathered at single points in time for a diverse sample, whereby each individual was compared to each other. To measure the relationship between participant backgrounds and self-concept measures, this study conducted multi-variate and univariate analysis of variance. The independent factors were genetic subtype, gender, age, and BMI. Socio-economic status and IQ were not included as one of the independent factors because they were previously assessed in another study, using many of the same participants, and tested as having no effect on several results of self-concept analysis, including the Brief Incomplete Sentences Task (Dykens et al., 2007). The dependent factors were the self-concept content categories, which were coded based on the Brief Incomplete Sentences Task, the results of the Body Image Task, and the overall behavioral scores of the CBCL. Using multi-variate ANOVA where age was controlled as a covariate, the relationships between these factors were analyzed.

Procedure

Each participant was assessed in Dr. Dykens' and Elizabeth Roof's Prader-Willi syndrome lab by either a research analyst or graduate student. One work day was dedicated to each participant because of the extensive evaluations, including cognitive, neurological, and medical examinations. The measures utilized for this study were part of the comprehensive battery of evaluations.

BMI

In order to make BMI score comparisons across all ages, the sample was standardized according to the CDC federal guidelines for age and gender. All participants were categorized by one of the following BMI labels: underweight, normal weight, overweight, or obese. Participants who were 20 years or older were categorized by their BMI score; however, participants younger than 20 years were categorized according to their BMI percentile rank (see Appendices).

Coding

The Brief Incomplete Sentences Task required a coding system for data analysis. First, we did a content analysis of responses, and came up with a coding system that seemed to reflect most answers. The resulting categories included the following: Academics, Activities, Dating/Romance, Family, Food, Friends, Help Others, Idiosyncratic, Money, Music, Negative Self, Negative Physical, Objects, Occupation, Pets, Positive Self, Positive Physical, Sports, Travel, and No Response. Responses that were categorized into "negative" or "positive" descriptions were analyzed within the context of the full sentence. For example, the statement, "am thin" may appear positive; yet, if it was in response to "I wish…" (i.e. "I wish I am thin"), then this statement would be categorized as negative. More examples of how these content categories were coded can be found in the Appendices.

After content coding all qualitative measures *twice,* a second person (a graduate student of Dr. Dykens) blindly coded approximately 16% of the sample for reliability. Kappa values for all content categories ranged from 0.929 to 1.000, indicating a reliable and consistent analysis of self-concept content.

Results

Data Analysis Overview

The purpose of this study was to explore any psycho-social trends in self-concept content within the PWS population. In other words, this research investigated whether individuals with PWS varied significantly, in terms of self-concept (e.g. the Brief Incomplete Sentences Task and the Body Image Task) or in their psychological and behavioral assessments (e.g. CBCL) across *genetic subtypes, gender, age,* or *BMI*.

Using frequency analysis, the sample (N=128) showed the expected breakdown of genetic subtypes (UPD: N=56; Deletion: N=72) and gender (male: N=64; female: N=64) (see Table 1.). However, the sample did very significantly by age (*M*=15.07, *SD*=10.90) and BMI label (N=110). Of the total sample, 2.7% were underweight, 23.6% were normal weight, 20.0% were overweight, and 53.6% were obese (see Table 1.). The overall frequency of self-concept content responses was not of interest in this study, but a summary of these results can be found in Table 2. In addition, there is a summary of responses from the Body Image Task in Table 3.

Genetic Subtype and Self-Concept

Using univariate analysis of variance, where age was controlled as a covariate, no significant relationships were found between the independent variables: genetic subtype, gender, or BMI label and the dependent measures of self-concept. In other words, univariate ANOVA revealed no significant ties between the profile of the participants to their content responses from Brief Incomplete Sentences Task, responses on the Body Image Task or the Body Dissatisfaction Scale, or behavioral assessments (CBCL).

However, an independent sample t-test was conducted to investigate whether any relationship existed between genetic subtype or gender and self-concept content. As a result, there was a significant

difference in the mention of "Friends" from the Brief Incomplete Sentences Task between UPD (*M*=0.143, *SD*=0.401) and Deletion subtype (*M*=0.389, *SD*=0.832); t(126)=2.036, p=.044. According to this analysis, participants with the deletion subtype were mentioning friends more often, on average, in the Brief Incomplete Sentences Task than participants with UPD subtype (see Figure 1.). This may be the consequence of behavioral differences between genetic subtypes; yet, there were no significant findings across the behavioral measures (CBCL internalizing and externalizing subscales, and total score) or the Body Image Task responses.

An independent sample t-test was also conducted to compare gender and the self-concept content, as well as with the behavioral and body image measures. Though no significant relationships were found, one can deduce from this finding that the self-concept content is a consistent measure in its application to both genders.

Overall, these findings did not strongly support the hypothesis that genetic subtype (except for the frequency of "Friends" statements) and gender were significantly related to the self-concept of individuals with PWS.

Age and Self-Concept

Although univariate ANOVA did not reveal any significant relationships between genetic subtype, gender, or BMI label and the self-concept measures, correlational analysis demonstrated significant findings. A Pearson correlation coefficient was computed to assess the relationship between the age of participants and their self-concept responses on the Brief Incomplete Sentences Task. As a result, there was a positive correlation between age and the mentioning of "Dating/Romance", r=0.248, n=128, p=0.004. There was also a negative correlation between age and the mentioning of "Objects", r=-0.253, n=128, p=0.004, as well as a positive correlation between age and the mentioning of "Travel" in their responses to the Brief Incomplete Sentences Task, r=0.227, n=128, p=0.010. In other words, older

individuals were more likely to mention dating and travel, but less likely to mention objects than younger participants. Nevertheless, these self-concept content categories make developmental sense, and are likely age-related in most populations.

The correlational analyses also revealed a positive correlation between age and the mentioning of "Negative Physical", r=0.365, n=128, p=0.000. Therefore, as the age of participants increased, the frequency of "Negative Physical" attributes in the Brief Incomplete Sentences Task also increased. For instance, the older the participant, the more likely he would have responses similar to "I am…fat" or "I would like most to…be pretty" or "I wish…I was skinny." In addition, there was a positive correlation between age and the mentioning of "Positive Self", r=0.281, n=128, p=0.001. Thus, younger participants mentioned fewer "Positive Self" attributes as compared to older participants. Such "Positive Self" responses include "People think that I…am kind" or "I am…good." These significant correlations are displayed in Figure 2. There are also two scatter plots illustrating the relationship between age and "Negative Physical" statements (see Figure 3.) and age and "Positive Self" statements (see Figure 4.)

There were no significant correlations between age and measures of behavior (CBCL internalizing and externalizing subscales, and total score) or responses on the Body Image Task. However, these findings do support the hypothesis that the age of the individual with PWS has a significant relationship with certain aspects of self-concept content.

BMI Label and Self-Concept

The relationship between self-concept responses and BMI label was assessed using Spearman's rank order correlation. The analysis revealed that BMI level was negatively correlated with the mentioning of "Negative Self" statements (Spearman's rho=-0.254, n=110, p=0.007). A summary of this significant relationship can be found in Figure 5. A bar graph was created to further scrutinize the significant relationship between the frequency of "Negative Self" statements and participants' BMI label

(see Figure 6.). This figure demonstrated that participants with a normal-weight BMI label reported, on average, more "Negative Self" statements (e.g. "I am…bad", "People think that I…am dumb", "I wish…I was good") than individuals with other BMI labels.

To further investigate this correlation, a one-way ANOVA was conducted with BMI label and self-concept measures, including Body Image Task and behavioral report responses (CBCL internalizing and externalizing subscales, and total score). Although the F-value did not show a significant relationship between BMI label and self-concept measures, including "Negative Self" statements, the post-hoc analyses (LSD) revealed mean differences (I-J) between participants with a normal weight (I) and participants who were obese (J) for Negative Self statements (0.41199), for Positive Self statements (-0.428), and for Positive Physical statements (0.163). These mean differences were significant at the 0.05 level (see Figure 7.). In other words, participants with a normal weight said significantly more "Negative Self", fewer "Positive Self", and more "Positive Physical" statements than individuals with an obese BMI label.

Because of the drastically different group N's for BMI Label in the ANOVA, it is possible that there was simply not enough power to detect differences among all four groups. Therefore, an independent sample t-test was conducted to compare participants with a normal weight (N=26) to participants who were obese (N=59) across these 'negative' and 'positive' self-concept categories. There was a significant difference between individuals with a normal weight (M=0.615, SD=0.852) and individuals who were obese (M=0.203, SD=0.550) for the mentioning of "Negative Self" statements; t(83)=2.668, p=0.009. There was also a significant difference between individuals with a normal weight (M=0.539, SD=0.647) and individuals who were obese (M=0.966, SD=0.909) for the mentioning of "Positive Self" statements; t(83)=-2.166, p=0.033. Thus, participants with a normal weight were more likely than participants who were obese to use Negative Self statements (e.g. "I wish…I didn't have this

syndrome", but less likely to use Positive Self statements (e.g. "People think that I…am a good person"). A summary of this t-test can be found in Figure 8. These findings support this study's hypothesis that specific demographics of the PWS population, in this case BMI label, have a significant relationship with aspects of their self-concept.

Discussion

This study aimed to refine previous psychometric methods and focus on self-perception, self-esteem, and self-awareness in people with PWS. Research on how these individuals develop a self-concept can assist in our understanding of their well-being, and also help guide interventions or preventative strategies for co-morbid disorders.

The results of this study supported some of the hypotheses that demographic factors of individuals with PWS have a significant relationship with the content of their self-concept. However, the Body Image Tasks and behavioral measures (CBCL externalizing and internalizing subscales and total CBCL score) did not demonstrate any significant relation to the demographic factors of the sample.

Genetic Subtype and Social Self-Concept

Regarding major findings, analyses revealed that genetic subtype was significantly related to the frequency of "Friends" statements in the Brief Incomplete Sentences Task, whereby individuals with the Deletion subtype were more likely to mention "Friends" in their statements of self (e.g. "I would like most to…play with my friends") than individuals with the UPD subtype. These findings support the idea that different genetic subtypes are associated with different behaviors (Roof, Kulbaba, Deisenroth, & Dykens, 2011; Soni et al., 2007). And although gender did not demonstrate any significant findings, one can infer that this lack of significance with the Brief Incomplete Sentences Task and self-concept

content categorization indicate they are valid measures of self-concept, in terms of their application to both genders.

Age and Physical vs. Non-Physical Self-Concept

Critical to this discussion were the significant findings on age and self-concept. First, the age of the participant demonstrated a positive correlation with the frequency of "Negative Physical" statements, as well as a positive correlation with the frequency of "Positive Self" statements on the Brief Incomplete Sentences Task. This result indicates that individuals with PWS, as they grow older, may be more likely to think of their physical selves as negative, and at the same time, to view their personal selves as positive. Thus, younger individuals with PWS are less likely to say positive attributes about themselves (e.g. "I am…good and kind"), but also less likely to say negative statements about their physical appearance (e.g. "I am…fat and ugly"). On the other hand, older individuals with PWS are more likely to say positive statements about themselves as a person, but also more negative statements about their physical appearance.

One possible reason for this difference, as individuals get older and became more aware of their place in society, they will development a more complex and differentiated self-concept, regardless of IQ. Another possible explanation would be that as these individuals age, they are more likely to become overweight or obese and develop an awareness of their physical appearance (however, BMI label was not significantly correlated with age). However, it *is* surprising that the frequency of these negative physical statements increase, but not negative self statements. Rather, positive statements about the self increase. One reason for this unexpected finding, individuals with PWS were able to cultivate a positive self-esteem and awareness because of their supportive and nurturing environment. It would be interesting to explore further how individuals with PWS develop a positive self-esteem, while at the same time develop a negative physical self-awareness, with age.

BMI and Physical vs. Non-Physical Self-Concept

The second interesting finding was how participants' BMI label showed a significant relationship with the frequency of negative statements concerning the 'self.' This negative correlation revealed that an individual with a lower BMI would be more likely to think negatively about himself (e.g. "I am…bad"). However, this was not clear-cut, as demonstrated by the bar graph, which broke down this correlation. In actuality, it was the individuals with a normal weight BMI label who were most likely to mention negative statements about themselves. Analyses revealed that people who were a normal weight, on average, said more negative statements about their non-physical selves, fewer positive statements about their non-physical selves, but more positive statements about their physical selves than people who were obese. However, there were no significant findings between participants' BMI label and the Body Image Task or behavioral measures (CBCL).

One explanation for this finding ties into the behavioral manifestations of hyperphagia. Individuals with PWS need life-long dietary controls and supervision around food and meals. As such, because their food intake is restricted, they are "constantly hungry, never full." If they are unable to *try* to satiate themselves, due to caregiver restriction, they may be suffering more than individuals who are allowed to try and satisfy their hunger. Thus, individuals who are of a normal weight are likely restricted, which may translate into more obsessions and compulsions, leading to a higher frequency of negative statements about themselves. On the other hand, individuals who are obese are likely more able to find and consume food (despite being supervised), which could reduce distress, or obsessive or compulsive behaviors.

Based on these findings, one can infer that age and BMI label may play a significant role in the development of self in PWS, as well as the risk of acquiring a psychopathologic disorder. The importance of such study is far-reaching. In particular, previous work framed problems in those with IDs

around their cognitive impairments. This study, however, attempted to examine a more balanced perspective that went beyond IQ to examine both positive and negative views of the self. This could have implications for how to improve the lives of other vulnerable populations, such as children with other developmental and intellectual disabilities. If we can find a way to assess the psychological well-being and awareness of individuals with IDs (i.e. populations where this is a difficult feat), then we can look toward alternative strategies of promoting the lives of adults and children with IDs.

Limitations

Not unlike other studies, this research had its limitations. Only those with PWS were sampled, which makes it difficult to generalize findings to others with IDs. One way to improve the design of this study would be to include other populations with IDs. Secondly, the semi-projective tools utilized for this study are still in their infancy, and have yet to be widely used in ID populations. Thirdly, this study did not identify ways in which one can ameliorate any poor self-concept outcomes. Instead the purpose of this study was to investigate the self-esteem and self-awareness of a population with IDs; ways in which one can connect this to the development of psychopathological co-morbidity and prevention is still unclear.

Future Directions

In terms of significance, this study could be applied to psychological investigations of other populations with IDs. Because this research reflected an innovation in the methodology of 'well-being' (i.e. adapted measure for an ID), it could contribute to both disability policies and services. This study could inform researchers or disability policy makers about how to best evaluate and promote self-concept and well-being, so that these individuals have every and equal opportunity to live a fulfilling life. Regardless of the "dis-ability" label used to categorize an individual, researchers and other

individuals who work with populations with IDs can refocus their energy on contributing to their emotional happiness and psychological empowerment.

Furthermore, this study could have implications for other vulnerable populations. In other words, if one could accurately adapt the measure of self-concept to other populations, such as children in poverty or children struggling with chronic illness, one might be able to uncover the psychological well-being (as well as the likelihood of a psychopathological disorder) of at-risk, vulnerable populations worldwide.

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Tables

Table 1.

Summary of Descriptive Data of Sample Demographics

Demographics	N	*M*	*SD*
Age	128	15.0656	10.89694
BMI Label	110	3.2455	0.91055

Note. *M*=mean and *SD*=standard deviation.

Genetic Subtype	Frequency	%
Deletion	72	56.3
UPD	56	43.8

Note. Total N=128.

BMI Label	Frequency	Valid %
Underweight	3	2.7
Normal Weight	26	23.6
Overweight	22	20.0
Obese	59	53.6

Note. Total N=110.

Table 2.

Self-Concept Content Descriptive Statistics

	N	*M*	*SD*
Academics	128	0.2578	0.56466
Activities	128	2.2891	1.69368
Dating/Romance	128	0.375	0.81328
Family	128	0.6094	0.99791
Food	128	0.5312	0.97962
Friends	128	0.2812	0.68663
Help Others	128	0.1406	0.44782
Idiosyncratic	128	1.8438	1.60431
Money	128	0.125	0.39684
Music	128	0.2031	0.99098
Negative Self	128	0.3906	0.72345
Negative Physical	128	0.2813	0.74175
Objects	128	1.0469	1.50516
Occupation	128	0.3359	0.75584
Pets	128	0.8438	1.41665
Positive Self	128	0.8125	0.84881
Positive Physical	128	0.1016	0.35137
Sports	128	0.2656	0.76831
Travel	128	0.2031	0.57997
No Response	128	1.0547	2.29449

Note. *M*=mean number of mentions and *SD*=standard deviation.

Table 3.

Body Image Task Descriptive Statistics

"Which picture looks most like you?"

Body Image Picture	Frequency	Percent (%)
1	18	32.1
2	20	35.7
3	18	32.1

Note. N=56. Body Image Picture 1 was the smallest in weight and size, while Picture 2 was a little larger in weight and size, and Picture 3 was the largest in weight and size.

"Which picture do you want to look like?"

Body Image Picture	Frequency	Percent (%)
1	26	46.4
2	15	26.8
3	15	26.8

Note. N=56. Body Image Picture 1 was the smallest in weight and size, while Picture 2 was a little larger in weight and size, and Picture 3 was the largest in weight and size.

Table 3. (continued)

Body Dissatisfaction Scale

	Frequency	Percent (%)
Not Dissatisfied	12	21.4
Dissatisfied	29	51.8
Very Dissatisfied	15	26.8

Note. N=56. Body Dissatisfaction was calculated according to the difference between the participants' response to the first question ("What do you look like?") and their response to the second question ("Which picture do you wish you looked like?"). For example, if someone responded that he looked like Picture 3, but wanted to look like Picture 1, then he would be categorized as (2), "Very Dissatisfied", because that would be the greatest disparity between what the participant thinks he looks like and what he wishes to look like. If someone replied that she looked like Picture 2, but wanted to look like Picture 1, then she would be categorized as (1), "Dissatisfied", because that would be a less severe disparity between what she thinks she looks like and what she wishes to look like. If someone replied that he looked like Picture 2 and wanted to look like Picture 2, then he would be categorized as (0) or "Not Dissatisfied."

Figures

Figure 1.

Genetic Subtype and Self-Concept

Group Statistics					
	Genetic Subtype	N	*M*	*SD*	t
Friends	Deletion	72	0.3889	0.83169	2.036**
	UPD	56	0.1429	0.4013	--

Note. *M*=mean and *SD*=standard deviation. ** Significant correlation, $p<0.01$. Participants with the Deletion subtype were more likely to mention friends than individuals with the UPD subtype.

Figure 2.

Age and Self-Concept

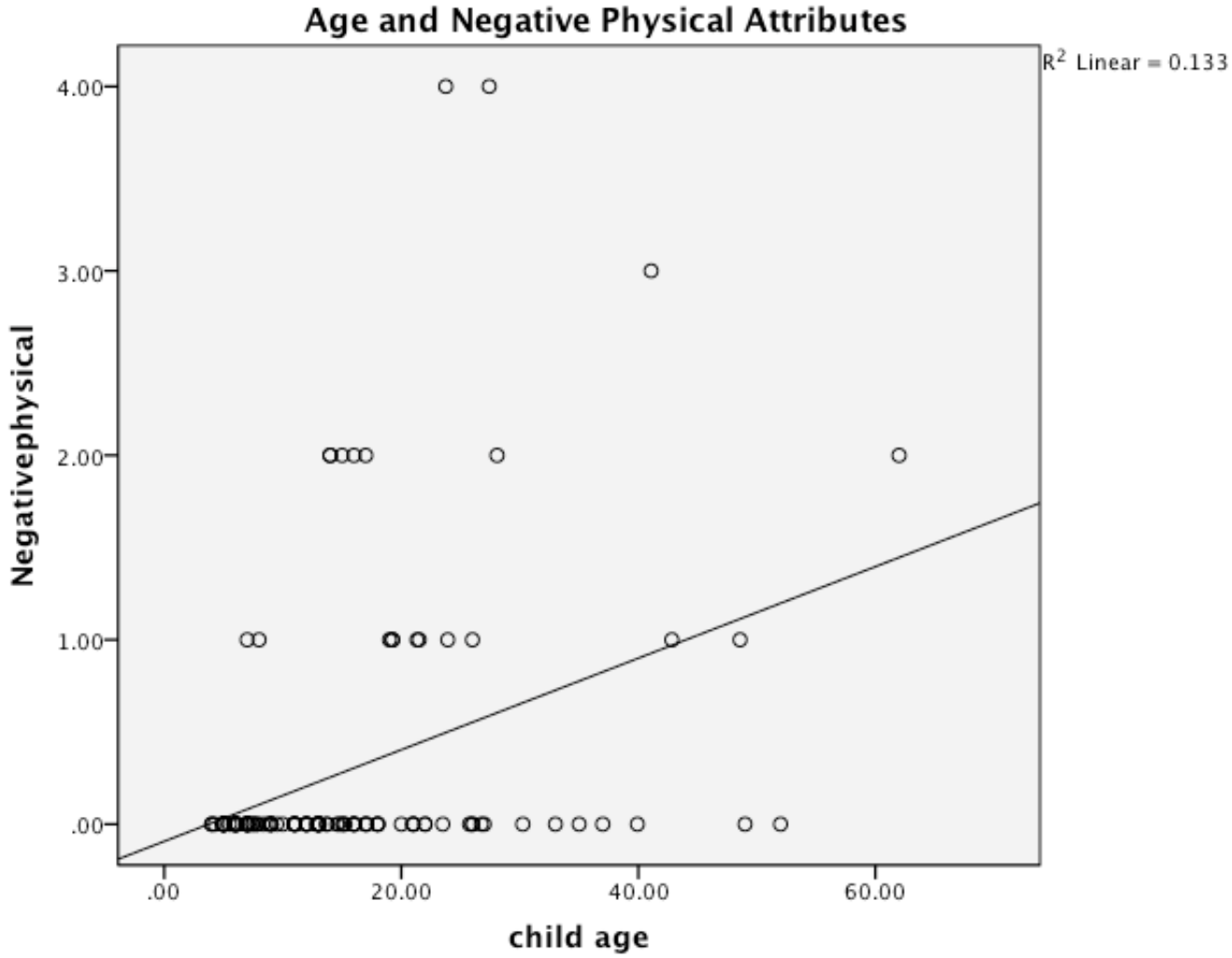
	r
Dating Romance	.255**
Objects	-.253**
Travel	.227**
Negative Physical	.365**
Positive Self	.293**

Note. N=128. The Pearson correlation (r) was conducted with Child age and self-concept content responses. Dating/Romance, Objects, Travel, Negative Physical, and Positive Self were significantly correlated with participate age.

**p<0.01.

Figure 3.

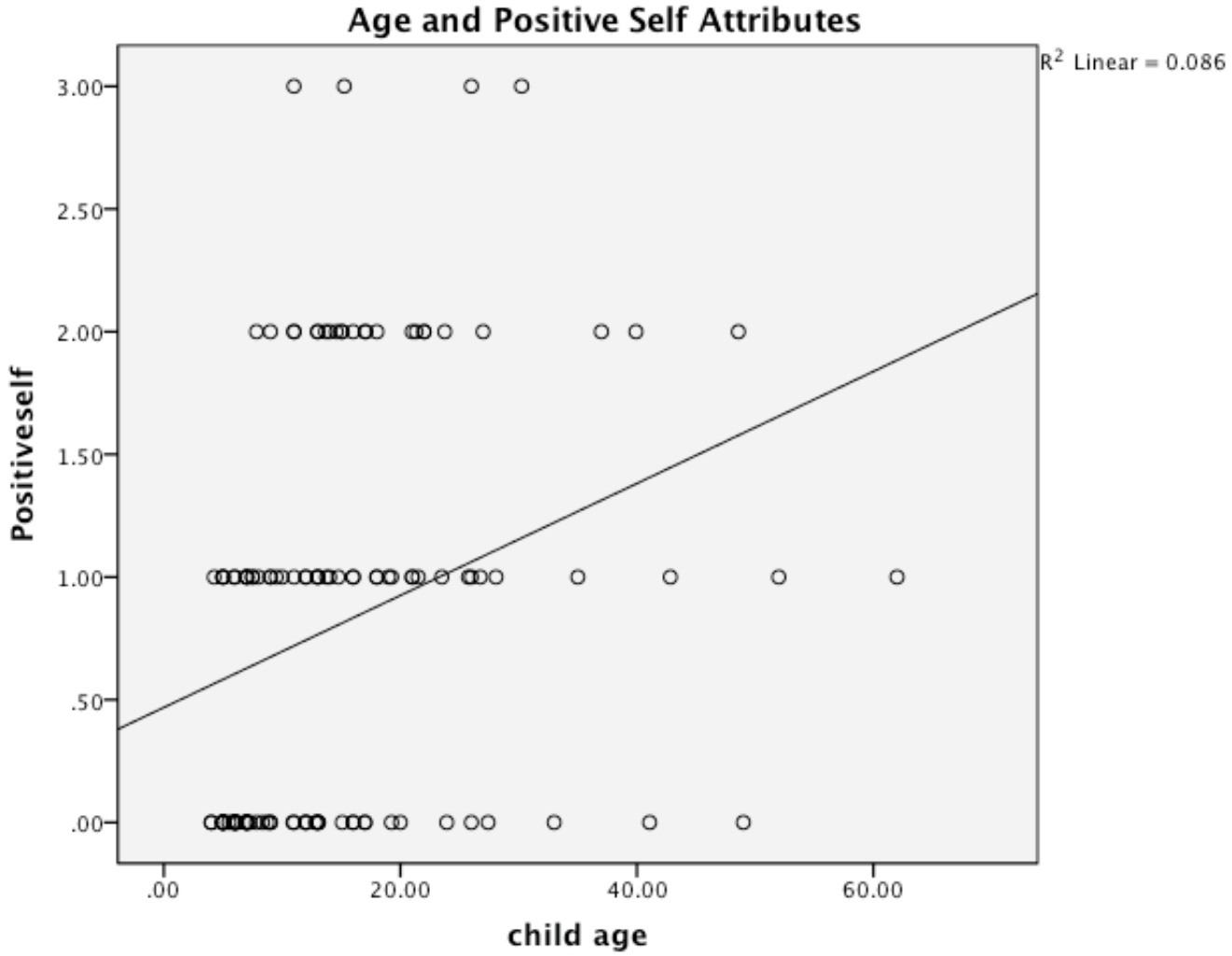
Age and Negative Physical



Note. N=128. There was a positive correlation between child age and mentioning "Negative Physical" attributes in the self-concept measure. The older the participant, the higher the frequency of "Negative Physical" statements (e.g. "I am…fat" or "People think that I…am ugly").

Figure 4.

Age and Positive Self



Note. N=128. There was a positive correlation between child age and mentioning "Positive Self" attributes in the self-concept measure. The older the participant, the higher the frequency of "Positive Self" statements (e.g. "I am…good" or "People think that I…am nice").

Figure 5.

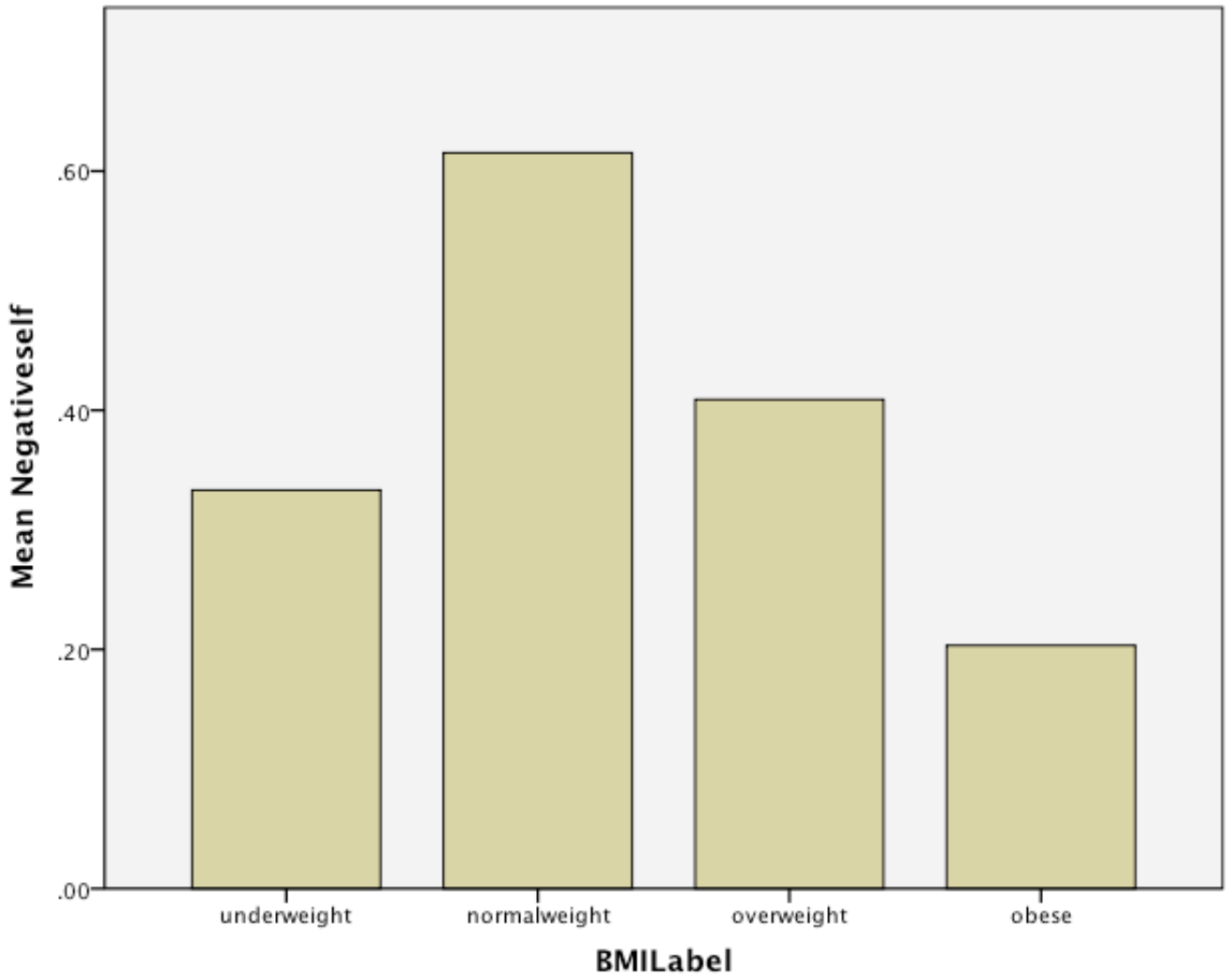
BMI Label and Negative Self

	rho
Negative Self	-.254**

Note. N=110. Spearman's rho (rho) correlation was conducted with BMI Label and self-concept content responses. BMI Label was significantly correlated with Negative Self statements at **p<0.01.

Figure 6.

BMI Label and Mean Number of Negative Self Statements



Note. N=110. There was a negative correlation between BMI label and mentioning "Negative Self" attributes in the self-concept measure (e.g. "I am…bad" or "I wish that I…didn't have PWS"). This bar graph demonstrates that it was individuals with a normal weight BMI who mentioned more "Negative Self" statements, on average, than the participants with other BMI labels.

Figure 7.

BMI Label One-Way ANOVA

	Normal Weight		Overweight		Obese		F
	M	*SD*	*M*	*SD*	*M*	*SD*	
Negative Self	0.615	0.852	0.409	0.734	0.203	0.550	2.352
Negative Physical	0.115	0.431	0.364	0.727	0.339	0.883	0.753
Positive Self	0.539	0.647	0.864	0.834	0.966	0.909	1.589
Positive Physical	0.231	0.430	0.046	0.213	0.068	0.314	1.880

Note. *M*=mean and *SD*=standard deviation. Post-hoc LSD showed: Mean difference significant between normal weight (I) and obese (J) = (.41199) for Negative Self; between normal weight (I) and obese (J) = (-0.428) for Positive Self; between normal weight (I) and obese (J) = (.163) for Positive Physical. ** Significant at p=0.05.

Figure 8.

Normal Weight and Obese Comparison t-test

	t	df	Sig. (2-tailed)
Negative Self	2.668	83	.009*
Negative Physical	-1.225	83	.224
Positive Self	-2.166	83	.033*
Positive Physical	1.961	83	.053

Note. Normal Weight N=26; Obese N=59. Equal variances were assumed. Although the N was not large enough for a significant F value in the one-way ANOVA, a t-test was run to compare the self-concept of individuals with a normal weight and individuals who were obese. *There were significant findings in the frequency of Negative Self and Positive Self statements between normal weight and obese individuals.

Appendices:

Brief Incomplete Sentences Task (and Three Wishes)

Subject name/ID#___ _____ Date_____

Brief Incomplete Sentences

Please read each stem out loud to the participant and record their answers verbatim. Do not give any feedback to the participant to avoid response bias. If he/she says "I don't know", encourage them to think about it or come back to it later.
Say, "I am going to read the beginning of a sentence out loud and I want you to finish it with whatever you think or feel, whatever comes to your mind. There is no right or wrong answer, just what you feel, think or your opinion. I am going to write your answers down. Ready? Here's the first one".

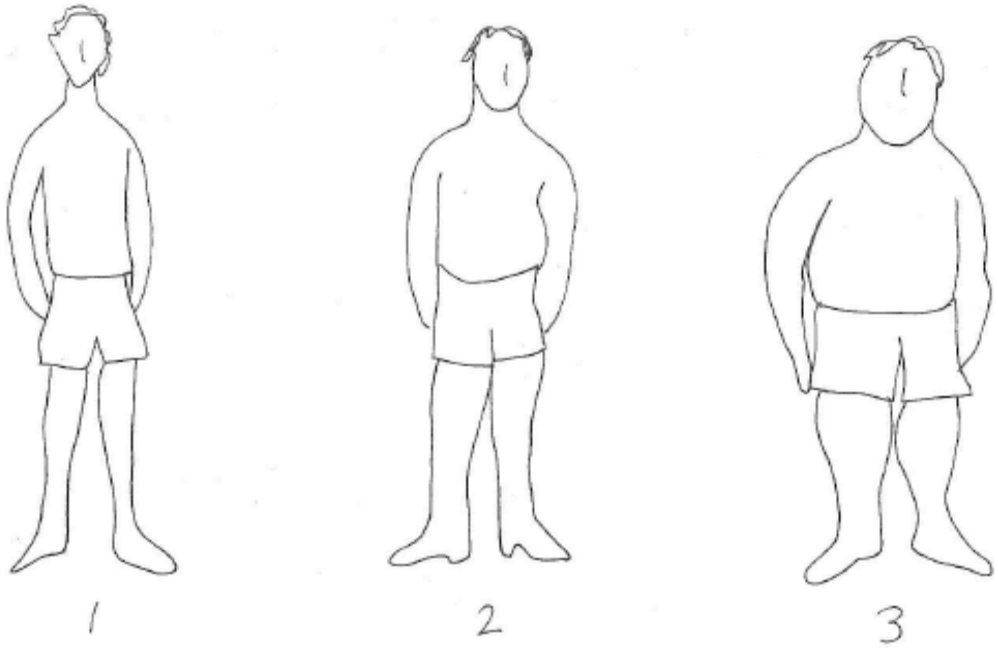
1. **I would like to** _____.
2. **I wish that I** _____.
3. **If I only**_____
4. **I hope**_____.
5. **I am**_____.
6. **I would like most to**_____.
7. **I am best when**_____.
8. **People think that I** _____.
9. **Sometimes I think about**_____.
10. **If I had three magic wishes that could true, I would wish for**

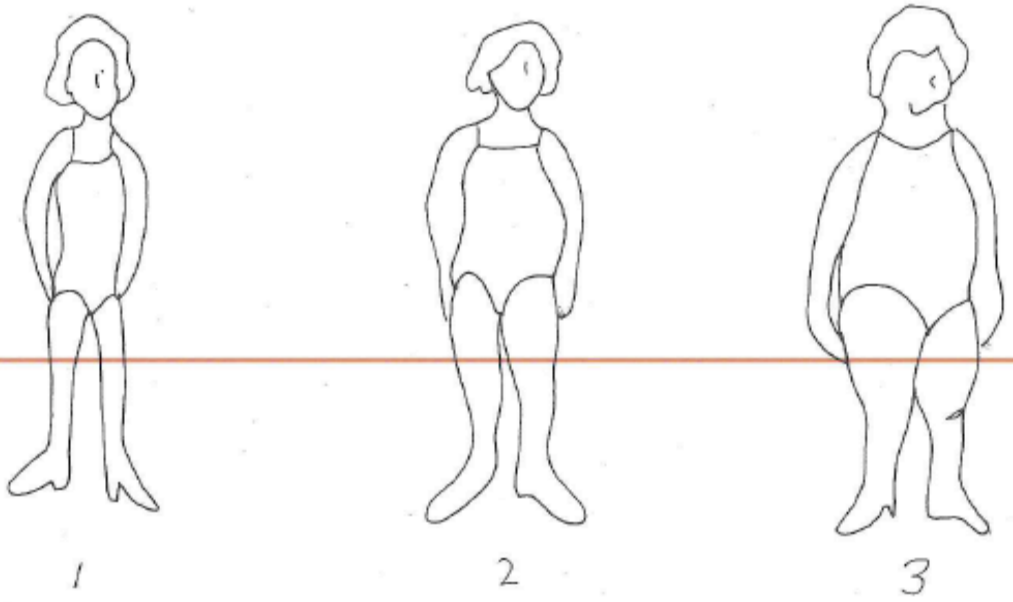
    (1)_____.

    (2)_____.

    (3)_____.

Body Image Task





(1) Which one of these pictures looks the most like you…your weight and size?

(2) Which one is the weight and size that you would like to be? (Prompt if needed, that you wish you could be?)

CBCL

Please print. **CHILD BEHAVIOR CHECKLIST FOR AGES 1½-5**

For office use only
ID #

CHILD'S FULL NAME First Middle Last

CHILD'S GENDER ☐ Boy ☐ Girl | CHILD'S AGE | CHILD'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo.____ Day____ Year____ | CHILD'S BIRTHDATE Mo.____ Day____ Year____

Please fill out this form to reflect *your* view of the child's behavior even if other people might not agree. Feel free to write additional comments beside each item and in the space provided on page 2. ***Be sure to answer all items.***

PARENTS' USUAL TYPE OF WORK, even if not working now. *Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.*

FATHER'S TYPE OF WORK _____

MOTHER'S TYPE OF WORK _____

THIS FORM FILLED OUT BY: (print your full name)

_____

Your relationship to child:

☐ Mother ☐ Father ☐ Other (specify):

Below is a list of items that describe children. For each item that describes the child ***now or within the past 2 months***, please circle the ***2*** if the item is ***very true or often true*** of the child. Circle the ***1*** if the item is ***somewhat or sometimes true*** of the child. If the item is ***not true*** of the child, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to the child.

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 1. Aches or pains (without medical cause; ***do not*** include stomach or headaches)
0 1 2 2. Acts too young for age
0 1 2 3. Afraid to try new things
0 1 2 4. Avoids looking others in the eye
0 1 2 5. Can't concentrate, can't pay attention for long
0 1 2 6. Can't sit still, restless, or hyperactive
0 1 2 7. Can't stand having things out of place
0 1 2 8. Can't stand waiting; wants everything now
2 9. Chews on things that aren't edible
0 1 2 10. Clings to adults or too dependent
0 1 2 11. Constantly seeks help
0 1 2 12. Constipated, doesn't move bowels (when not sick)
0 1 2 13. Cries a lot
0 1 2 14. Cruel to animals
0 1 2 15. Defiant
0 1 2 16. Demands must be met immediately
0 1 2 17. Destroys his/her own things
0 1 2 18. Destroys things belonging to his/her family or other children
0 1 2 19. Diarrhea or loose bowels (when not sick)
0 1 2 20. Disobedient
0 1 2 21. Disturbed by any change in routine
0 1 2 22. Doesn't want to sleep alone
0 1 2 23. Doesn't answer when people talk to him/her
0 1 2 24. Doesn't eat well (describe): _____
0 1 2 25. Doesn't get along with other children
0 1 2 26. Doesn't know how to have fun; acts like a little adult
2 27. Doesn't seem to feel guilty after misbehaving
0 2 28. Doesn't want to go out of home
0 1 2 29. Easily frustrated
0 1 2 30. Easily jealous
0 1 2 31. Eats or drinks things that are not food—***don't*** include sweets (describe): _____
0 1 2 32. Fears certain animals, situations, or places (describe): _____
0 1 2 33. Feelings are easily hurt
0 1 2 34. Gets hurt a lot, accident-prone
0 1 2 35. Gets in many fights
0 1 2 36. Gets into everything
0 1 2 37. Gets too upset when separated from parents
0 1 2 38. Has trouble getting to sleep
0 1 2 39. Headaches (without medical cause)
0 1 2 40. Hits others
0 1 2 41. Holds his/her breath
0 1 2 42. Hurts animals or people without meaning to
0 1 2 43. Looks unhappy without good reason
0 1 2 44. Angry moods
0 1 2 45. Nausea, feels sick (without medical cause)
0 1 2 46. Nervous movements or twitching (describe): _____
0 1 2 47. Nervous, highstrung, or tense
0 1 2 48. Nightmares
0 1 2 49. Overeating
0 1 2 50. Overtired
0 1 2 51. Shows panic for no good reason
0 1 2 52. Painful bowel movements (without medical cause)
0 1 2 53. Physically attacks people
0 1 2 54. Picks nose, skin, or other parts of body (describe): _____

Be sure you answered all items. Then see other side.

7-28-00 Edition-601

Please print your answers. Be sure to answer all items.

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 55. Plays with own sex parts too much
0 1 2 56. Poorly coordinated or clumsy
0 1 2 57. Problems with eyes (without medical cause) (describe): _____
0 1 2 58. Punishment doesn't change his/her behavior
0 1 2 59. Quickly shifts from one activity to another
0 1 2 60. Rashes or other skin problems (without medical cause)
0 1 2 61. Refuses to eat
0 1 2 62. Refuses to play active games
0 1 2 63. Repeatedly rocks head or body
0 1 2 64. Resists going to bed at night
0 1 2 65. Resists toilet training (describe): _____
0 1 2 66. Screams a lot
0 1 2 67. Seems unresponsive to affection
0 1 2 68. Self-conscious or easily embarrassed
0 1 2 69. Selfish or won't share
0 1 2 70. Shows little affection toward people
0 1 2 71. Shows little interest in things around him/her
0 1 2 72. Shows too little fear of getting hurt
0 1 2 73. Too shy or timid
0 1 2 74. Sleeps less than most kids during day and/or night (describe): _____
0 1 2 75. Smears or plays with bowel movements
0 1 2 76. Speech problem (describe): _____
0 1 2 77. Stares into space or seems preoccupied
0 1 2 78. Stomachaches or cramps (without medical cause)
0 1 2 79. Rapid shifts between sadness and excitement
0 1 2 80. Strange behavior (describe): _____
0 1 2 81. Stubborn, sullen, or irritable
0 1 2 82. Sudden changes in mood or feelings
0 1 2 83. Sulks a lot
0 1 2 84. Talks or cries out in sleep
0 1 2 85. Temper tantrums or hot temper
0 1 2 86. Too concerned with neatness or cleanliness
0 1 2 87. Too fearful or anxious
0 1 2 88. Uncooperative
0 1 2 89. Underactive, slow moving, or lacks energy
0 1 2 90. Unhappy, sad, or depressed
0 1 2 91. Unusually loud
0 1 2 92. Upset by new people or situations (describe): _____
0 1 2 93. Vomiting, throwing up (without medical cause)
0 1 2 94. Wakes up often at night
0 1 2 95. Wanders away
0 1 2 96. Wants a lot of attention
0 1 2 97. Whining
0 1 2 98. Withdrawn, doesn't get involved with others
0 1 2 99. Worries
0 1 2 100. Please write in any problems the child has that were not listed above.
0 1 2 _____
0 1 2 _____
0 1 2 _____

Please be sure you have answered all items. Underline any you are concerned about.

Does the child have any illness or disability (either physical or mental)? ☐ **No** ☐ **Yes—Please describe:**

What concerns you most about the child?

Please describe the best things about the child:

LANGUAGE DEVELOPMENT SURVEY FOR AGES 18-35 MONTHS

For office use only
ID #

The Language Development Survey assesses children's word combinations and vocabulary. By carefully mpleting the Language Development Survey, you can help us obtain an accurate picture of the child's veloping language. ***Please print your answers. Be sure to answer all items.***

I. Was the child born earlier than the usual 9 months after conception?

☐ No ☐ Yes—how many weeks early? _____weeks early.

II. How much did the child weigh at birth? _____ pounds _____ounces; or _____ grams.

III. How many ear infections did the child have before age 24 months?

☐ 0-2 ☐ 3-5 ☐ 6-8 ☐ 9 or more

IV. Is any language beside English spoken in the child's home?

☐ No ☐ Yes—please list the languages: _____ _____

_____ _____

V. Has anyone in the child's family been slow in learning to talk?

☐ No ☐ Yes—please list their relationships to the child; for example, brother, father:

_____

VI. Are you worried about the child's language development?

☐ No ☐ Yes—why? _____

_____

VII. Does the child spontaneously say words in any language? (not just imitates or understands words)?

☐ No ☐ Yes—if yes, please complete item VIII and page 4.

VIII. Does the child combine 2 or more words into phrases? For example: "more cookie," "car bye-bye."

☐ No ☐ Yes—please print 5 of the child's longest and best phrases or sentences.

For each phrase that is not in English, print the name of the language.

1. _____
2. _____
3. _____
4. _____
5. _____

Be sure you answered all items. Then see other side.

PAGE 3

Please circle each word that the child says SPONTANEOUSLY (not just imitates or understands). If your child says non-English versions of words on the list, circle the English word and write the first letter of the language (e.g., S for Spanish). Please include words even if they are not pronounced clearly or are in "baby talk" (for example: "baba" for bottle).

FOODS
1. apple
2. banana
3. bread
4. butter
5. cake
6. candy
7. cereal
8. cheese
9. coffee
10. cookie
11. crackers
12. drink
13. egg
14. food
15. grapes
16. gum
17. hamburger
18. hotdog
19. ice cream
20. juice
21. meat
22. milk
23. orange
24. pizza
25. pretzel
26. raisins
27. soda
28. soup
29. spaghetti
30. tea
31. toast
32. water

TOYS
33. ball
34. balloon
35. blocks
36. book
37. crayons
38. doll
39. picture
40. present
41. slide
42. swing
43. teddy bear

OUTDOORS
44. flower
45. house
46. moon
47. rain
48. sidewalk
49. sky
50. snow
51. star
52. street
53. sun
54. tree

ANIMALS
55. bear
56. bee
57. bird
58. bug
59. bunny
60. cat
61. chicken
62. cow
63. dog
64. duck
65. elephant
66. fish
67. frog
68. horse
69. monkey
70. pig
71. puppy
72. snake
73. tiger
74. turkey
75. turtle

BODY PARTS
76. arm
77. belly button
78. bottom
79. chin
80. ear
81. elbow
82. eye
83. face
84. finger
85. foot
86. hair
87. hand
88. knee
89. leg
90. mouth
91. neck
92. nose
93. teeth
94. thumb
95. toe
96. tummy

VEHICLES
97. bike
98. boat
99. bus
100. car
101. motorcycle
102. plane
103. stroller
104. train
105. trolley
106. truck

ACTIONS
107. bath
108. breakfast
109. bring
110. catch
111. clap
112. close
113. come
114. cough
115. cut
116. dance
117. dinner
118. doodoo
119. down
120. eat
121. feed
122. finish
123. fix
124. get
125. give
126. go
127. have
128. help
129. hit
130. hug
131. jump
132. kick
133. kiss
134. knock
135. look
136. love
137. lunch
138. make
139. nap
140. open
141. outside
142. pattycake
143. peekaboo
144. peepee
145. push
146. read
147. ride
148. run
149. see
150. show
151. shut
152. sing
153. sit
154. sleep
155. stop
156. take
157. throw
158. tickle
159. up
160. walk
161. want
162. wash

HOUSEHOLD
163. bathtub
164. bed
165. blanket
166. bottle
167. bowl
168. chair
169. clock
170. crib
171. cup
172. door
173. floor
174. fork
175. glass
176. knife
177. light
178. mirror
179. pillow
180. plate
181. potty
182. radio
183. room
184. sink
185. soap
186. spoon
187. stairs
188. table
189. telephone
190. towel
191. trash
192. T.V.
193. window

PERSONAL
194. brush
195. comb
196. glasses
197. key
198. money
199. paper
200. pen
201. pencil
202. penny
203. pocketbook
204. tissue
205. tooth brush
206. umbrella
207. watch

PLACES
208. church
209. home
210. hospital
211. library
212. park
213. school
214. store
215. zoo

MODIFIERS
216. all gone
217. all right
218. bad
219. big
220. black
221. blue
222. broken
223. clean
224. cold
225. dark
226. dirty
227. dry
228. good
229. happy
230. heavy
231. hot
232. hungry
233. little
234. mine
235. more
236. nice
237. pretty
238. red
239. stinky
240. that
241. this
242. tired
243. wet
244. white
245. yellow
246. yucky

CLOTHES
247. belt
248. boots
249. coat
250. diaper
251. dress
252. gloves
253. hat
254. jacket
255. mittens
256. pajamas
257. pants
258. shirt
259. shoes
260. slippers
261. sneakers
262. socks
263. sweater

OTHER
264. any letter
265. away
266. booboo
267. byebye
268. excuse me
269. here
270. hi, hello
271. in
272. me
273. meow
274. my
275. myself
276. nightnight
277. no
278. off
279. on
280. out
281. please
282. Sesame St.
283. shut up
284. thank you
285. there
286. under
287. welcome
288. what
289. where
290. why
291. woofwoof
292. yes
293. you
294. yumyum
295. any number

PEOPLE
296. aunt
297. baby
298. boy
299. daddy
300. doctor
301. girl
302. grandma
303. grandpa
304. lady
305. man
306. mommy
307. own name
308. pet name
309. uncle
310. name of TV or story character

Other words your child says, including non-English words:

_____
_____
_____
_____

ASEBA

Please print **CHILD BEHAVIOR CHECKLIST FOR AGES 6-18**

For office use only
ID #

CHILD'S FULL NAME First Last

CHILD'S GENDER ☐ Boy ☐ Girl

CHILD'S AGE

CHILD'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo._____ Date _____ Yr. _____

CHILD'S BIRTHDATE Mo._____ Date _____ Yr. _____

GRADE IN SCHOOL _____

NOT ATTENDING SCHOOL ☐

Please fill out this form to reflect *your* view of the child's behavior even if other people might not agree. Feel free to print additional comments beside each item and in the space provided on page 2. ***Be sure to answer all items.***

PARENTS' USUAL TYPE OF WORK, even if not working now. *(Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S TYPE OF WORK _____

MOTHER'S TYPE OF WORK _____

THIS FORM FILLED OUT BY: (print your full name)

_____

Your gender: ☐ Male ☐ Female

Your relation to the child:

☐ Biological Parent ☐ Step Parent ☐ Grandparent
☐ Adoptive Parent ☐ Foster Parent ☐ Other (specify)_____

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do each one?			
	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average	Don't Know
a. _____	☐	☐	☐	☐	☐	☐	☐	☐
b. _____	☐	☐	☐	☐	☐	☐	☐	☐
c. _____	☐	☐	☐	☐	☐	☐	☐	☐

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, computers, singing, etc. (Do ***not*** include listening to radio or TV.)

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do each one?			
	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average	Don't Know
a. _____	☐	☐	☐	☐	☐	☐	☐	☐
b. _____	☐	☐	☐	☐	☐	☐	☐	☐
c. _____	☐	☐	☐	☐	☐	☐	☐	☐

III. Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

	Compared to others of the same age, how active is he/she in each?			
	Less Active	Average	More Active	Don't Know
a. _____	☐	☐	☐	☐
b. _____	☐	☐	☐	☐
c. _____	☐	☐	☐	☐

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

	Compared to others of the same age, how well does he/she carry them out?			
	Below Average	Average	Above Average	Don't Know
a. _____	☐	☐	☐	☐
b. _____	☐	☐	☐	☐
c. _____	☐	☐	☐	☐

Be sure you answered all items. Then see other side.

6-1-01 Edition - 201

Please print. Be sure to answer all items.

. 1. About how many close friends does your child have? (Do *not* include brothers & sisters)
☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. About how many times a week does your child do things with any friends outside of regular school hours? (Do *not* include brothers & sisters) ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

/I. Compared to others of his/her age, how well does your child:

	Worse	Average	Better	
a. Get along with his/her brothers & sisters?	☐	☐	☐	☐ Has no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Behave with his/her parents?	☐	☐	☐	
d. Play and work alone?	☐	☐	☐	

/II. 1. Performance in academic subjects. ☐ Does not attend school because _____

Check a box for each subject that child takes	Failing	Below Average	Average	Above Average
a. Reading, English, or Language Arts	☐	☐	☐	☐
b. History or Social Studies	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Science	☐	☐	☐	☐
e. _____	☐	☐	☐	☐
f. _____	☐	☐	☐	☐
g. _____	☐	☐	☐	☐

Other academic subjects–for example: computer courses, foreign language, business. Do *not* include gym, shop, driver's ed., or other nonacademic subjects.

2. Does your child receive special education or remedial services or attend a special class or special school?
☐ No ☐ Yes—kind of services, class, or school:

3. Has your child repeated any grades? ☐ No ☐ Yes—grades and reasons:

4. Has your child had any academic or other problems in school? ☐ No ☐ Yes—please describe:

When did these problems start?_____
Have these problems ended? ☐ No ☐ Yes–when?

Does your child have any illness or disability (either physical or mental)? ☐ No ☐ Yes—please describe:

What concerns you most about your child?

Please describe the best things about your child.

Be sure you answered all items.

Please print. Be sure to answer all items.

Below is a list of items that describe children and youths. For each item that describes your child ***now or within the past 6 months***, please circle the ***2*** if the item is ***very true or often true*** of your child. Circle the ***1*** if the item is ***somewhat or sometimes true*** of your child. If the item is ***not true*** of your child, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1. Acts too young for his/her age
0 1 2 2. Drinks alcohol without parents' approval (describe):_____
_____
0 1 2 3. Argues a lot
0 1 2 4. Fails to finish things he/she starts
0 1 2 5. There is very little he/she enjoys
0 1 2 6. Bowel movements outside toilet
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): _____
_____
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot
0 1 2 15. Cruel to animals
0 1 2 16. Cruelty, bullying, or meanness to others
0 1 2 17. Daydreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide
0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things
0 1 2 21. Destroys things belonging to his/her family or others
0 1 2 22. Disobedient at home
0 1 2 23. Disobedient at school
0 1 2 24. Doesn't eat well
0 1 2 25. Doesn't get along with other kids
0 1 2 26. Doesn't seem to feel guilty after misbehaving
0 1 2 27. Easily jealous
0 1 2 28. Breaks rules at home, school, or elsewhere
0 1 2 29. Fears certain animals, situations, or places, other than school (describe): _____
_____
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): _____
_____
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense
0 1 2 46. Nervous movements or twitching (describe): ____
_____
_____
0 1 2 47. Nightmares
0 1 2 48. Not liked by other kids
0 1 2 49. Constipated, doesn't move bowels
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy or lightheaded
0 1 2 52. Feels too guilty
0 1 2 53. Overeating
0 1 2 54. Overtired without good reason
0 1 2 55. Overweight
56. Physical problems ***without known medical cause:***
0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (***not*** if corrected by glasses) (describe): _____
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): _____
_____

 Be sure you answered all items. Then see other side.

Please print. Be sure to answer all items.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 57. Physically attacks people
0 1 2 58. Picks nose, skin, or other parts of body (describe): _____
_____
0 1 2 59. Plays with own sex parts in public
0 1 2 60. Plays with own sex parts too much
0 1 2 61. Poor school work
0 1 2 62. Poorly coordinated or clumsy
0 1 2 63. Prefers being with older kids
0 1 2 64. Prefers being with younger kids
0 1 2 65. Refuses to talk
0 1 2 66. Repeats certain acts over and over; compulsions (describe): _____
_____
0 1 2 67. Runs away from home
0 1 2 68. Screams a lot
0 1 2 69. Secretive, keeps things to self
0 1 2 70. Sees things that aren't there (describe): _____
_____
_____
0 1 2 71. Self-conscious or easily embarrassed
0 1 2 72. Sets fires
0 1 2 73. Sexual problems (describe): _____
_____
_____
0 1 2 74. Showing off or clowning
0 1 2 75. Too shy or timid
0 1 2 76. Sleeps less than most kids
0 1 2 77. Sleeps more than most kids during day and/or night (describe): _____
_____
0 1 2 78. Inattentive or easily distracted
0 1 2 79. Speech problem (describe): _____
_____
0 1 2 80. Stares blankly
0 1 2 81. Steals at home
0 1 2 82. Steals outside the home
0 1 2 83. Stores up too many things he/she doesn't need (describe): _____
_____
_____
0 1 2 84. Strange behavior (describe): _____
_____
0 1 2 85. Strange ideas (describe): _____
_____
0 1 2 86. Stubborn, sullen, or irritable
0 1 2 87. Sudden changes in mood or feelings
0 1 2 88. Sulks a lot
0 1 2 89. Suspicious
0 1 2 90. Swearing or obscene language
0 1 2 91. Talks about killing self
0 1 2 92. Talks or walks in sleep (describe): _____
_____
0 1 2 93. Talks too much
0 1 2 94. Teases a lot
0 1 2 95. Temper tantrums or hot temper
0 1 2 96. Thinks about sex too much
0 1 2 97. Threatens people
0 1 2 98. Thumb-sucking
0 1 2 99. Smokes, chews, or sniffs tobacco
0 1 2 100. Trouble sleeping (describe): _____
_____
0 1 2 101. Truancy, skips school
0 1 2 102. Underactive, slow moving, or lacks energy
0 1 2 103. Unhappy, sad, or depressed
0 1 2 104. Unusually loud
0 1 2 105. Uses drugs for nonmedical purposes (***don't*** include alcohol or tobacco) (describe): _____
_____
_____
0 1 2 106. Vandalism
0 1 2 107. Wets self during the day
0 1 2 108. Wets the bed
0 1 2 109. Whining
0 1 2 110. Wishes to be of opposite sex
0 1 2 111. Withdrawn, doesn't get involved with others
0 1 2 112. Worries
113. Please write in any problems your child has that were not listed above:
0 1 2 _____
0 1 2 _____
0 1 2 _____

Please be sure you answered all items.

2. Content codes (Dykens et al., 2007)

Table 1 Content codes and examples of responses for Sentence Completion and Three Wishes tasks

Activities	Go to store, movies, shopping, do puzzles, dance
Dating/Romance	Kiss, get married, dates, have girl/boyfriend
Family	Spend time with my sister, be with parents
Food	Chocolate, sweets, corn bread, cooking
Friends	Hang out with my friends, have good friends
Help Others	Stop hunger, cure cancer, help homeless, peace
Idiosyncratic	Ghosts, Coach Randy, take nap, I am 14, sunny day
Money	Be rich, lots of money
Music	Listen new CDs, play guitar, new drum sticks
Negative Self	Stupid, bad, mean, afraid, worried, lazy
Negative Physical	Not have syndrome, ugly, fat
Objects	Motorcycle, palace, computer, new hat, theme park
Occupation	Be teacher, animal doctor, work at a store
Pets	Own a horse, have a dog, puppy
Positive Self	Famous, successful, fun, great, happy
Positive Physical	Healthy, beautiful, big muscles, handsome
Sports	Play baseball, basketball, tennis, golf, get on team
Travel	Go to New York, Hawaii, London, Disney

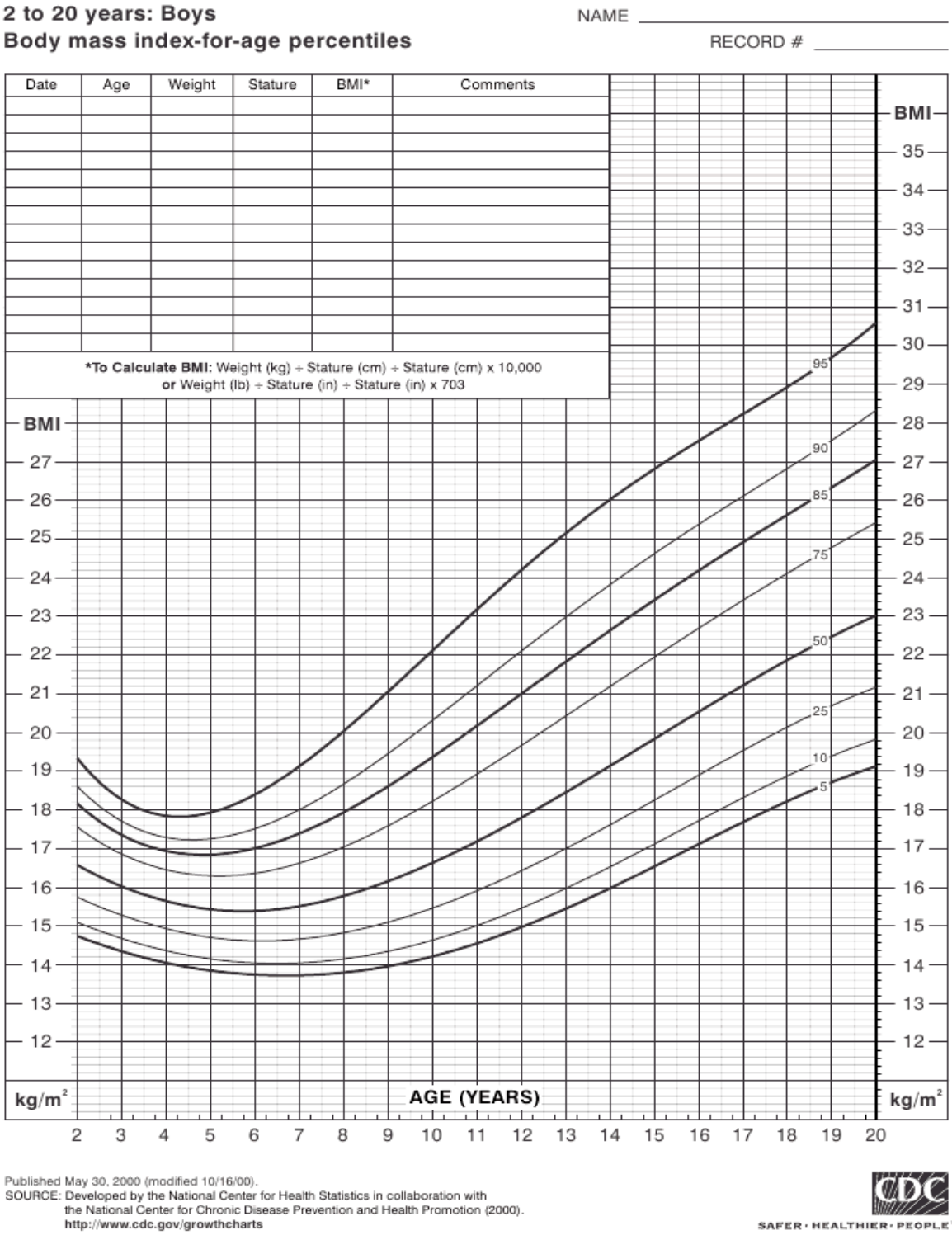
(From Dykens et al., 2007)

3. BMI charts ("Body Mass Index," 2011)

CDC Guidelines for BMI Categories

BMI Label	20 years and older	19 years and younger
Underweight	<18.5 BMI	<5th percentile
Normal Weight	18.5-24.9 BMI	5-85th percentile
Overweight	25-29.9 BMI	85-95th percentile
Obese	30 or greater BMI	95th or greater percentile

CDC Growth Charts



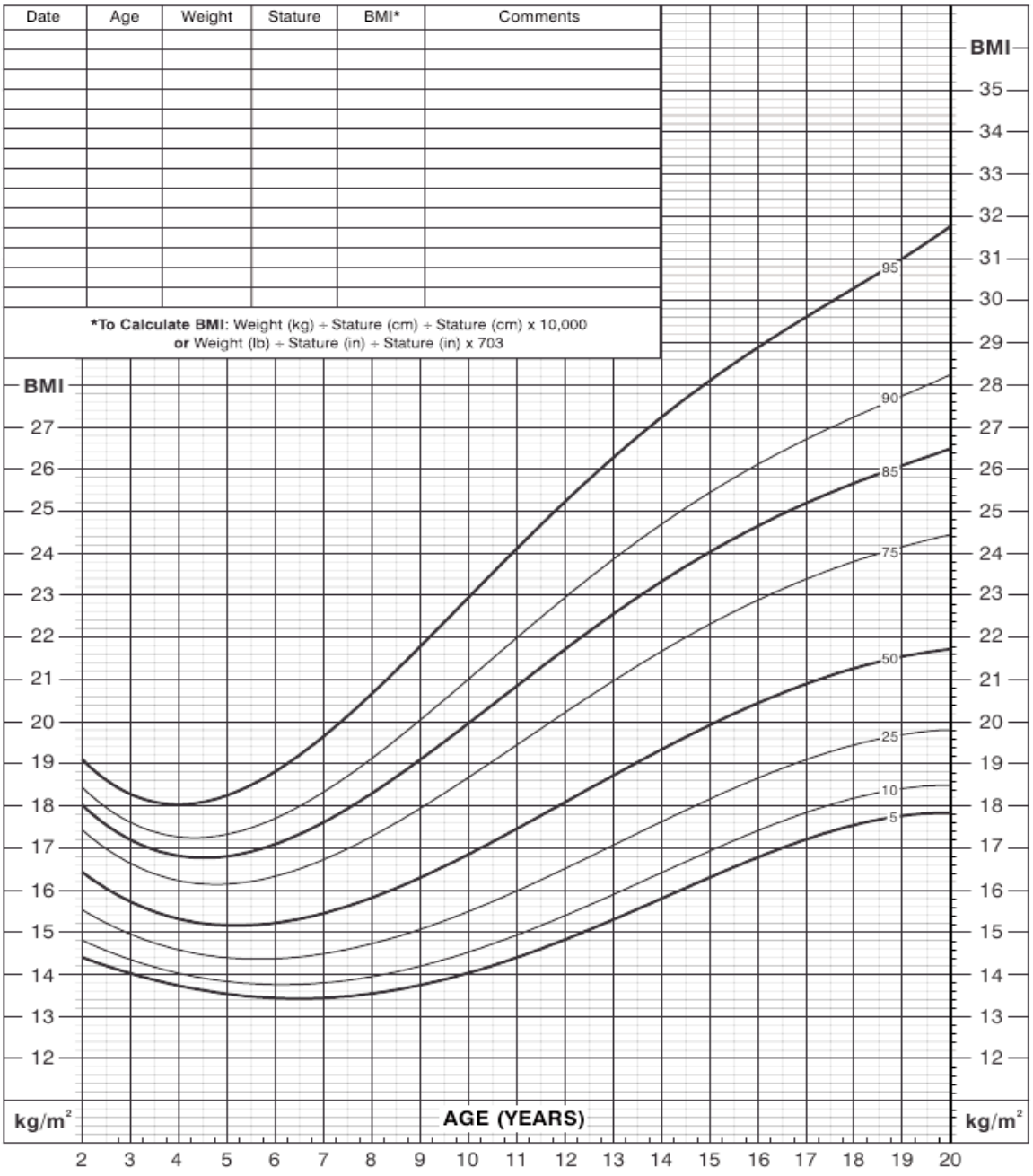
2 to 20 years: Girls
Body mass index-for-age percentiles

NAME _____

RECORD # _____

Date	Age	Weight	Stature	BMI*	Comments

***To Calculate BMI:** Weight (kg) ÷ Stature (cm) ÷ Stature (cm) x 10,000
or Weight (lb) ÷ Stature (in) ÷ Stature (in) x 703



Published May 30, 2000 (modified 10/16/00).
SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).
http://www.cdc.gov/growthcharts

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