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Examining Variables Associated With Age of First Concern and Diagnosis in Children with Autism Spectrum Disorder

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EXAMINING VARIABLES ASSOCIATED WITH AGE OF FIRST CONCERN AND DIAGNOSIS IN CHILDREN WITH AUTISM SPECTRUM DISORDER

By

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Abstract

Autism Spectrum Disorder is a disorder that is present during a child's early developmental ages; affects that child's ability to communicate and socially interact with others; and involves the presentation of restrictive interests and/or repetitive behaviors. Autism Spectrum Disorder (ASD) symptoms/behaviors are recognized by parents and can be reliably diagnosed at age two but often are not diagnosed until after age four. Delay in diagnosis results in loss of important intervention services that can improve the well-being of children with ASD. This study examined ethnicity, severity of symptoms, and type of symptoms and their effect on the age at which parents first became concerned about their child's development and the age at which the child was diagnosed with ASD. Data was collected from archived client records at a regional children's clinic. Results indicated that there were no ethnic differences in age of first parental concern or diagnosis; Severity of symptoms was associated with earlier age of first parental concern and diagnosis; and while parents reported Speech/Communication concerns most often, multiple first concerns was associated with earlier recognition by parents and diagnosis. Efforts should be made to educate the public on the more subtle symptoms and behaviors associated with ASD. It is recommended that autism evaluation services be available in schools as part of pre-school screening services.

Key words: Autism, Diagnosis, Early Indicators

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Examining Variables Associated with Age of First Concern in Children Diagnosed with Autism

CHAPTER I

Introduction

Autism Spectrum Disorder is a disorder characterized by deficits in social-emotional and communication skills and excesses of circumscribed interests and/or repetitive behaviors. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) identifies the diagnostic criteria for Autism Spectrum Disorder (ASD) as having persistent deficits in social communication and social interactions across multiple environments and having restricted, repetitive patterns of behavior, interests, or activities. Additionally, the DSM-V specifies that symptoms must be present in the early developmental period; cause significant impairment in social, occupational or other area of functioning; and are not attributable to an intellectual disability or global developmental delay (American Psychiatric Association, 2013.) With the publication of the DSM-V in 2013, the diagnoses of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified were consolidated into the encompassing diagnosis of Autism Spectrum Disorder. Diagnostic symptoms of language and communication that were classified in the diagnostic category of "Communication" in the Diagnostic and Statistical Manual- Fourth Edition Text Revision (DSM-IV-TR) were subsumed in the "Social Communication and Social Interactions"

and “Restricted Activities” categories in the DSM -V. Diagnosis of Autism Spectrum Disorder per the DSM-V also includes specification of accompanying intellectual impairment, language impairment, association with a known medical or genetic condition or environmental factor, and/or association with other neurodevelopmental, mental, or behavioral disorder and with catatonia (American Psychiatric Association, 2013).

According to the Center for Disease Control and Prevention (CDC, 2014), an individual with ASD may have trouble relating to others or not have an interest in others at all or may be interested in them but not know how to talk, play or relate to them. An individual with ASD may also avoid eye contact and may have trouble understanding other’s feelings or talking about their own feelings.

Current CDC (2015) statistics indicate that about one in sixty eight children have been identified as having an Autism Spectrum Disorder. Autism Spectrum Disorder is more prevalent in boys than girls. The Center for Disease Control and Prevention collects data on Autism Spectrum Disorders through the Autism and Developmental Disabilities Monitoring Network. The data collected from eleven states on eight years olds diagnosed with Autism Spectrum Disorder indicated that one in forty two boys were diagnosed with Autism Spectrum Disorder while the prevalence among girls was one in one hundred and eighty nine (Christianson, et al., 2016).

Parents of children with Autism Spectrum Disorder report that developmental problems, including delays in social, communication and fine motor skills were evident before their child’s first birthday. Research has shown that a child can be reliably

diagnosed with ASD at age two, however, children identified with ASD on average are not diagnosed until after age four (CDC, 2015). A study of 6,176 parent surveys on the Interactive Autism Network, found that diagnoses of Autism Spectrum Disorders have significantly increased since 2001, especially among school-based diagnostic teams **(**Rosenberg, Daniels, Law, Law, & Kaufman, 2009). The delay between parental recognition of developmental concerns and the eventual diagnosis of Autism Spectrum Disorder results in the loss of critical early intervention services.

Research on Autism Spectrum Disorder has identified a number of possible variables associated with age of first parental concerns and age of diagnosis. As Autism Spectrum Disorder is a disorder that impairs a child's ability to communicate and interact socially, behaviors that indicate these deficits are often reported as arousing initial parental concerns. These reported behaviors include: limited eye contact, difficulties understanding and using non-verbal communication, lack of play or interaction with others, insisting on sameness in routine or activities, and unusual movements (Oswald, Haworth, Mackenzie, & Willis, 2015). Other variables associated with early parental concern include abnormal social emotional response, medical problems, and delay in meeting developmental milestones (Giacomo & Fombonne, 1998). Additionally, studies have found that having an older sibling is associated with earlier parental recognition of developmental problems in their child (Herlihy, Knoch, Vibert, & Fein, 2015; Rosenberg, Landa, Law, Stuart, & Law, 2011.)

This project reviewed the current literature on identification and diagnosis of Autism Spectrum Disorder and conducted research to examine the variables of ethnicity, severity of symptoms, and type of first parental concern; and their effects on age of first concern and age of diagnosis in children diagnosed with Autism Spectrum Disorder at a multidisciplinary children's clinic in Northwest Louisiana.

CHAPTER II

Review of Literature

The review of literature for this research project surveyed research that encompassed the topics related to the evaluation of children diagnosed with Autism Spectrum Disorder and the variables associated with early parental concerns and early diagnosis. The topics reviewed included appropriate diagnostic instruments, the importance of early identification and diagnosis, early intervention for ASD, and research associated with the variables studied in the project including ethnicity, severity of symptoms, and types of symptoms and their effects on age of first concerns and age of diagnosis of Autism Spectrum Disorder.

Diagnostic Measures

In order to provide valid diagnosis of Autism Spectrum Disorder, it is critical that the evaluator utilize effective diagnostic instruments. One instrument that has been determined beneficial in ASD diagnostic research is the Autism Diagnostic Interview-Revised (ADI-R) (Volkmar, 2005). The ADI-R is a semi-structured interview conducted between a clinician and a parent or caregiver who is familiar with the child's developmental history and current behavior. The interview focuses on behaviors in three content domains: quality of social interaction, (e.g., emotional sharing, offering and seeking comfort, social smiling and responding to other children); communication and language (e.g., stereotyped utterances, pronoun reversal, social usage of language); and

repetitive, restricted and stereotyped interests and behavior (e.g., unusual preoccupations, hand and finger mannerisms, unusual sensory interests). The psychometric properties of the ADI-R are strong. Authors Rutter, Couteur, and Lord (2017) report excellent test-retest and interrater reliability with most correlation coefficients greater than .90. The ADI-R's concurrent validity was very good at .74. Additionally, criterion validity (sensitivity 1.0, specificity > .97) indicated very good discrimination between Autism Spectrum Disorder and Non-Autism Spectrum Disorder (Rutter, Couteur, & Lord, 2017).

In a review of the ADI-R, Volkmar (2005) reported that the ADI-R is an unparalleled diagnostic tool as it operationalizes the diagnostic constructs of Autism Spectrum Disorder. Giacomo and Fombonne (1998) used the ADI-R in research to identify factors related to identification of children with Pervasive Developmental Disabilities in a specialized clinical sample. The ADI-R was selected for Giacomo and Fombonne's research because it contained items related to early presentation of developmental problems. Specifically, the ADI-R queries parents about the age at which they first had concerns regarding their child's development, the nature of these first concerns, the age at which parents first sought assistance and who they saw for initial assistance.

In a longitudinal study of children with Autistic Disorder (now Autism Spectrum Disorder), researchers utilized the ADI-R to collect information from parents or caregivers about their child's behaviors at age two, three, five, and nine. The ADI-R was found effective at collecting and quantifying behaviors associated with Autism Spectrum

Disorder as the child develops (Hus, Taylor, & Lord, 2011). While the ADI-R provides an algorithm to determine the likelihood of presentation of Autism Spectrum Disorder, the instrument is solely based on caregiver report of symptoms.

Another effective instrument in diagnosis of Autism Spectrum Disorder is the Autism Diagnostic Observation Schedule-Second Edition (Lord, Rutter, DiLavore, Risi, Gotham, & Bishop, 2012). This instrument is a semi-structured standardized assessment of communication, social interaction, and play or imaginative use of materials for individuals suspected of having pervasive developmental disorders. The Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) consists of standard activities that allow the clinical examiner to observe the occurrence or non-occurrence of behaviors that have been identified as important to the diagnosis of Autism Spectrum Disorder across developmental and chronological ages. This instrument is divided into five modules corresponding to a child's age or developmental level. The module used is selected on the basis of the expressive language level and chronological age of the child. Structured activities and materials, and less structured interactions, provide standard contexts in which social, communicative and other behaviors relevant to Autism Spectrum Disorder are observed via prearranged social situations. Each behavior rated is assigned a score of zero, one, or two based on the presence and severity of behaviors associated with Autism Spectrum Disorder. The overall scores are converted to a comparison score from 1-10. The diagnostic probability of Autism Spectrum Disorder is obtained based on the comparison score as follows: 1-2 points—Minimal to No evidence

of Autism Spectrum Disorder; 3-4 points—Low level of Autism Spectrum-related symptoms; 5-7 points—Moderate level of Autism Spectrum Related symptoms; or 8-10 points—High level of Autism Spectrum-related symptoms (Lord et al., 2012).

The psychometric properties of the ADOS-2 are strong (Lord, et al. 2012). The interrater reliability is high for Modules 1 – 3 (.97, .96, and .94 respectively). The interrater reliability for Module 4 is not reported in the current ADOS-2 manual as the algorithm did not change in the second edition. The test-retest reliability was determined by administering the instrument twice within approximately 10 months. The test-retest reliability is high for modules 1 -3 (.87, .83, and .87 respectively) (Lord, et al. 2012). Because the ADOS-2 utilizes objective behavioral observations conducted by trained clinicians, it is considered an effective measurement that is also culturally sensitive (El-Ghoroury & Krackow, 2012).

In order to collect a complete diagnostic picture of the child based both on caregiver report and clinical observation of behavior, the ADI-R and ADOS-2 are often used together to evaluate diagnostic characteristics of young children referred due to concerns associated with social and/or language development. Gray, Tonge, and Sweeney (2008) examined the diagnostic validity of the ADI-R and ADOS in 209 children, aged 20 to 55 months, referred for assessment in Melbourne, Australia. Of the study sample, 120 received the diagnosis of Autism. The autism group scored significantly higher than the non-autism group on both the ADI-R and ADOS. Separate clinicians conducted the ADI-R and ADOS evaluations blind to the other's scores. The

clinicians then arrived at a consensus clinical diagnosis. Both the ADI-R and ADOS performed well in relation to consensus clinical diagnosis with overall high classification rates. In other words, raters for both instruments were consistent in identification of Autism Spectrum Disorder. The results of this study indicated that both instruments collect information in the valid diagnosis of Autism Spectrum disorder and are best used in conjunction with each other (Gray, Tonge, & Sweeney, 2008).

Age of First Parental Concerns

One of the earliest studies that specifically addressed the age and nature of first parental concerns pertaining to their child's development was conducted by Giacomo and Fombonne (1998). This research team examined 82 consecutive referrals to an outpatient program specializing in developmental delays in the United Kingdom. All program participants were assessed using the ADI-R and first parental concerns were coded and ranked in order of parents' reported importance. The mean age of parental first concern was 19.1 months and the mean age of seeking professional help was 24.1 months. The most often reported concern was speech/language abnormalities. In this study about one third of the parents reported that they had recognized developmental concerns before their child's first birthday and eighty percent by the second birthday (Giacomo & Fombonne, 1998). As reported by the Center for Disease Control and Prevention (CDC, 2015), current research indicates that parents of children with Autism Spectrum Disorder have reported concerns regarding their child's development arising before the age of one. Early parental recognition of behaviors that eventually resulted in diagnosis of Autism

Spectrum Disorder was confirmed by researchers examining 1,478 toddlers in a statewide early intervention program. These researchers found that the age of first concerns was approximately one month younger for parents of toddlers with Autism Spectrum Disorder, Mean age =12.05 months; than for those with atypical development not associated with Autism Spectrum Disorder, Mean age = 13.16 months (Jang, Matson, Cervantes, & Konst, 2014).

Although often parents report concerns prior to their child's first birthday (CDC, 2015) it is not uncommon for parents to delay seeking professional diagnosis of Autism Spectrum Disorder. Oswald, et al. (2015) reported that in some cases, concerns were brought to the attention of health care providers, but parents were advised to "wait and see" as developmental concerns often resolve themselves. Oswald, et al. (2015) analyzed data from the Pathways survey which was a follow-up to the National Survey of Children with Special Health Care Needs designed to collect parental information on the emergence of developmental concerns, diagnosis, the providers who made the diagnosis, and types of clinical treatment recommendations and interventions used to address parental concerns. Oswald, el al. (2015) compared the experiences of parents of children diagnosed with Autism Spectrum Disorder to those diagnosed with other developmental disabilities and included a large sample size (N=1,420) of children diagnosed with Autism Spectrum Disorder. Limited eye contact, responding to sounds, lack of understanding non-verbal communication, limited playing/interacting with others, insisting on sameness, and unusual movement were the most commonly reported causes

for first parental concern. The results of this study found that despite early parental recognition of problems, Autism Spectrum Disorder children were diagnosed seven months later than children with other developmental disabilities. Two thirds of the parents of children diagnosed with Autism Spectrum Disorder were informed that nothing was wrong, the behavior was normal, and/or that their child might grow out of it (Oswald, et al., 2015). A professional recommendation resulting in a delay in assessment for a child with Autism Spectrum Disorder could result in added parental stress and the parent's questioning of their own perceptions of their child.

Another issue related to parental report of early developmental deficits is a phenomenon known as "telescoping". This term refers to the tendency of parent's retrospective report to change with the passage of time. Hus, Taylor, & Lord (2011) conducted repeated interviews with parents of children with Autism Spectrum Disorder across their child's developmental stages. The interviews were conducted at age two, three, five, and nine and found that although over time parents reported earlier language delays than in previous reports, the age of first concerns remained stable at 13-14 months. In an attempt to control for telescoping effects, Chawarska et al. (2007) examined initial parental recognition of developmental problems in a group of children diagnosed with Autism Spectrum Disorder before the age of three, and found the mean age of first concerns to be 14.7 months. Chawarska et al.'s (2015) research indicated that despite earlier parental interview, the age of reported first developmental concerns were consistent with Hus, Taylor, and Lord's (2011) findings based on parental interviews

across time and indicate that parental recognition of concerns in their child's development occur before the age of two.

The research of Hus, Taylor and Lord (2011) and Chawarska et al. (2015), which consistently indicates parental recognition of behaviors associated with Autism Spectrum by age two, denotes the importance of health care providers' taking a proactive approach to improve early detection of Autism Spectrum Disorder in order to obtain the most accurate parental reports of developmental problems and make the most appropriate referrals for therapeutic services. Research has indicated that early behavioral intervention has been effective in improving outcomes for children with Autism Spectrum Disorder. Dawson et al. (2012) examined 48 children aged 18 to 30 months diagnosed with Autism Spectrum Disorder. Results indicated that children assigned to an early behavioral intervention program that included applied behavioral analysis, a developmental approach, and parent coaching for two years showed greater improvements in autism symptoms, cognitive processing, language, and adaptive skills than children assigned to traditional community services which included speech-language therapy, occupational therapy, and/or applied behavioral analysis treatments. Additionally, children receiving the early intervention program exhibited brain activity, as measured by Electroencephalography (EEG) upon completion of the program, which was similar to typically developing children. This group of children was examined two years after the intervention ended and results indicated that the group that received the early behavioral intervention had maintained the positive gains in improved symptoms

and adaptive behaviors (Estes, Munson, Rogers, Greenson, Winter & Dawson, 2015). Additionally, early behavioral intervention has been associated with improved intellectual functioning, measured by the Psycho-Educational Profile- Revised; and educational functioning, measured by the British Abilities Scale, for children with severe ASD symptoms (Reed & Osborne, 2012).

General Variables Associated With Age of First Concerns

There are many factors associated with age of first concerns in parents of children diagnosed with Autism Spectrum Disorder. Autism Spectrum Disorder is characterized by deficits in speech/communication, social interactions, and presentation of restrictive or stereotyped behaviors that are present during a child's early developmental period. Additionally, children with Autism Spectrum Disorder may have significant impairments in cognitive and/or adaptive functioning (American Psychiatric Association, 2013.) It is difficult to determine which characteristics of development lead to earlier parental concern. Giacomo & Fombonne (1998) found the most common parental concern was for speech development; followed by abnormal social emotional response, medical problem, and delay in meeting milestones. Similarly, Kozlowski, Matson, Horovitz, Worley, & Neal (2010) also found the area of parents' first concern was in communication. However, a study by Guinchat et al. (2012) indicated that abnormal social-emotional development was the most cited parental concern and concerns regarding motor abnormalities and behaviors that were non-specific to Autism Spectrum Disorder had lower age for parents' seeking assistance while concerns associated with

ASD diagnostic criteria (social communication deficits and stereotypic/restrictive behaviors) were associated with later recognition and diagnosis. Charwarska et al. (2007) reported that the earliest recognized symptoms were delays in social smiling and walking. This varying research indicates that there is not one specific behavioral characteristic that is consistently reported by parents as the earliest recognized symptom of Autism Spectrum Disorder.

The diagnosis of Autism Spectrum Disorder in some studies is associated with earlier parental concerns in comparison to children with other developmental problems. Kozlowski et al. (2010) reported that the age of first concern of parents was significantly younger for toddlers with Autism Spectrum Disorder than those diagnosed with other developmental disorders. Also, Horowitz , Matson, Turgin, & Beighley (2011) reported the age of first concern was younger for toddlers with Autism Spectrum Disorder than those with atypical development and was also younger for females. However, Chawarska et al. (2007) found that children whose parents identified problems between birth and ten months were four times more likely to be diagnosed with Pervasive Developmental Disorder while Giacomo and Fombonne (1998) found that parental age of first concern was earlier for those with history of intellectual disability or medical problems.

Chawarska (2007) and Giacomo and Fombonne's (1998) results are not surprising as it is possible that pervasive developmental delay, intellectual disability, and medical problems result in more noticeable behaviors and symptoms. The mixed results of these

studies may suggest that it is not the set of diagnostic characteristics but rather the severity of presentation of symptoms that may first alert parents to developmental problems in their child. Autism Spectrum Disorder is a disorder that encompasses a varying range of symptoms, skills, and levels of disability in functioning. Some individuals with Autism Spectrum disorder require intense support to perform activities while others require minimal support (American Psychiatric Association, 2013.) Daniels and Mandell (2014) reviewed 42 articles that addressed age of diagnosis of Autism Spectrum Disorder and found that children who were considered higher functioning (e.g. had higher communication skills and/or higher IQ) were associated with later diagnosis.

One factor that is associated with earlier reported concerns and in shorter delay in seeking evaluation service involves having an older sibling. Herlihy, et al. (2015) examined a sample of 69 children diagnosed with Autism Spectrum Disorder. The sample was divided into three groups: "no siblings", "sibling(s) with typical development", and" sibling(s) with Autism Spectrum Disorder". Parents in the "siblings with Autism Spectrum Disorder" group reported the earliest concerns about their child; the mean age of first concerns for this group was ten months. Parents in the "siblings with typical development" group reported a mean age of first concerns of fourteen months; and the latest age of first concern (sixteen months) was reported by parents in the "no siblings" group (Herlihy, et al, 2015). Data collected from the Interactive Autism Network, a national on-line registry of parents of children with Autism Spectrum Disorders found the age of initial parental concern was later for first born children, older

children, and those initially diagnosed with a disorder other than autism (Rosenberg, et al., 2011). The results of Herlihy (2015) and Rosenberg et al. (2011) are not surprising as parents with older children with Autism Spectrum Disorder have knowledge and awareness of the developmental characteristics associated with Autism Spectrum Disorder and parents with typically developing children have knowledge and awareness of normal developmental milestones which provide a frame of reference in identifying concerns in their younger children.

Cultural Issues in Assessment of Autism Spectrum Disorder

Ethical practice mandates that psychologists respect individual differences with regards to race, ethnicity, and cultural beliefs when conducting assessment and providing interventions (APA, 2010). However, Rupasinha (2015) found that cultural issues arise in the evaluation of children with Autism Spectrum Disorder. The clinicians in Rupasinha's (2015) study reported a lack of confidence in conducting effective Autism Spectrum Disorder assessment when there was ethnic, minority, or cultural factors involved such as attitudes toward gender, disability, and the extent to which parents sought help. This indicates a need for culturally competent approaches to training psychologists in working with minorities.

In order to alleviate any cultural bias, it is important for psychologists to implement services that are culturally competent. One model of implementing culturally sensitive childhood assessment of Autism Spectrum Disorder was proposed by El-Ghoroury and Krackow (2012). This model includes conducting a thorough

developmental history to include records review; conducting the Autism Diagnostic Observation System-Second Edition (ADOS-2) or a test of language development; administering an autism screening measure, consulting with clinicians more experienced in autism assessment and following up with the family in a timely manner (El-Ghoroury & Krackow, 2012).

Despite efforts to utilize culturally competent instruments and assessment practices research indicates that cultural issues exist in the evaluation of young children with Autism Spectrum Disorder. Rosenberg, et al.'s (2009) analysis of a large sample (*N*=6,176) of children diagnosed with Autism Spectrum Disorder from 1994 through 2007 found that Children diagnosed with Autism Spectrum Disorder were most likely to be Caucasian and least likely to be Hispanic. However, this data was taken from the Interactive Autism Network which is an online network where parents of children diagnosed with Autism Spectrum Disorder are invited to complete several questionnaires related to their experiences in evaluation and treatment of their children. As such, these results may be skewed as this sample is biased towards families with higher education and sufficient resources to complete on-line surveys (Rosenburg, et al., 2009).

Another study that may represent a skewed sample is that of Thomas et al. (2012). This study examined data from four counties in New Jersey as a follow up to prior findings of a higher prevalence of Autism Spectrum Disorder in New Jersey compared to thirteen other states. Three of the four counties examined represented a range of socioeconomic statuses. The fourth county studied, Ocean County, was included to

continue the CDC's evaluation of unusually high prevalence of Autism Spectrum Disorder reported in this county. Data was extracted from the Center for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) network on children from the selected counties who were eight years old in 2000 or 2002 with the objective of examining possible associations between socioeconomic status and prevalence of Autism Spectrum Disorder diagnosis. The results of this analysis found that diagnosis of Autism Spectrum Disorder was higher in Caucasian and Asian participants and that the number of evaluations was higher and the diagnosis of Autism Spectrum Disorder was given at a younger age in higher income populations. In multivariable models race/ethnicity did not predict diagnosis of Autism Spectrum Disorder but the prevalence of diagnosis was 2.2 times higher when comparing highest to lowest socioeconomic status. The authors speculated that this may be due to parents with higher incomes having greater resources and access to higher quality of services both in schools and in medical care (Thomas et al., 2012). This suggests that regardless of ethnicity, socio economic status may be a greater predictor of whether or not parents are able to identify concerns and access services.

Another variable associated with earlier identification of Autism Spectrum Disorder is that of language spoken in the home. Jo, et al., (2015) examined a sample of 2,729 children, aged three–seventeen, diagnosed with Autism Spectrum Disorder utilizing the National Survey of Children with Special Health Care Needs. This study examined age of first concern and household language finding that non-English speaking

Hispanic individuals were more likely to be diagnosed earlier than the other English speaking ethnic groups. These results contradict previous studies on race/ethnicity and diagnosis age and serve as an indicator of the need for further research on this topic (Jo et al., 2015).

Ethnicity and Age of First Concerns

It is difficult to ascertain if there is a significant relationship between variables associated with ethnicity and age of parent's first concerns in children diagnosed with Autism Spectrum Disorder. The research addressing these variables is inconsistent. Some research indicates an ethnic disparity in recognition and diagnosis of Autism Spectrum Disorder (Mandel, el al., 2009; Rosenberg, Landa, Law, Stuart, & Law, 2011); while other research studies indicate no statistical differences in ethnicity and diagnosis of Autism Spectrum Disorder (Jang, Matson, Cervantes, & Konst, 2014; Rice, 2007; Williams, Matson, Beighley, & Konst, 2015).

One of the earliest research studies to examine ethnic variables in recognition of Autism Spectrum Disorders was conducted by Mandell, et al., (2009). This study sample included all 2,568 children born in 1994 who met the diagnostic criteria for Autism Spectrum Disorder as defined in the Center for Disease Controls and Prevention's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) network in the study year 2002. This study specifically examined ethnicity as the independent variable. The following ethnic categories were identified: Asian, Black/African American, Hispanic, White, or Other. Results indicated that children who were Black, Hispanic or other

ethnicity were less likely than White children to be diagnosed with Autism Spectrum Disorder (Mandell et al., 2009). Another study finding later identification of Autism Spectrum Disorder in Non-Caucasian participants was conducted by Rosenberg, et al., (2011). This multivariate study examined many variables associated with both age of first concern and age of diagnosis in a large sample (N= 6,214) of individuals diagnosed with Autism Spectrum Disorder with completed primary history profiles in the Interactive Autism Network (IAN) database. Similar to Mandel's findings, this study found that Non-Caucasian individuals were associated with later age of first concern and later diagnosis (Rosenberg, et al., 2011).

While the studies of Mandel et al. (2009) and Rosenberg et al. (2011) indicate a racial disparity in identification and diagnosis of Autism Spectrum Disorder, other researchers have found no statistical differences associated with race/ethnicity and parental first concerns and diagnosis of Autism Spectrum Disorder (Jang, et al., 2014; Rice, 2007; Williams, et al. 2015). Jang et al. (2014) examined the relationship between ethnicity and the age of first parental concerns in toddlers diagnosed with Autism Spectrum Disorder participating in a state's Early Steps early intervention services. The study sample consisted of 1,478 children whose ages ranged from 17 to 37 months. Of the study's sample 255 were diagnosed with Autism Spectrum Disorder while the other 1,223 were diagnosed with a developmental delay or conditions such as Down syndrome, seizure disorder, sickle cell anemia, premature birth or microcephaly. The participants' ethnic groups were "Caucasian" (n=799), "African-American" (n=552), and "other"

(n=127). An Analysis of Covariance was conducted with Ethnicity and diagnostic group used as independent variables and age of first concern used as the dependent variable. The results of this study indicated no differences in race/ethnicity and age of first parental concerns (Jang, et al., 2014).

Another study that utilized Early Steps data but included a larger participant sample was conducted by Williams, et al. (2015). This study examined toddlers who failed an Autism screening instrument and were referred for assessment for Autism Spectrum Disorder. The sample consisted of 7,464 toddlers between the ages of 17 and 37 months. The ethnicity of the participants was classified as "Caucasian" (n= 3,906) and "Other" (n=3,558). Multivariate Analysis of Variance (MANCOVA) was conducted using Age, Severity of Symptoms, and Race as variables. The results of this study found that the age of diagnosis of Autism Spectrum Disorder did not differ between Caucasian and children of African American or other ethnicities (Williams, et al., 2015).

Rice (2007) reported on data from the Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance for the year 2000. Utilizing this multisite network, information on 1,252 children aged eight years old identified as having Autism Spectrum Disorder was analyzed to determine prevalence characteristics for this population. Results indicated that the majority of children with Autism Spectrum disorders had documented concerns before age three, and had a median diagnosis age of 52-56 months of age. There were no significant differences in prevalence of Autism Spectrum Disorder in Non-Caucasian and Caucasian children (Rice, 2007).

Given the differing results in research examining ethnicity and age of first concerns and diagnosis of Autism Spectrum Disorder, there is a need for further research on these variables and other variables that may impact age of first concerns and diagnosis.

Severity of Diagnosis and Age of First Concerns

Autism Spectrum Disorder is a disorder that is characterized by symptoms that result in a varying range of impairments in communication, cognitive, social, and adaptive functioning. The DSM-V classifies severity of Autism Spectrum Disorder symptoms into three levels. Level Three, "Requiring very substantial support", includes individuals who present with severe symptomology that significantly impacts their functional abilities. Level two, "Requiring substantial support", includes individuals with moderate symptomology that limits functional abilities. Lastly, Level one, "Requiring support", includes individuals who have minimal symptomology and may require support services to function optimally (American Psychiatric Association, 2013.)

It is likely that the presentation of symptoms in young children may have an impact on age of first parental concern and subsequent diagnosis of Autism Spectrum Disorder with less severe symptoms resulting in later recognition and diagnosis. Giacomo and Fombonne (1998) examined a sample of children diagnosed with an Autism Spectrum Disorder at a specialized clinic in the United Kingdom. Information pertaining to diagnosis and severity of symptoms was obtained through clinical evaluation using the Autism Diagnostic Interview-Revised and appropriate psychological tests of language

and intelligence. The authors reported that the severity of cognitive and physical delays were associated with earlier parental recognition of problems as opposed to impairments in social communication or presentation of circumscribed interests or restrictive behaviors that are characteristic of Autism Spectrum Disorders. Giacomo and Fombonne (1998) utilized appropriate clinical assessment protocols for determination of diagnosis and severity of symptoms, however, this study did not examine ethnicity to determine if this variable influenced age of first concerns reported by parents.

It is possible that the severity of Autism Spectrum Disorder may affect ethnic/racial variations in recognition and diagnosis. Jo et al. (2015) examined severity of symptoms as one variable in the evaluation of Autism Spectrum Disorder by race, ethnicity and household language. Information pertaining to the diagnosis of Autism Spectrum Disorder and Severity was obtained through parental survey. As part of the National Survey of Children with Special Needs parents were asked "Has a doctor or other health care provider ever told you that [CHILD] had autism, Asperger's disorder, pervasive developmental disorder or other autism spectrum disorder?' and if yes, "Does [CHILD] currently have autism or an autism spectrum disorder?" Children of parents answering yes to both questions were classified as participants having Autism Spectrum Disorder. Information pertaining to severity of diagnosis was obtained through parental description of their child's symptoms as mild, moderate, or severe. The results of this study indicated that for parents reporting mild or moderate Autism Spectrum symptomology, Non-Caucasian children were identified and diagnosed earlier; while for

parents reporting severe symptomology, Non-Caucasian children were diagnosed later than Caucasian children (Jo et al. 2007). One limitation of this study was that categorization of severity of symptoms relied solely on the report of parents which is subjective. Additionally, the authors did not utilize a valid and reliable measurement to categorize severity of symptoms.

Another study which examined how ethnicity was associated with age and severity of Autism Spectrum Disorder was conducted by Williams, et al., (2015). Utilizing data from a state Early Steps program 7464 participants were designated in the ethnic categories of Caucasian or Other. The Baby and Infant Screen for Children with aUtIm Traits- Part One (BISCUIT-Part 1) was administered to parents in order to identify the level of observed impairment in their child. Additionally, the Battelle Developmental Inventory, Second Edition (BDI-2) was used to measure multiple domains of development. While results did not indicate statistical differences in age of diagnosis between Caucasian and other ethnicities, the authors did note that Non Caucasian children did score higher and present with more deficits on the diagnostic assessment of Autism Spectrum Disorder. These results indicate that Non Caucasian children that are identified for assessment are those with more severe symptoms. This could indicate that milder symptoms in Non Caucasian children go unrecognized by parents and/or caregivers. The brevity of research on the severity of symptoms, ethnicity, and age of first concerns and diagnosis warrants continuing research.

Limitations in Existing Literature

The research on Autism Spectrum Disorders indicates that symptoms of developmental problems are noticeable by a child's first birthday; however, there is a delay in referral for evaluation and diagnosis of Autism Spectrum Disorder (CDC, 2015). Research has produced varying results in determining a specific variable associated with earlier versus later parental recognition of developmental problems in children diagnosed with Autism Spectrum Disorder (Charwarska, et al., 2007; Giacomo & Fombonne, 1998; Guinchat, et al., 2002). There are mixed results also in the research examining race/ethnicity and age of recognition and diagnosis of Autism Spectrum Disorder with some research indicating Non-Caucasian are diagnosed later than Caucasian children (Mandel, et al., 2009; Rosenburg, et al., 2011); while other studies indicate no racial/ ethnic differences in recognition and diagnosis of Autism Spectrum Disorder (Jang, et al., 2014; Price, 2007; Williams, et al., 2015). There is very limited research that examined both race/ethnicity and severity of symptoms in age of first concerns and diagnosis of ASD. The results were again inconsistent with Jo, et al. (2015) reporting that mild/ moderate symptom in Non-Caucasian participants resulted in earlier recognition and Williams, et al. (2015) reporting that Non-Caucasian participants were associated with more severe symptomology. The research conducted by Jo, et al. (2015) utilized information obtained solely through parental report of symptomology while Williams, et al. (2015) utilized both a parent report assessment, BISCUIT-Part 1 and a clinical assessment, Battelle Developmental Inventory- Second Edition of developmental

problems. There is a need for continuing research utilizing both parental report and clinical evaluation procedures to clarify the relationship between race/ethnicity, severity of symptoms, and age of first parental concern and diagnosis of Autism Spectrum Disorder. The information learned from continuing research utilizing comprehensive evaluative procedures will help improve the diagnostic process for all ethnicities and severity levels. Education on early recognition and intervention will improve the outcomes for all individuals with Autism Spectrum Disorder.

Discussion of Purpose of this Research Project

Research has demonstrated that early intervention for children diagnosed with Autism Spectrum Disorders has resulted in positive outcomes (Dawson et al., 2012, Estes et al., 2015, and Reed & Osborne, 2012), however there is a gap between parental recognition of developmental problems in their child and eventual diagnosis of Autism Spectrum Disorder (CDC, 2015; Giacomo & Fombonne, 1998; Jang, et.al, 2014). There is no clear behavioral symptom of ASD that is identified in the research as being recognized earliest by parents (Charwarska, et al., 2007; Giacomo & Fombonne, 1998; Guinchat, et al., 2002). Understanding the type of symptoms that parents report recognizing earliest will help the professional community to better recognize potential symptoms, screen for Autism Spectrum Disorder and make appropriate referrals for thorough evaluative procedures.

Autism Spectrum Disorder is characterized by difficulties in communication and social interaction and presentation of restrictive and/or repetitive behaviors.

Additionally, the behaviors characteristic of Autism Spectrum disorder may range from mild to severe (American Psychiatric Association, 2013). It is likely that the most severe symptoms and behaviors of Autism Spectrum Disorder are recognized early by both parents and professionals resulting in earlier diagnosis. Understanding the dynamic relationship between severity of symptom presentation and parent recognition and help-seeking behaviors could lead to the development of public awareness and education programs to increase parents' recognition of the more subtle and discrete symptoms and behaviors of ASD that are apparent early in a child's development.

The research on racial disparities in age of diagnosis of Autism Spectrum disorder is contradictory. The fact that some researchers find that Non Caucasian children are identified and diagnosed later than Caucasian children (Mandel, et al., 2009; Rosenburg, et al., 2011) and others find no racial/ethnic differences (Jang, et al., 2014; Price, 2007; Williams, et al. 2015) may represent differences in study samples or regional differences in referral and evaluative processes. Identifying and examining racial/ethnic differences in recognizing and diagnosing Autism Spectrum Disorder could lead to improved and more ethical clinical practice which would benefit all individuals seeking diagnosis and treatment for developmental concerns. Additionally, examining the dynamics of both race / ethnicity and severity of symptoms would provide information to help clinicians understand if there are ethnic differences in perceptions of severity of symptoms and if these different perceptions result in later diagnosis of Autism Spectrum disorder.

To add to the body of literature on predictive factors of Autism Spectrum Disorder, the purpose of this research proposal was to determine if there are variables associated with earlier parental concerns and diagnosis in children with Autism Spectrum Disorders served in the regional area of Northwest Louisiana. Specifically, this research examined the variables of ethnicity and severity of symptoms to determine if one or both are associated with earlier report of parental concerns and earlier diagnosis. This study also categorized and examined type of first concerns reported by parent to determine if certain characteristics of Autism Spectrum Disorder are recognized earlier by parents. The information obtained in this research could allow for earlier intervention and thus better outcomes for children with Autism Spectrum Disorder at all severity levels and within all ethnic classifications.

The following hypotheses were considered in the analysis of data:

Hypotheses

Age of First Parental Concerns

1. It was hypothesized that parents of non-Caucasian children would have a higher age of first concern.
2. It was hypothesized that parents of children with higher severity of diagnosis would have lower age of first concern.
3. When both ethnicity and severity are examined, it was hypothesized that parents of non-Caucasian children with more severe symptoms would have a lower age of first reported concerns.

4. It was hypothesized that concerns related to communication delays would be associated with earlier age of first concerns.

Age of Diagnosis

1. It was hypothesized that non-Caucasian children would have a higher age at diagnosis.
2. It was hypothesized that children with higher severity of symptoms at diagnosis would have a lower age at diagnosis.
3. When both ethnicity and severity are examined, it was hypothesized that non-Caucasian children with more severe symptoms would have a lower age at diagnosis.
4. It was hypothesized that concerns related to communication delays will be associated with earlier age of diagnosis.

CHAPTER III

Methods

Participants

The participants in this study consisted of children evaluated at Louisiana State University- Health Sciences Center, Shreveport's (LSUHSC-S) Children's Center. Archival data was utilized to include children that received the diagnosis of Autism Spectrum Disorder using the Autism Diagnostic Interview- Revised (ADI-R) and the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2). The age of participants in this research reflected the ages served at the LSU-HSC Shreveport's Children's Center and ranged from 1year, 9 months to 15 years, 10 months. One hundred forty nine archived charts were utilized from the case files of the LSUHSC-S Children's Center ranging from services dates of January 2012 through June 2016. Each case was recognized using a numerical code/chart number. The primary investigator in the study had access to information to link the numerical code/chart number to the archived clinical record. No name or other information that would identify an individual was used in the course of this research. Prior to evaluation at LSU-HSC Shreveport Children's Center, parents sign written permission indicating that their child's evaluation information could be reviewed for assessment, research, and/or teaching purposes with the understanding that their child's name will be kept confidential.

Setting

The LSUHSC-S Children's Center provides comprehensive evaluation of children in the region of Northwest Louisiana. This region includes the metropolitan area of Shreveport/Bossier City and the surrounding rural areas. The majority of participants in this study resided in parishes in the Northwestern part of the state of Louisiana to include: Caddo, Bossier, Claiborne, Desoto, Lincoln, Natchitoches, Red River, Sabine, and Webster, however, 37 participants resided outside this regional area. Previous statistics from the Children's Center indicated the ethnic population seen was 55% Caucasian; 40% African American, and 5% Other (Hispanic, Bi-Racial, Asian, and Native American).

The LSUHSC-S Children's Center faculty has been trained in the administration of the ADOS-2 and the ADI-R instruments which are considered psychometrically sound in the diagnosis of Autism Spectrum Disorder. Children who are suspected of having a developmental disability were referred for evaluation. Referrals were made for a variety of reasons including: educational/academic difficulties, psychological problems, delays in gross and/or fine motor skills, visual perceptual and sensory issues, speech-language-hearing development, and counseling requests. Children were referred by school system personnel, pediatricians, speech-language therapists, occupational therapists, mental health professionals, and/or by their parents. The LSUHSC-S Children's Center provided an Interdisciplinary team of professionals that may have participated in the evaluation process according to the child's individual needs. The interdisciplinary team included the

following disciplines: medicine, psychology, physical therapy, occupational therapy, speech/language therapy, marriage and family therapy, social work, audiology, and education.

Measures

Age of first parental concern. The outcome variable of Age of First Parental Concern was measured using the Autism Diagnostic Interview- Revised (ADI-R). The ADI-R is a semi-structured interview conducted between a clinician and a parent or caregiver of an individual for whom the diagnosis of Autism Spectrum Disorder was considered. The examiner asked the parent/caregiver questions regarding the family's medical and social history, and the child's developmental history. Questions included asking the parent/caregiver the age when they first noticed that something was not quite right in their child's language, relationships, and/or behavior and what were the symptoms/behaviors to first arouse parental concerns. Additional questions focused on behaviors in three content domains: quality of social interaction, communication and language, and repetitive, restricted and stereotyped interests and behaviors. The variable of Age of First Parental Concern was collected through information provided on the ADI-R question #2- "Age in months when parents first noticed that something was not quite right in language, relationships, or behavior". The age variable was coded months. In instances where the parent did not report a specific age that symptoms were first noticed but rather reported an age range, a median age was calculated. For example, if the parent

reported first recognition of symptoms between the ages of one and two, the age of first concerns was calculated at 18 months.

Age of diagnosis. The outcome variable of Age of Diagnosis was obtained from calculating the age of the child at the time of the evaluation resulting in the diagnosis of Autism Spectrum Disorder. The child's chronological age was recorded on both the ADI-R and ADOS-2 protocols at the time of evaluation. During data collection the age of diagnosis was recorded using the age recorded on the ADI-R. The Age of Diagnosis variable was coded in months.

Ethnicity. The variable of Ethnicity was identified through the participant's demographic data completed as part of the application for evaluation. The application for evaluation was created by the Children's Center and is part of the intake packet that was completed in writing by parents before the evaluation was scheduled. The ethnicity variable was coded as either Caucasian or Non-Caucasian to reflect the ethnic population served through the LSUHSC-S Children's Center. The ethnicity of the children receiving evaluation at the Children's Center are primarily Caucasian or African American with an estimated slight majority of Caucasian children served through the center. The ethnic breakdown of children identified in this study were Caucasian (*N*= 84) and Non Caucasian *(N*=65). The Non Caucasian category was distributed as follows: African American (*N*=43), Hispanic (*N*=9), Asian (*N*=3) and Other/ BiRacial (*N*=10).

Severity of symptoms. The Severity of Symptoms variable was obtained through the child's scores on the Autism Diagnostic Observation System –Second Edition

(ADOS-2). The ADOS-2 is a semi-structured, standardized assessment of communication, social interaction, play, and restricted and repetitive behaviors. This assessment presented various activities that elicited behaviors related to a diagnosis of Autism Spectrum Disorder. Two trained clinicians observed and coded the child's behaviors in three categories; Communication, Reciprocal Social Interaction, and Restricted and Repetitive Behavior. The scores for each of the categories were compiled utilizing an algorithm based on the child's age and language level. The scores were converted to a comparison score from 1-10. The diagnostic probability of Autism Spectrum Disorder was obtained based on the comparison score as follows: 1-2 points—Minimal to No evidence of Autism Spectrum Disorder; 3-4 points—Low level of Autism Spectrum-related symptoms; 5-7 points—Moderate level of Autism Spectrum Related symptoms; or 8-10 points—High level of Autism Spectrum-related symptoms. The Severity of Symptoms variable was coded numerically based on the participants' total score on the ADOS-2 assessment. The ADOS- 2 scores for this research ranged from 8-36.

Type of first parental concern. The Type of First Parental Concern variable was categorized based on parental report on the ADI-R question #3, "What was it that gave you concern at that time?" The type of concern was coded by the principle researcher as either "Social", "Communication", "Restrictive, repetitive, and/or stereotyped behavior", "Other", "No concerns" or "Multiple concerns" based on the diagnostic categories

identified through the ADOS-2. The criteria used to code Type of Concern are depicted in Table 1 below.

Table 1

Type of Concern

Type of Concern	Definition	Example
Communication	Lack of or delay in spoken language with failure to compensate with gestures; lack of varied spontaneous make believe or social imitative play, relative failure to initiate or sustain a conversational interchange, or idiosyncratic speech	"she wouldn't talk, she'd only repeat what she heard others say"
Social	Failure to use non-verbal behaviors to regulate social interactions, failure to develop peer relationships, lack of shared enjoyment, & lack of social-emotional reciprocity	"he was not interested in playing with other kids"
Restrictive/ Repetitive or Stereotypic Behaviors	Reported preoccupation or circumscribed interest, compulsive adherence to nonfunctional routines or rituals, stereotyped or repetitive motor mannerisms, or preoccupation with parts of objects on nonfunctional elements of materials	"he spent most of his time lining things up"
Other	Any other reported behavior that didn't involve communication, social interaction, or restrictive, repetitive or stereotyped behavior	"she would scream for no apparent reason".
Multiple concerns	Parent reports behaviors is two or more of the identified types of concerns	"he wouldn't talk" (communication) & "he would flap his hands" (repetitive behavior)
No Concerns	The parents report that they were not concerned about child's development; someone else advised them to seek evaluation	

Procedure

Prior to the collection of data approval to conduct research involving human subjects was obtained through the Institutional Review Boards of both Stephen F. Austin State University and Louisiana State University Health Sciences Center's School of Allied Health. Case data utilized for this study was entered in a database using the software program Statistical Package for the Social Sciences (SPSS). Efforts to insure patient confidentiality were followed during all phases of data extraction and analysis. The evaluation files were stored in locked file cabinets in the offices of the LSU-HSC-S School of Allied Health Sciences. Cases that involved an Autism Evaluation utilizing both the ADOS-2 and the ADI-R and resulting in a diagnosis of Autism Spectrum Disorder were identified by name and case number and were provided to the researcher in this project. The researcher located each case file and recorded the information required for this project on a paper data sheet. Data was subsequently entered in the SPSS database and analyses were run. No identifying information was entered into the data system. All data recording took place within the confines of the workspace at the LSUHSC-S Children's Center offices. Case files were returned to the locked file cabinets upon completion of data extraction. The paper data sheets containing participant information were kept by LSU-HSC Children's Center staff and were stored in a locked file cabinet when not in use for this project.

The principle researcher on this project was the only person that coded information contained in the case files and entered information into SPSS. The research

variables were sufficiently defined as to be straightforwardly identified in the case file as reported by parent or determined by diagnostic algorithm. The LSUHSC-S Children's Center faculty including the clinical staff responsible for evaluation and diagnosis were available for consultation for any questions that arose regarding coding parental report of types of concerns.

Data Analysis

Appropriate statistical analysis was conducted to determine each targeted variable's effect on both age of first parental concern and age of diagnosis of Autism Spectrum Disorder. T-tests were conducted to determine if there were differences in Caucasian and Non-Caucasian's report of parental first concern and subsequent diagnosis. A Correlation was run to evaluate if severity of symptom was associated with age of first parental concern and diagnosis. A linear regression was utilized to examine the effect of both ethnicity and severity of symptoms on age of first parental concern and age of diagnosis. A one-way Analysis of Variance (ANOVA) was conducted to examine the type of first reported parental concern and a post-hoc multiple comparison analysis was run to compare each type of concern.

CHAPTER IV

Results

Ethnicity

In order to test the hypothesis that Non- Caucasian children will have a higher age of first parental concern and a higher age of diagnosis independent samples t-tests were conducted to evaluate whether there was a difference between Caucasians and Non-Caucasians. For Age of first concern the results indicated that the mean for Caucasians (*M*=24.15, *SD*= 19.45) was not statistically different from the mean for Non-Caucasians (*M*=20.12, *SD* = 14.63); *t* (147) =1.39, (*p* = .166, *p* > .05). Similarly, for age of diagnosis the results indicated that the mean for Caucasians (*M*=54.82, *SD*=39.68) was not statistically different from the mean for Non-Caucasians (*M*=54.49, SD=31.87); *t* (147) = 0.55, (*p* = .957, *p* > .05) Thus, for these t-tests we retain the null hypothesis that there are no statistical differences in age of first concern or age of diagnosis between Caucasians and Non-Caucasians.

The ethnic breakdown of children identified in this study were Caucasian (*N*= 84) and Non Caucasian *(N*=65). The Non Caucasian category consisted of: African American (*N*=43), Hispanic (*N*=9), Asian (*N*=3) and Other/ BiRacial (*N*=10). As there were so few other ethnicities other than Caucasians and African Americans, a second independent samples t-test was conducted to examine only these two ethnicities for both age of first concerns and age of diagnosis. The results indicated that for age of first

concern the mean for Caucasians (M=24.15, SD= 19.45) was not statistically different from the mean for African Americans (M=22.07, SD = 15.55); t (125) =.61, (p = .54, p > .05). The results for age of diagnosis indicated that the mean for Caucasians (M=54.82, SD=39.68) was not statistically different from the mean for African Americans (M=51.58, SD=32.17); t (125) = 0.46, (p = .64, p > .05). These results indicated that there were no differences in age of first concern or diagnosis in participants from the two ethnic categories that represented the majority of the study's population.

Severity of Symptoms

To test the second hypothesis that parents of children with higher severity of symptoms will have a lower age of first concerns and diagnosis, a Pearson's product moment correlation coefficient was conducted to evaluate whether severity of symptoms was associated with age of reported first parental concerns and diagnosis. The results for age of first concern, shown in Table 2, indicate a negative correlation between age of first concerns and severity of symptoms r (149) = -.291, p < .01. This correlation indicates that as the severity of symptoms increases, the age of parent's first concern decreases.

Table 2
Severity of Symptoms and First Concerns Correlation

		Age of First Concern	ADOS-2 score
Age of first concerns	Pearson Correlation	1	-.291**
	Sig. (2-tailed)		.000
	N	149	149
ADOS-2 score	Pearson Correlation	-.291**	1
	Sig. (2-tailed)	.000	
	N	149	149

Note. ADOS-2 = Autism Diagnostic Observation System- Second Edition

Similar results were found for age of diagnosis shown in Table 3. These results also indicate a negative correlation between age of diagnosis and severity of symptoms $r(149) = -.404$, $p < .01$. This correlation indicates that as the severity of symptoms increases the age of diagnosis decreases. These results reject the null hypothesis and support the proposed hypotheses for this project variable.

Table 3

Severity of Symptoms and Age of Diagnosis Correlation

		Age when Diagnosed	ADOS-2 score
Age when	Pearson Correlation	1	-.404**
diagnosed	Sig. (2-tailed)		.000
	N	149	149
ADOS-2 score	Pearson Correlation	-.404**	1
	Sig. (2-tailed)	.000	
	N	149	149

Note. ADOS-2 = Autism Diagnostic Observation System- Second Edition

Ethnicity and Severity of Symptoms

For the third hypothesis which stated that parents of Non-Caucasian children with more severe symptoms will have a lower age of first concerns and diagnosis, a multiple linear regression was calculated to predict age of parents' first concerns and diagnosis based on Ethnicity and Severity of Symptoms. For age of first concerns a significant regression was found (F [2, 146] = 7.74, $p < .001$), with an R^2 of .1. Participants' predicted age of parents' first concern is equal to 47.72 – .96 (Severity of Symptoms) - 3.75 (Ethnicity), where Severity of Symptoms is measured numerically, and Ethnicity is coded as 1 = Caucasian, 2 = Other. Age of first concerns decreased .96 months for each severity of symptom score and Caucasians reported 3.75 months earlier age of first concern than Non-Caucasian participants. Only the Severity of Symptoms was a

significant predictor of age of first concern. The results indicated that more severe symptoms are recognized earlier than less severe symptoms. Results are displayed in Table 4.

Table 4

Ethnicity and Severity Effect of Age of First Concerns

		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	T	Sig.
1	(Constant)	47.720	6.808		7.009	.000
	White_other	-3.755	2.779	-.106	-1.351	.179
	ADOS-2 score	-.956	.261	-.288	-3.657	.000

a. Dependent Variable: Age of first concern

Note. ADOS-2 = Autism Diagnostic Observation System- Second Edition

For age of diagnosis, a significant regression was found (F [2, 146] = 14.22, $p <$ .000), with an R^2 of .16 Participants' predicted age of diagnosis is equal to 111.87 – 2.775 (Severity of Symptoms) + .473 (Ethnicity). Age of diagnosis decreased 2.78 months for each severity of symptoms score and Caucasians reported .473 months later age of diagnosis than Non-Caucasian participants. Only the severity of symptoms was a

significant predictor of age of diagnosis. Results indicate that when the severity level increases the age of diagnosis decreases. Results are displayed in Table 5.

Table 5

Ethnicity and Severity effect on Age of Diagnosis

		Unstandardized Coefficients		Standardized Coefficients		
Model		B	Std. Error	Beta	T	Sig.
1	(Constant)	111.870	13.558		8.251	.000
	White_other	.473	5.535	.006	.086	.932
	ADOS-2 score	-2.775	.520	-.404	-5.333	.000

a. Dependent Variable: Age when diagnosed

Note. ADOS-2 = Autism Diagnostic Observation System- Second Edition

Type of Concern

To address the fourth hypothesis which stated that communication concerns will be associated with earlier age of first concerns and diagnosis. A One-way Analysis of Variance was conducted to compare the effect of the type of concern reported by parents on the age of first concerns and age of diagnosis. Types of concerns were representative of the symptom categories associated with Autism Spectrum Disorder diagnosis and included: Speech/Communication, Social Interactions, and Restrictive/Repetitive

behaviors. Additionally, the categories of Other, No concerns, and Multiple concerns were included to account for possible parent reported concerns. Due to low responses, the categories of "Social Interactions" and "Restrictive/Repetitive behaviors" were combined into one category, "Social or Behavioral"; likewise the categories of "Other" and "No concerns" were combined into the one category of "Other or No concerns". The results showed that the effect of type of concern on age of first concerns was significant, $F(3, 145) = 2.80$, $p = .042$. The means and standard deviations for each type of concern are displayed in Table 6.

Table 6

Type of Concerns and Age of First Concerns Characteristics

Age of first concern

Type of concern	N	Mean	Std. Deviation	Std. Error
Speech / Communication	82	20.33	8.53	.94
Social or Behavioral	24	29.71	24.64	5.03
Other/ No concern	24	26.25	31.35	6.40
Multiple concerns	19	17.21	6.29	1.44
Total	149	22.40	17.57	1.44

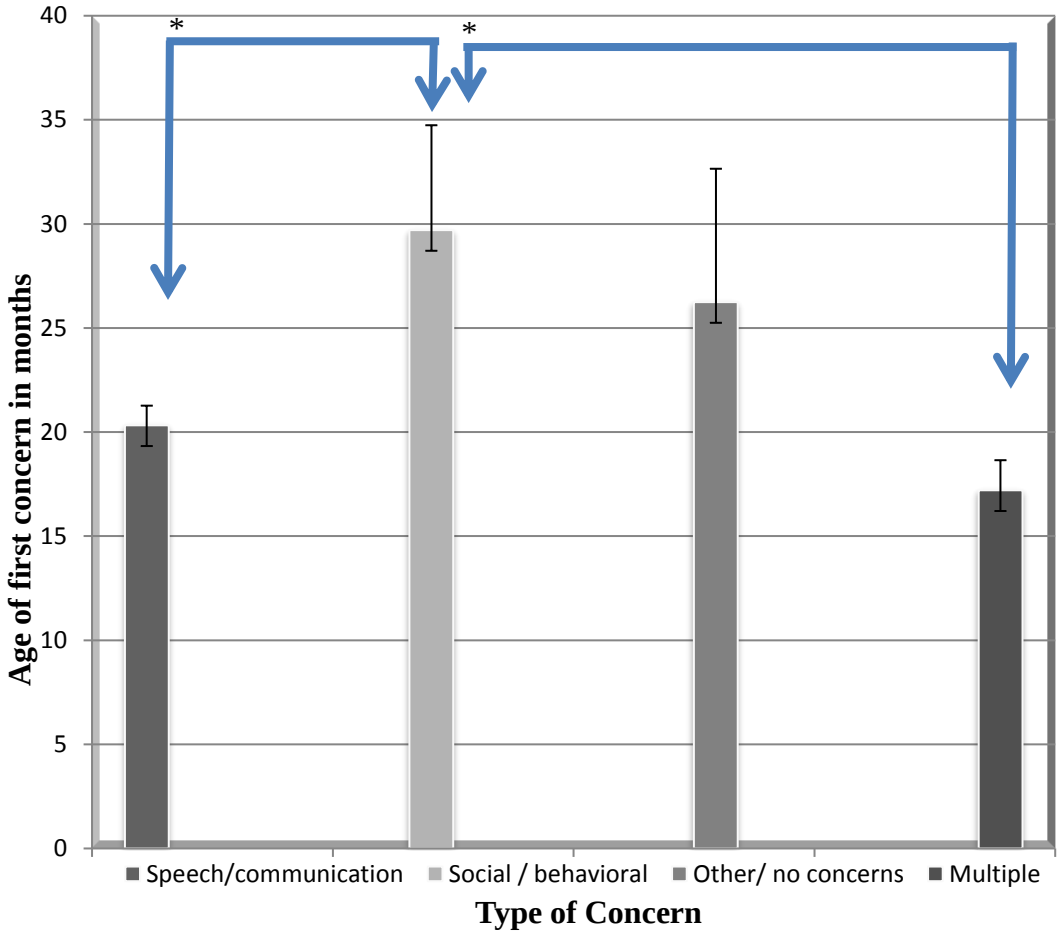
Note. The Mean for age of first concerns is coded in months.

Comparison of Type of Concern

The number of participants who identified Speech/Communication problems (*N*=82) was greater than each of the other types of concern: Social or Behavioral (*N*= 24), Other or No concerns (*N*= 24), or Multiple concerns *(N*= 19). A Post Hoc multiple comparison test compared the effect of each type of concerns reported by parents. Types of concerns were coded as 1= Speech/ Communication, 2= Social or Behavioral, 3=

Other or No concerns reported, or 4= Multiple concerns reported. There was a significant variance in the means of age of first concerns in those reporting speech /communication concerns (*M*= 20.33, *SD*=8.53) and those reporting Social or Behavioral concerns (*M*=29.71, *SD*=24.64). These results indicate parents reporting Speech/Communication concerns reported recognizing these concerns 9 months earlier than parents reporting Social or Behavioral problems as their first concern. Additionally, there was a significant variance in the means of age of first concerns in those reporting Multiple first concerns (*M* = 17.21, *SD*=6.29) and those reporting Social or Behavioral concerns (*M* = 29.71, *SD*=24.64) suggesting that children with multiple types of symptoms are recognized 12 months earlier that those with social or behavioral symptoms. These results are depicted in Figure 1.

Figure 1. Age of First Concerns Variance in Type of Concerns



* The mean difference is significant at the 0.05 level

The Analysis of Variance of type of concern and age of diagnosis showed that the effect of type of concern on age of diagnosis was significant, F (3, 145) = 9.586, p =.000. The means and standard deviations of each type of concern and age of diagnosis are displayed in Table 7.

Table 7

Type of Concern and Age of Diagnosis Characteristics

Age of Diagnosis

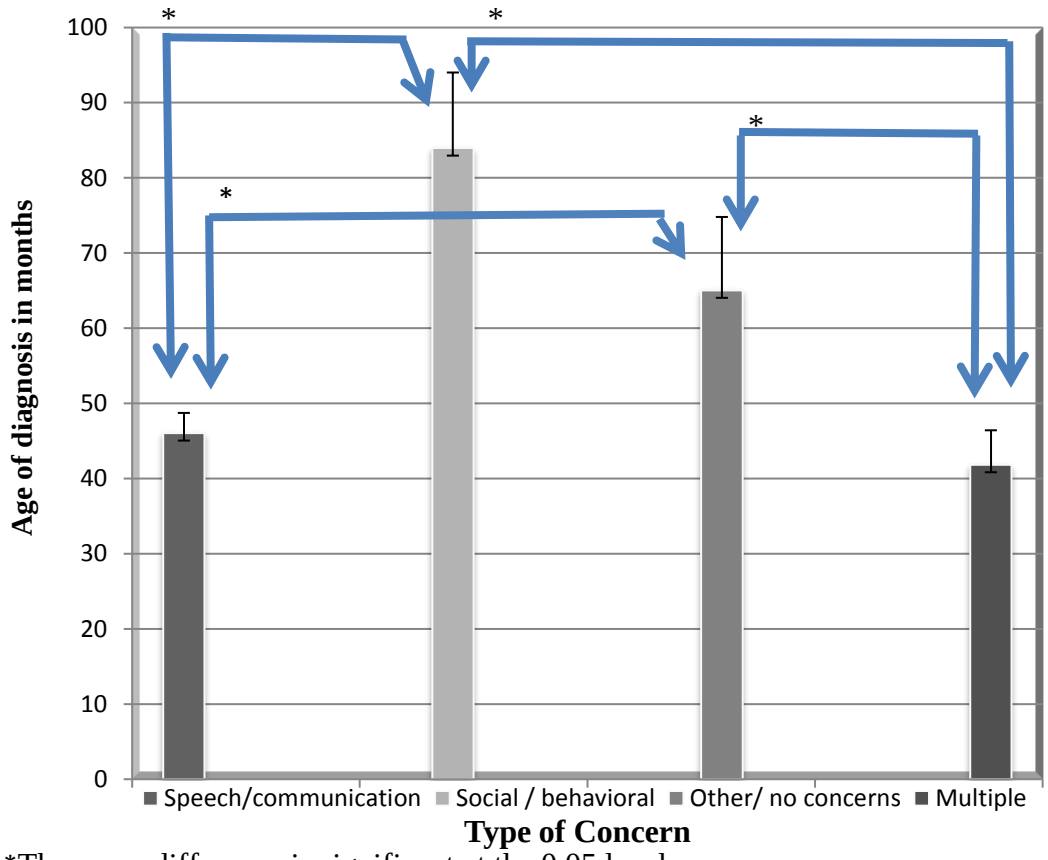
Type of concern	N	Mean	Std. Deviation	Std. Error
Speech / Communication	82	46.05	24.26	2.68
Social or behavioral	24	83.96	49.28	10.06
Other/ No concern	24	65.04	47.l8	9.76
Multiple	19	41.84	19.96	4.58
Total	149	54.68	36.36	2.98

Note. The Mean for age of diagnosis is coded in months.

A Post Hoc multiple comparison test compared the effect of each type of concerns reported by parents on the age of diagnosis. There was a significant variance in the means of age of diagnosis in those reporting Speech/Communication concerns (*M*= 46.05, *SD*=24.26) and those reporting Social or Behavioral concerns (*M*= 83.96, *SD*=49.28) and those reporting Other or No concerns (*M*=65.04, SD=47.18). These results indicate parents reporting first concerns related to Speech/Communication are diagnosed 37.9 months earlier than parents reporting Social or Behavioral problems as

their first concern and 18 months earlier than parents reporting Other or No concerns. Additionally, there was a significant variance in the means of age of diagnosis in those reporting Multiple first concerns (*M* = 41.84, *SD*=19.96) and those reporting initial Social or Behavioral concerns (*M* = 83.96, *SD*=49.28) and those reporting Other or No concerns (*M*=65.04, *SD*=47.18). These results indicate that children with multiple types of problems identified initially by parents are diagnosed 42 months earlier that those with social or behavioral symptoms and 23 months earlier than those whose parents reported other or no initial first concerns. These results are depicted in Figure 2.

Figure 2. Age of Diagnosis Variance in Type of Concerns



*The mean difference is significant at the 0.05 level

The results of analysis on the variable of type of concerns do not support the proposed hypothesis that Speech/Communication types of concerns would be associated with earlier ages of first concern and diagnosis.

CHAPTER V

Discussion

Overview of the Study

This study involved the compilation of data from archived client files for children diagnosed with Autism Spectrum Disorder at Louisiana State University Health Sciences Center Shreveport's (LSU-HSC S) Children's Center. The Children's Center provides a multidisciplinary team approach to evaluation of children's therapeutic needs and serves children from birth to age twenty-one. The children referred for evaluation for Autism were assessed by trained evaluators using the both the Autism Diagnostic Interview – Revised (ADI-R) and the Autism Diagnostic Observation Scale- Second Edition (ADOS-2). The principle researcher collected information on the child's demographic information and the targeted variables of ethnicity, severity of symptoms, and type of symptoms in efforts to determine if there was an effect on the age of first reported parental concerns regarding their child's development and the age of child's diagnosis with Autism Spectrum Disorder. It was hypothesized that Non Caucasian would have a higher age of first concern and diagnosis; that higher severity of symptoms would have a lower age of first concern and diagnosis; that Non Caucasian children with more severe symptoms would have a lower age of first concern and diagnosis; and that first concerns associated with communication would have a lower age of first concern and diagnosis.

The charts reviewed included records dating from January 2012 to June of 2016. A total of 149 charts were found to meet all criteria for inclusion in this research:

evaluation utilizing both the ADI-R and ADOS-2 resulting in diagnosis of Autism Spectrum Disorder. A paper data sheet was created to record the information extracted from the participants' charts. Data was then entered into the Statistical Package for Social Sciences (SPSS) database and analyzed to determine the effect of each variable on the age of first parental concern and diagnosis.

Interpretation of Findings

Ethnicity. It was hypothesized that Non-Caucasian children would have a higher age of first concerns and diagnosis. This hypothesis was not supported. There was no statistical difference in Caucasian and Non-Caucasian participants in this study. The ethnic groups in this research study consisted of primarily Caucasian and African American as there were very few other ethnicities included in the Non-Caucasian category. An examination of these two majority ethnic categories also indicated no statistical differences in age of first concern and diagnosis of Autism Spectrum disorder. As the previous research that had analyzed variables of ethnicity has been inconclusive this research adds to body of literature. This research refuted results found by Mandell et al. (2009) and Rosenberg et al. (2011) each of whom found that Non-Caucasian individuals were associated with later recognition of symptoms and diagnosis of Autism Spectrum Disorder. The results in this research supported results found by Jang et al., (2014), Beighly & Konst, (2015) and Price (2007).

Jang et al. (2014) and Beighly and Konst (2015) utilized large samples consisting of participants in a statewide early intervention program while Price (2007) utilized a large sample of children from a multisite monitoring network. The results of this research

indicate that even when the scope of evaluation is narrowed to a small sample of participants from one regional clinic that diagnostic procedures for Autism show no ethnic disparity in the age of first parental concern and age of diagnosis. The findings of no ethnic differences in recognition of symptoms and diagnosis of Autism Spectrum Disorder also indicate that the procedures conducted by the multidisciplinary team at the LSUHSC-S Children's Center are conducive with Ghoroury and Krackow's (2012) proposed model of cultural competent assessment and supports the use of the ADI-R (Rutter, Couteur, & Lord, 2017) and ADOS-2 (Lord et al., 2012) as culturally sensitive instruments in the evaluation of Autism Spectrum Disorder.

The results of this project were contradictory to research findings of Mandel et al. 2009 and Rosenburg et al. 2011. Mandel et al. (2009) utilized secondary data from the Autism and Developmental Disabilities Monitoring network which included case information from community data across fourteen sites while Rosenburg et al. (2011) utilized information from the Interactive Autism Network (IAN) database. Rosenburg (2011) indicated that use of the IAN database could have resulted in a skewed sample as it involves parents to complete an online survey, thus parents in this sample would have to have the education and resources to complete the survey. It is possible that the use of multi-site and on-line data had confounding variables related to demographic characteristics and diagnostic procedures that may have affected their results. This data collected for this project utilized the same diagnostic procedures with a core multi-disciplinary evaluation team.

Severity of Symptoms. It was hypothesized that parents of children with higher severity of symptoms at diagnosis will have lower age of first concern and diagnosis. This research supported this hypothesis. The results of the statistical analysis showed that severity of symptoms was related to age of first concern and age of diagnosis. This variable was coded using the total score from the ADOS-2 instrument. The ADOS-2 evaluation consists of standard social/play scenarios in which trained clinicians observe and score the presence of behavioral symptoms of Autism Spectrum Disorder. The behaviors are scored based on the severity of presentation (Lord et al. 2012). The analysis indicated that the higher the ADOS 2 score at evaluation the earlier the child's symptoms were recognized by parents and diagnosed by clinicians. These findings were consistent with Giacomo and Fombonne's (1998) early research on variables related to Autism diagnosis that indicated that severity of physical and cognitive delays were associated with earlier parental concerns and diagnosis. This inherently makes sense as the more severe a child's symptoms are the more likely parents will be to notice them earlier and seek evaluation resulting in earlier diagnosis of Autism Spectrum Disorder.

Ethnicity and Severity of Symptoms. When both ethnicity and severity of symptoms were examined, it was hypothesized that parents of Non-Caucasian children with more severe symptoms would have a lower age of first concern and diagnosis. This hypothesis was not supported. The analysis from this research showed that when both variables of ethnicity and severity of symptoms were examined there was an effect on the age for first parental concerns and diagnosis. The analysis indicated that severity of symptoms had a significant effect on both age of parent's first concern and diagnosis and

ethnicity had an insignificant effect. This indicated that as severity of symptoms increased the age of first concerns and diagnosis decreased and Caucasians had a slightly lower age of first concerns and diagnosis. When examining the interactions of both ethnicity and severity of symptoms, the only variable that was statistically significant was that of severity of symptoms indicating that the results of this analysis of combined variables was similar to the analysis of each of these variables separately.

This research project added to the very limited research that examined both ethnicity and severity of symptoms and their effect on age of first concern and age of diagnosis of Autism Spectrum Disorder. The two research articles reviewed for this project found conflicting results (Jang et al. 2007; Williams et al. 2015). Jang et al (2007) utilized parent survey data and found that Non-Caucasian children with more severe symptom presentation were diagnosed later than Caucasian children. However, severity of symptoms in Jang et al.'s (2007) research was identified by parental classification of their child's symptoms. It is possible that there may be racial variations in how parents rate their child's symptoms with one parent identifying symptoms as severe whereas another parent may rate the same symptoms as moderate or mild. As this research uses a subjective parent report of severity of symptoms it warrants further research utilizing a psychometric measurement of severity of symptoms. Williams et al. (2015) utilized instruments to measure severity of symptoms in a large sample of participants from a statewide early intervention program and found that Non-Caucasian participants that were identified for assessment were those who presented with more severe symptomology. The findings from this research project found that while severity

of symptoms did result in earlier parental first concerns and diagnosis; the participants that were served by the LSUHSC- S Children's Center did not vary by ethnicity in their recollection of age of first developmental concerns in their child and the age of subsequent diagnosis of Autism Spectrum Disorder.

Type of Concern. It was hypothesized that concerns related to communication would be associated with earlier age of first concern and diagnosis. The results of this research indicated that communication was the most often reported first concern of participants in this study. Of the 149 participant charts that were reviewed, 82 reported speech or communication as the type of concern that was first noticed; while 24 participants reported social or behavioral concerns, 24 reported other concerns or no concerns at all, and 19 participants reported multiple types of concerns. These results support previous research by Giacomo and Fombonne (1998) and Kozlowski et al. (2010) who also found that the most often reported first concern was related to speech/communication anomalies.

When developing the proposal for this project the variable of type of concern was to be broken down into six types of concerns:: "Speech/Communication," "Social Interaction" and "Restrictive or Repetitive Behavior" based on the diagnostic domains associated with Autism Spectrum Disorder; and "Other", "No Concerns", and "Multiple Concerns" to capture other possible parental responses to the ADI-R question #3, "What was it that gave you concern at that time?". Due to the marginal responses in the concern types other than "Speech/Communication" the categories of "Social Interaction" and

"Restrictive/Repetitive Behavior" were combined into one type "Social/Behavioral"; and the categories of "Other" and "No concerns" were combined, "Other/No concerns".

Those reporting Multiple concerns had the earliest age of first concern and diagnosis, followed by Speech/Communication, Other/No concerns, and Social/Behavioral. It is logical that multiple concerns would result in earlier first concerns and diagnosis as with severity of symptoms, those with multiple behaviors and symptoms are likely to be more noticeable for parents and thus arousing greater concern leading to earlier help-seeking behavior.

In examination of the types of concerns that align with the diagnostic criteria of Autism Spectrum Disorder Speech/Communication was associated with earlier age of recognition and diagnosis than Social/Behavioral. This is possibly due the fact that speech and communication skills are anticipated in the early development stages of young children and thus parents are more likely to become concerned when these skills are delayed or impaired.

An interesting finding in the examination of the type of concerns was that parents reporting "Other/no concerns" were also associated with earlier age of first concerns and diagnosis that those reporting "Social/Behavioral" concerns. It is possible the "other" category of concerns included behaviors that were extreme and alarming enough to parents to arouse concerns and prompt them to seek evaluation. Another possibility is that those parents reporting "no concerns" had astute family members, pediatricians, daycare workers, etc. who recognized ASD symptoms and encouraged them to seek evaluation. In considering "Social/Behavioral" types of concerns, impairments in social

interactions may not become noticeable until a child has routine exposure to other children in social situations which may not occur until they enter a daycare, preschool, or kindergarten type program. This is especially true if the child does not have siblings. Likewise, the presence of restrictive or repetitive behaviors may not be noticed if the behaviors are discreet or parents may presume that their child may lose interest or grow out of these behaviors.

Limitations of the Study

The study involved collection of data from archival patient charts and was limited to the information contained within these charts. Some records were not included in the sample as there were study elements missing (there was not an ADOS-2 or ADI-R available). The researcher had to review charts dating back four years to collect enough charts to meet the desired sample size. As all information was collected by the principle researcher there was no mechanism to capture interrater agreement on the data collected. Interrater agreement helps to ensure the reliability and validity of the data. Also the participants in this study were representative of a small regional clinic in Northwest Louisiana. The results from this study may not be an accurate representation of larger geographic regions of the United States or of parents of children with Autism Spectrum in general. One other limitation of this study is the use of the ADI-R which is a parent interview which relies of recollection of events. It is possible that parents may not recall situations accurately or may not recall some symptoms or behaviors at all.

Implications

This research project found no ethnic differences in age of first concerns and age of diagnosis. This indicates that within the catchment area of this clinic both Caucasian and Non-Caucasian participants have children whose symptoms are recognized and diagnosed early and some that are recognized and diagnosed later. The implication of this finding is that there is a need for public awareness and education on early ASD behaviors to parent populations in general regardless of ethnic backgrounds.

The results of this study found that evaluation participants whose ADOS-2 scores were higher at the time of evaluation, indicating more severe symptom presentation, were identified earlier by their parents and were subsequently diagnosed earlier. These findings suggest that parents and those working with young children would benefit from education on the symptoms and behaviors of Autism Spectrum Disorder that are more subtle and less severe in their presentation.

The findings also indicate parents reporting multiple types of first concerns were also recognized and diagnosed earlier and parents most often reported their initial concerns were associated with Speech/Communication problems. As multiple symptoms/behaviors are recognized earliest and communication deficits are most noticeable to parents in this study, it is important to increase the awareness of early behavioral symptoms of Autism Spectrum Disorder, especially more discrete behaviors that are related to social communication and/or restrictive/repetitive behaviors. It is also critical that once a parent has concerns regarding their child's development that they seek professional evaluation to diagnose or rule out the presence of Autism Spectrum Disorder.

Practitioner Level Recommendations

It is very important that any practitioner working with young children be aware of the symptoms associated with Autism Spectrum Disorder. This includes pediatricians, daycare/preschool workers, speech therapist, occupational therapists, etc. Parents expression of concerns about their child's development merit respectful and responsive behavior from their practitioner. It is expected that practitioners will be considerate of a parent's concern and will take appropriate actions to investigate concerns further. Practitioner's should be trained on the use of valid and reliable Autism Spectrum Disorder screening instruments and be afforded the opportunity to screen children at early developmental ages. It is crucial that the individual working with children suspected of having Autism Spectrum provide parents with information regarding Autism Spectrum Disorder symptoms, behaviors, and resources for more comprehensive evaluation. Information provided in nonclinical terminology with specific examples of behaviors associated with the disorder would be helpful to a parent struggling with the possibility that their child may meet criteria for Autism Spectrum Disorder. Parents would also benefit from information about early intervention services and evidence based treatment approaches for remediating ASD behaviors.

Funding and Policy Level Recommendations

One recommendation for policy makers and funding agencies would be to create and disseminate public service awareness campaigns to educate parents and stakeholders on the symptoms of Autism Spectrum Disorder that may be present in a child's early development. Public Awareness campaigns would not only help educate the public but

would also help emphasize the benefits of early diagnosis and entry into appropriate treatment services. Additionally, funding should be provided for training of skilled clinicians that can conduct comprehensive diagnostic evaluation of Autism Spectrum Disorder utilizing both the ADI-R and ADOS-2. Lastly, policy makers should insure that critical evidence based interventions are widely available to families of children Autism Spectrum Disorder regardless of ethnicity, socio-economic status, or place of residence (rural). One way to make Autism Spectrum Disorder evaluation and intervention services accessible to children would be to provide them within the schools along with other mandated related services. Autism Spectrum Services would be an appropriate adjunct to pupil appraisal, speech, physical and occupational therapies already provided routinely within the school system.

Recommendations for Future Research

There are many variables that could be researched further to determine what factors are associated with earlier age of first parental concern and age of diagnosis. One variable that warrants further investigation would be that of socio-economic status. A family's socio- economic status could be related to earlier recognition of symptoms as a higher income family can afford quality childcare and healthcare providers who may be more knowledge of ASD behaviors and symptoms. Also, it is possible that families with higher wealth and income have the means to obtain earlier diagnoses through private evaluation providers. This research could help to determine if families with greater

economic resources are diagnosed earlier that those with fewer resources. Similarly, parental age and/or parental educational level may be variables warranting further exploration to determine if either or both are related to earlier recognition of developmental problems by parents. Parents that are older and/or more educated will likely have a better understanding of Autism Spectrum Disorder, its symptoms, and the importance of obtaining an early diagnosis and intervention services. Lastly, the variable of geographic location warrants further examination. It would be important to determine if children who reside in metropolitan areas that have greater access to resources and services are recognized and diagnosed earlier than those who reside in more rural communities. Future research would help to close the gap between parental recognition of symptoms and diagnosis of Autism Spectrum Disorder. Research would help parents and practitioners recognize symptoms of Autism Spectrum Disorder at an earlier age. Early diagnosis and entry into intervention services help to improve outcomes for children with Autism Spectrum Disorder.

Conclusion

Autism Spectrum Disorder is a neurodevelopmental disorder that is comprised of a compilation of symptoms and behaviors that indicate impairment in social communication and presentation of restrictive and repetitive behaviors. Autism Spectrum disorder symptoms range from mild to severe requiring substantial support. The findings of the current research added to the existing literature on early recognition and diagnosis of Autism Spectrum Disorder. The principle researcher collected and analyzed data from participants diagnosed with Autism Spectrum Disorder at a regional

university based children's health clinic to determine if the variables of ethnicity, severity of symptoms, and type of first reported symptoms were associated with earlier age of first parental concern and earlier age of diagnosis. The results indicated that there were no ethnic differences in either age of first parental concern or diagnosis. Severity of symptoms had a negative correction with both age of first concern and diagnosis indicating that more severe symptoms are recognized and diagnosed earlier than less severe symptoms. Parents most often reported Speech/Communication problems as the first type of concern they had and those reporting two or more types of concerns were recognized and diagnosed earlier than other types of concerns. The results of this project indicate that while children diagnosed with Autism Spectrum Disorder who exhibit severe symptomology and behaviors are efficiently recognized and diagnosed; those with more subtle deficits in social communication and interactions or restricted interests/repetitive behavior are recognized and diagnosed later which delays access to early intervention services. Research has demonstrated that early intervention services for children diagnosed with Autism Spectrum Disorder have been effective at decreasing symptoms and disruptive behaviors associated with Autism Spectrum Disorder and improving cognitive processing, language and adaptive skills (Dawson, et al., 2012). Additionally, early intervention services result in sustained improvements and behavioral gains in young children with Autism Spectrum Disorder (Estes, et al., 2015) and improvements in children at all severity levels on the spectrum (Reed & Osborne, 2012).

Future research should continue to examine variables related to early recognition of symptoms and behaviors of Autism Spectrum Disorder. Funding programs should

strive to educate parents and providers of the early behavioral symptoms of Autism Spectrum Disorder and the importance of obtaining diagnosis and early interventions.

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Appendix A

SFASU IRB Approval Letter

Institutional Review Board for the Protection of Human Subjects in Research
P.O. Box 13018, SFA Station • Nacogdoches, Texas 75962-3046
Phone (936) 468-5496 • Fax (936) 468-1573

TO: Dr. Ginger Kelso & Amy Creel
School Psychology
PO Box 13019
Nacogdoches, TX 75962

RE: Project Title: Autism: Age of First Concern
Case # AY2016-1280

TYPE OF RESEARCH: Project Type: Dissertation

FROM: Pauline M. Sampson, Chair, IRB-H

DATE: April 1, 2016

I would like to thank you for submitting your project entitled "Autism: Age of First Concern" to the IRB for review It has been reviewed and has been **Approved.**

Your project has approval through **April 1, 2017,** should you need additional time to complete the study you will need to apply for an extension prior to that date. The IRB should be notified of any planned changes in the procedures during the approval period, as additional review will be required by the IRB, prior to implementing any changes, except when changes are necessary to eliminate immediate hazards to the research participants. The researcher is also responsible for promptly notifying the IRB of any unanticipated or adverse events involving risk or harm to participants or others as a result of the research.

All future correspondence regarding this project should include the case number **AY2016-1280.**

Appendix B

LSUHSC-Shreveport IRB Approval Letter

HEALTH SCIENCES CENTER - SHREVEPORT
INSTITUTIONAL REVIEW BOARD

FWA 00000653
00000178 IRB

HUMAN RESEARCH, NOT ENGAGED DETERMINATION

April 25, 2016

Type of Review:	Initial Study
Title:	Examining Variables Associated with Age of First Concern in Children Diagnosed with Autism
Investigator:	Amy Creel
IRB ID:	STUDY00000592
Funding:	AH Child & Family Services
Grant ID:	None
IND, IDE or HDE:	None
Documents Received:	• SFASU IRB Application_March 5, 2016 •Creel_Dissertation_Lit.Review_Procedure_Methods_ March 2016 • Email Correspondence_LSUHSC-S Compliance Officer_Data Approval - SFASU Research Project • Email correspondence_Allied Health Dean Approval
Risk Level of Study:	No greater than minimal risk

Dear Ms. Creel:

On 4/25/2016 the Louisiana State University Health Sciences Center at Shreveport (LSUHSC-S) IRB reviewed the following protocol: *Examining Variables Associated with Age of First Concern in Children Diagnosed with Autism*.

The IRB determined that the proposed activity is research involving human subjects as defined by regulations at 45 CFR 46 but that this organization (LSUHSC-S) is not engaged in the research.

IRB approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities are research involving human subjects in which the organization's faculty, employees, students or agents are engaged, please submit a new request to the IRB for a determination.

It is our understanding that this research will be reviewed by the Stephen F. Austin State University IRB. A copy of the SFASU IRB initial determination letter to the above named investigator is requested for our IRB records.

HEALTH SCIENCES CENTER - SHREVEPORT

INSTITUTIONAL REVIEW BOARD

FWA 00000653
00000178 IRB

If you have any questions or concerns, please contact the IRB Administrative Office at (318) 813-1350.

Sincerely,
IRB Administration

Cc: Dennis Wissing, PhD, RRT, AE-C, FAARC
Michelle Yetman, PhD

Appendix C Data Collection Form

Autism in North West Louisiana

Name: _____ DOB: _____

Gender: _____ Race: _____

Parish: _____

Maternal Age: _____ Paternal Age: _____

Prematurity: _____

Gestation in weeks: _____

Birth weight: _____

Birth Trauma: _____

Prenatal Risk Factors: _____

-Drugs/Alcohols/Rx meds / cigarettes / SSRI _____

Age of Child when parent first became concerned : _____

Primary Parental Concern (e.g., speech, behavior): _____

Age When Child was Diagnosed: _____

Child's Name: _____ DOB: _____

Previous Diagnosis (e.g., Developmentally Delayed): _____

Had child received prior intervention services : _____

Referral Source (Early Steps vs PCP): _____

MCHAT score: _____

ADOS score: _____

ADI –A score: _____

ADI-B score: _____

ADI-C score: _____

ADI-D score: _____

Final Diagnosis (based on CC findings): _____

Co-occuring Intellectual Disability? _____

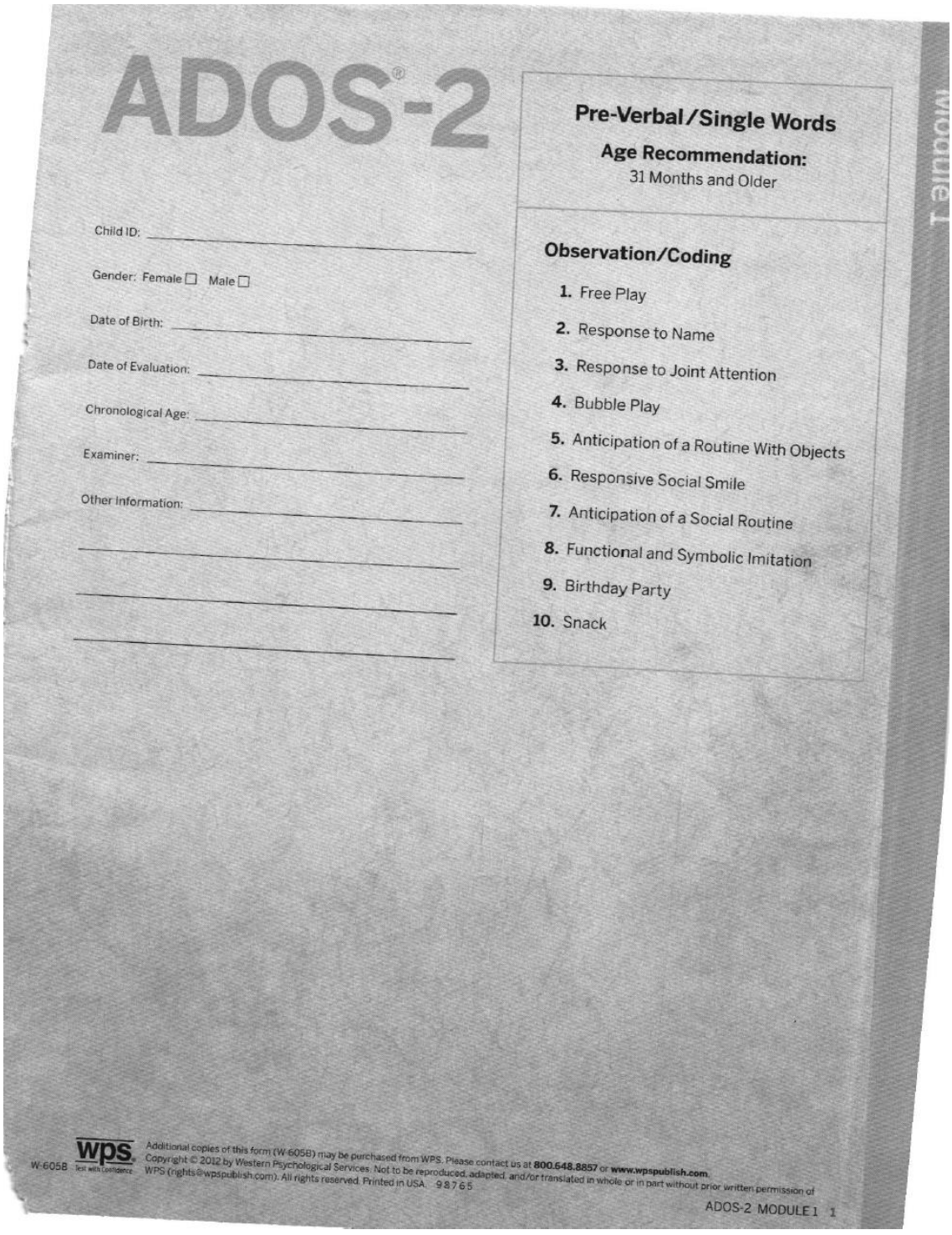
ABAS – GAC score _____

Conceptual _____

Social Composite _____

Practical _____

Appendix D-ADOS-2 Module 1 – Protocol



ADOS®-2

Module 1

Pre-Verbal/Single Words

Age Recommendation:
31 Months and Older

Child ID: _____

Gender: Female ☐ Male ☐

Date of Birth: _____

Date of Evaluation: _____

Chronological Age: _____

Examiner: _____

Other Information: _____

_____

_____

_____

Observation/Coding

1. Free Play
2. Response to Name
3. Response to Joint Attention
4. Bubble Play
5. Anticipation of a Routine With Objects
6. Responsive Social Smile
7. Anticipation of a Social Routine
8. Functional and Symbolic Imitation
9. Birthday Party
10. Snack

OBSERVATION

Note: **Initiation of joint attention** requires a spontaneous *3-point gaze shift* between an object and person with no apparent purpose other than to share interest or pleasure (it may or may not involve a pointing gesture as well).

A *3-point gaze shift* is defined by the child looking at an object, looking at a person (with the goal of catching his or her gaze in order to direct it to the object), and then looking back at the object, or by the child looking at the person first, then the object, and then looking back at the person.

NOTES

1 Free Play

Focus of Observation:

- Does the child *spontaneously* seek engagement with the parent/caregiver?
  - If so, how does he or she do this?
  - Does it involve joint reference to objects, such as giving and showing, or is it limited to seeking affection or help?
  - How does the child communicate, if at all?
- Does the child direct affect to others?
  - How is it conveyed?
- Does the child explore materials, either symbolically or functionally?
- Does the child stay with activities, flit from object to object, or engage in repetitive actions?

Communication Sample:

NOTES

2 Response to Name

Focus of Observation:

- Observe and evaluate the consistency of the child's response to the hierarchy of presses.
- What sounds and actions must you or the parent/caregiver make to get the child's attention?
- How does the child respond? Does the child...
  - Display eye contact?
  - Look at your face or in your general direction and/or look at the parent/caregiver's face or in the parent/caregiver's general direction?
  - Vocalize?

Hierarchy of Presses

(1) Call the child's name UP TO four times.
- If the child makes an appropriate vocal response without making eye contact with you upon one of the first *two* presses, start the task over with four new tries calling the child's name.

(2) Ask the parent/caregiver to call the child's name UP TO two times.

(3) Ask the parent/caregiver to say other words or make a familiar noise or sound (this can be in a way that implies physical contact but does not actually involve touching the child, e.g., "I'm gonna get you!") UP TO two times.

(4) Ask the parent/caregiver to do whatever necessary, including touching the child, to get him or her to look at the parent/caregiver.

NOTES

3 Response to Joint Attention

Focus of Observation:

- Does the child follow a shift in gaze alone or follow a shift in gaze when it is accompanied by pointing?
- Pay attention to the child's behaviors when playing with the remote-controlled toy, including eye contact, vocalizations, requesting, shared enjoyment, initiations of joint attention, and pretend play (e.g., hugging or kissing the toy animal).

Hierarchy of Presses

(1) Orient the child's body toward your face, if possible.
- Up to five attempts should be made to attract the child's attention toward your face before administering the activity.
- If the child's attention is NOT obtained, you should still proceed through the hierarchy of presses, including activation of the toy.

(2) Say: "**(Child's name), look!**" (exaggerate your gaze shift).

(3) Say: "**(Child's name), look at *that!***" (exaggerate your gaze shift), UP TO two times.

(4) Say: "**(Child's name), look at *that!***" (with a gaze shift and a point), UP TO two times.

(5) Activate the toy.

NOTES

4 Bubble Play

Focus of Observation:

- Observe the child's affect, initiation of joint attention, shared enjoyment, requesting, and motor behavior while the bubbles are present.
- Does the child display any unusual sensory behaviors or movements?

5 Anticipation of a Routine With Objects

Focus of Observation:

- Observe the child's affect, initiation of joint attention, shared enjoyment, requesting, and motor responses, particularly repetitive mannerisms.

NOTES

6 Responsive Social Smile

Focus of Observation:

- Evaluate the occurrence of the child's smile in response to:
  (a) you smiling,
  (b) the parent/caregiver smiling,
  (c) the parent/caregiver smiling and making a familiar noise or calling in a way that implies physical contact but without actually touching the child (e.g., "I'm gonna get you!"), or
  (d) being touched.
- This is a discrete task; decide when to carry out this task and do so (i.e., social smiles occurring at other times are rated under other items, not the "Responsive Social Smile" item).

7 Anticipation of a Social Routine

Follow this order and circle routine used: Peekaboo Tickle Swing in air

Focus of Observation:

- Evaluate the child's affect and his or her attempts to initiate repetition of the routine.
- Pay particular attention to the social directedness of the child's behaviors and the extent to which he or she integrates gaze, facial expression, vocalization, and gesture in actions directed to you or the parent/caregiver, especially those behaviors that are indicative of shared enjoyment.

NOTES

8 Functional and Symbolic Imitation

Focus of Observation:

- How does the child use miniature objects and a placeholder in imitation of familiar actions?
- Are these acts carried out with social awareness and shared enjoyment?

Hierarchy of Presses

(1) Teaching trial(s): Real object (car or frog) UP TO three trials total.

(2) Imitation trials, Phase 1: Real object UP TO three trials per object; use only objects not used in the teaching trials.

(3) Imitation trials, Phase 2: Placeholder representing object just demonstrated in Phase 1; UP TO three trials per object.

(4) Imitation trials, Phase 3: Placeholder representing object not previously demonstrated; UP TO three trials per object.

- The child has "successfully" completed the full hierarchy of presses when he or she is able to imitate your use of the placeholder as an object that has not been previously demonstrated in the task.
- Once all of the objects have been used, the child is "out" of chances and the activity is complete, regardless of whether there are remaining trials or not.

NOTES

9 Birthday Party

Focus of Observation:

- Evaluate the child's interest and ability to join in the "script" of a doll's birthday party.
- Does the child treat the doll as a representation of an animate being?
- Does the child spontaneously contribute to the enactment of the party?
  - If not, does the child imitate your actions spontaneously or participate when asked or directed to do so?
- Pay attention to shared enjoyment, overtures, and reciprocity.

10 Snack

Focus of Observation:

- Does the child indicate a preference and request food?
  - If so, how does he or she do this?
- How does the child use gaze, gesture, reaching, facial expression, and vocalization to communicate requests to you and to make social overtures?
- Does the child show his or her snack to the parent/caregiver or try to feed and/or share with the adults in the room?

CODING

- The overall ratings that you assign in this section should be made on the basis of the child's behavior throughout the entire ADOS-2 administration.
- Ratings should include only behavior that is directly observed during the ADOS-2 administration and should not be based on behavior reported or observed in other contexts (e.g., parent report).
- If the child's behavior changes in quality after a brief, initial adaptation period, ratings should be based on the period after the behavior stabilizes.
- Ratings should be assigned immediately after the ADOS-2 assessment.
- The ratings are organized according to five main groupings: "A. Language and Communication," "B. Reciprocal Social Interaction," "C. Play," "D. Stereotyped Behaviors and Restricted Interests," and "E. Other Abnormal Behaviors."

A Language and Communication

Unless stated otherwise, code in relation to chronological age expectations, not in comparison to developmental level or estimated expressive language skills.

A1. Overall Level of Non-Echoed Spoken Language

This item is coded for the complexity of spontaneous expressive language produced during the ADOS-2 evaluation. Ratings apply only to non-echoed words or word approximations that are used meaningfully. A routinized "unit" such as "go bye-bye" is treated as one word.

	0 = Regular use of utterances with two or more words.
	1 = Occasional phrases only; mostly single words.
	2 = Recognizable single words or word approximations only; must use at least five different words during the ADOS-2 evaluation.
	3 = At least one word or word approximation, but fewer than five words used during the ADOS-2 evaluation.
	4 = No words or word approximations used meaningfully.

A2. Frequency of Spontaneous Vocalization Directed to Others

This item is coded for the amount of socially directed vocalization; vocalizations must be spontaneous to be coded here.

A pragmatic context, as mentioned in the codes below, is defined within the ADOS-2 as the purpose or intention of a given utterance. For example, pragmatic contexts might include (but are not limited to) requesting, directing attention, sharing enjoyment, or seeking comfort.

	0 = Directs vocalizations to parent/caregiver or examiner in a variety of pragmatic contexts. Must include chatting or vocalizing to be friendly or to express interest, as well as to make needs known.
	1 = Directs vocalizations to parent/caregiver or examiner consistently in one pragmatic context, OR directs a limited number of vocalizations to parent/caregiver or examiner across a variety of pragmatic contexts.
	2 = Directs an occasional vocalization to parent/caregiver or examiner inconsistently in a limited number of pragmatic contexts. May include whining or crying due to frustration.
	3 = Vocalizations never or almost never appear to be directed to parent/caregiver or examiner, OR rarely or never vocalizes.

A3. Intonation of Vocalizations or Verbalizations

This is a general item that applies to all vocalizations or verbalizations, including crying and whining. Repetitive or odd nonword vocalizations should be rated here if the intonation is unusual. Do not include general loudness, but do code repeated whispering.

0 = Normal, appropriately varying intonation, with no peculiar or odd intonation.

1 = Little variation in pitch and tone; rather flat or exaggerated, or occasional peculiar intonation.

2 = Odd intonation or inappropriate pitch and stress, AND/OR markedly flat and toneless mechanical vocalizations, OR an odd cry and few other vocalizations.

8 = N/A (insufficient vocalizations for assessment of intonation; includes presence of normal cry and few other vocalizations).

A4. Immediate Echolalia

This item pertains to the child's immediate repetition of the last statement or series of statements made by the parent/caregiver or examiner. When coding, do not include repetitions that are a lead-in to a response to the examiner or that are used as a memory device in specific tasks. Beware of coding echolalia if the child has only a few words and repeats them meaningfully after others say these words to him or her. Code relative to the child's expressive language level.

If the child uses fewer than five words and DOES NOT have echoed speech, then code 8. If the child uses fewer than five words and DOES have echoed speech as described above, then use codes 1 to 3 as appropriate. The code of 0 is the only code that requires the spontaneous use of at least five words.

0 = Does not repeat others' speech. (Note: Requires at least five words to code 0 rather than 8.)

1 = Occasional echoing.

2 = Echoing words and phrases regularly, but some spontaneous language, which can be stereotyped.

3 = Speech largely consists of immediate echolalia.

8 = No echolalia noted, but language too limited to judge.

A5. Stereotyped/Idiosyncratic Use of Words or Phrases

Coding for this item includes delayed echolalia or other highly repetitive utterances with consistent intonation patterns. These words or phrases can be intended meaningfully and can be appropriate to conversation at some level. The focus of the item is on the stereotyped or idiosyncratic quality of the phrasing or unusual use of words and/or their arbitrary association with a particular meaning. Neologisms and referring to oneself by name should be coded here, as well as clear evidence of a pronoun error *across person* (e.g., *you* or *he* or *she* to mean *I*). Beware of coding language as repetitive because the child's language repertoire is limited, such as a child who has only two words and uses them repeatedly and appropriately. Code relative to the child's expressive language level. Repetitive or odd nonword vocalizations should not be rated here but can be rated in "A3. Intonation of Vocalizations or Verbalizations" if the intonation is unusual.

If the child uses fewer than five words and DOES NOT have stereotyped or idiosyncratic speech, then code 8. If the child uses fewer than five words and DOES have stereotyped or idiosyncratic speech, then use codes 1 to 3 as appropriate. The code of 0 is the only code that requires at least five words.

0 = Rarely or never uses stereotyped or idiosyncratic words or phrases. (Note: Requires at least five words to code 0 rather than 8.)

1 = Use of words or phrases tends to be more repetitive than that of most individuals at the same level of expressive language, but not obviously odd, OR occasional stereotyped utterances or use of odd words, OR use of phrases in an unusual way, with other flexible spontaneous language as well.

2 = Often uses stereotyped utterances or odd words or phrases, with some other language.

3 = Frequently uses odd or stereotyped speech, and rarely uses non-stereotyped spontaneous speech.

8 = Language too limited to judge.

A6. Use of Another's Body

The focus of this item is on the use of another person's body as a tool. It requires movement of a limb or a part of someone else's body without a previous or concurrent attempt to direct the person's attention using gaze.

0 = No use of another person's body for a specific goal (e.g., to manipulate an object), except in situations where other strategies have not worked (e.g., when others are conversing and the child cannot get their attention) and in conjunction with coordinated gaze.

1 = Takes another person's hand and leads him or her places without coordinated gaze, but no placement of hand on objects and no use of another person's body as a tool or for a specific goal.

2 = Placement of another person's hand or other body part on object OR movement of that person's hand when it is holding an object, OR use of another person's hand or other body part as a tool or to gesture "for" the child (such as pointing).

8 = Little or no spontaneous communication.

A7. Pointing

This item describes socially purposeful, visually directed pointing, which includes pointing for the purpose of requesting and/or for shared attention. The term *distal* here denotes pointing that does not involve touching an object or an attempt to touch an object (e.g., the target object should be more than about 2 inches/5 cm away).

0 = Points with index finger to show visually directed referencing (coordinated gaze to object and person) of distal objects in at least two activities (e.g., points to bubbles and to balloon).

1 = Uses pointing to reference objects, but without sufficient flexibility or frequency to meet criteria for a rating of 0 (e.g., only one instance of pointing that fits the preceding description for a rating of 0, or absence of coordinated gaze with distal pointing, though the child may vocalize); AND/OR produces an approximation of pointing (coordinated with gaze or vocalization) rather than an index finger point; AND/OR coordinates only pointing that includes touching a picture or other nearby objects with gaze or vocalization; AND/OR points with coordination (gaze or vocalization) only to a person or to himself or herself.

2 = Points only when close to or actually touching an object, without coordinated gaze or vocalization. Does not have to be well-formed index finger point.

3 = Does not point as described above.

A8. Gestures

This item pertains to the use of any kind of gesture other than pointing. Gestures may be conventional or idiosyncratic, but they must be communicative and cannot involve moving someone else's body or touching/holding an object. Do not include mannerisms. Gestures within routines (e.g., songs) may be coded here if they are carried out in a way that is communicative, spontaneous, and appropriate. Grabbing is not included as a gesture. If there is a clearly unusual gesture that is used appropriately (e.g., a child who consistently moves his head with his hand to indicate "yes" or "more"), a code of 1 should be used.

	0 = Spontaneous use of at least two different gestures of any type (descriptive, conventional, emotional, or instrumental, excluding pointing); at least one used more than once.
	1 = Spontaneous use of descriptive, conventional, instrumental, or emotional gestures, but exaggerated or limited in range and/or contexts (e.g., only one or used only once each). Communicative reaching can be coded here, but not as part of a code of 0.
	2 = No spontaneous use of descriptive, conventional, instrumental, or emotional gestures, OR inappropriate use only (e.g., a child who signs "more" when he wants something to stop).
	8 = N/A (e.g., limited by severe motor difficulties).

B Reciprocal Social Interaction

Code in relation to chronological age expectations, not in comparison to developmental level or estimated expressive language skills.

B1. Unusual Eye Contact

Coding for this item requires that clear, flexible, socially modulated, and appropriate gaze that is used for a variety of purposes be distinguished from gaze that is limited in flexibility, appropriateness, or contexts. If the child is shy initially, and his or her gaze changes markedly and consistently as he or she becomes more comfortable, do not base the code on earlier impressions. However, if eye contact never improves, coding must be based on what is observed, even if the child seems shy. Do not code eye contact that occurs between the child and individuals other than the examiner who may be in the ADOS-2 assessment room.

0 = Appropriate gaze with subtle changes meshed with other communication.

2 = Uses poorly modulated eye contact to initiate, terminate, or regulate social interaction.

B2. Responsive Social Smile

This item pertains to the child's facial response to a smile or playful verbal interaction with the examiner or parent/caregiver during the "Responsive Social Smile" activity.

0 = Smiles immediately in response to one of the first two smiles of the examiner and/or parent/caregiver. This must be a clear change from nonsmiling to a fully responsive smile that is not prompted by a specific request (e.g., "Give me a smile").

1 = Delayed or partial smile in response to one of the first two smiles of the examiner and/or parent/caregiver, OR smiles fully or partially only after more than two smiles by the parent/caregiver, OR smiles only in response to a specific request.

2 = Smiles fully or partially at the parent/caregiver only after being tickled or touched in some way OR in response to a repeated action with a physical component (even if the child is not actually touched).

3 = Does not smile in response to another person.

B3. Facial Expressions Directed to Others

The rating for this item should indicate whether the child's facial expressions are directed to another person for the purpose of communicating affective (e.g., enjoyment, frustration) or cognitive (e.g., puzzlement, skepticism) states. Facial expressions that are directed to objects or that are undirected are not rated here. Appropriate or slightly exaggerated facial expressions should be coded even if there are also odd expressions.

0 = Directs a range of appropriate facial expressions to the examiner and/or parent/caregiver in order to communicate affective or cognitive states.

1 = Some direction of facial expressions to the examiner and/or parent/caregiver (e.g., directs only expressions indicating emotional extreme(s) to others, or occasionally directs wider range of expressions). A child who has a limited range of facial expressions, but who directs most of his or her facial expressions to another person, may be rated here.

2 = Does not direct appropriate facial expressions to others.

B4. Integration of Gaze and Other Behaviors During Social Overtures

The focus of this item is on the *quality* of the child's attempts to initiate interaction, particularly the integration of gaze with other behaviors, not the frequency of initiations. When assigning a rating, consider attempts to get help or other highly motivated approaches. Rate the quality of the majority of these attempts, not the best attempts. Overtures to the examiner and parent/caregiver can both be considered here.

0 = Uses eye contact effectively with words or vocalizations or gestures to communicate social intention.

1 = Uses eye contact and other strategies independently of each other to communicate social intention (i.e., uses both eye contact and vocalization at different times, but does not coordinate them with each other).

2 = Uses either eye contact or other strategies (e.g., vocalization, gestures) to communicate social intention.

3 = Uses neither eye contact nor other strategies to communicate social intention, OR no social overtures.

B5. Shared Enjoyment in Interaction

Rate the child's directed pleasure during any of the activities or presses. This item should not be used to indicate his or her general emotional state during the ADOS-2 evaluation. The rating applies to the child's ability to *indicate* pleasure to the examiner, not just to interact or respond.

0 = Shows definite pleasure with the examiner that is appropriate to the context and occurs during more than one activity. Must include pleasure in at least one activity that is not purely physical in nature (e.g., not tickling).

1 = Shows some pleasure appropriate to the context during interactions with the examiner, OR shows definite pleasure directed to the examiner during one interaction (may be physical in nature).

2 = Shows little or no expressed pleasure during interaction with the examiner, but shows pleasure in his or her own actions, in interaction with a parent/caregiver, or in noninteractive components of the ADOS-2 materials or activities.

3 = Little or no expressed pleasure during the ADOS-2 evaluation and little interest in toys.

B6. Response to Name

This item codes the child's response to hearing his or her name called during a specific press. A full response is defined as orienting to *and making eye contact with* the person who calls his or her name. The number of presses is specified because of the increased likelihood that the child will look if provided many opportunities.

If the child verbalizes appropriately without making eye contact in response to either of the examiner's first two presses, the hierarchy of presses is recommenced and the coding disregards the initial press(es) (i.e., the examiner's first press upon restarting the activity after a vocal response is considered in the ratings as the examiner's first press).

0 = Looks toward the examiner and makes eye contact immediately on at least one of the first two presses made by the examiner.

1 = Looks toward the parent/caregiver and makes eye contact after first or second press of name only, OR makes eye contact with the examiner after the examiner's third or fourth press of name only.

2 = Does not immediately make eye contact with either the examiner or the parent/caregiver after his or her name is called in six attempts, but shifts gaze briefly (no eye contact), shifts gaze after a delay, OR looks at least once when an interesting or familiar vocalization or verbalization is made (e.g., tongue clucking, "I'm gonna get you").

3 = Does not look toward either the examiner or the parent/caregiver after any purely verbal or vocal attempt to get attention.

B7. Requesting

Requesting is defined as a conventional indication—through gesture, eye contact, vocalization, facial expression, or other means—of the child's desire for a particular action or object. This can include requests for a social routine, balloon, remote-controlled toy animal, bubbles, and so forth, as long as they are related to a specific event or object. It does not include a general desire to be held. When coding this item, exclude requests for snack items or to leave the room. If the child uses more than one strategy to request different objects or activities, rate the request that merits the higher rating level (i.e., closest to a rating of 0).

0 = Exhibits appropriate integration of eye contact and at least one behavior (e.g., vocalization, gesture, or handing an object to the examiner or the parent/caregiver) to request bubbles, the remote-controlled toy animal, object routine, or social routine. Must include eye contact and a definite indication of wanting the other person to do or give something (e.g., by persisting in the request if the other person pauses before responding). This does not include physically pulling or placing the examiner's hand on an object or to the child himself or herself.

1 = Uses one or more behavior(s) listed above to request the remote-controlled toy animal, bubbles, and/or a routine, without integrating eye contact and other behavior(s), such as vocalization or gesture. This includes handing an object to the examiner or parent/caregiver without looking at him or her, looking at the other person without another behavior, and brief requests without persistence. It does not include physically pulling the examiner's hand to an object or to himself or herself.

2 = Does not directly request, as specified above for ratings of 0 or 1, but uses some physical means to request at least one action as part of a routine (e.g., pulls the examiner's hand to an object or to himself or herself).

3 = May participate in routine(s) or try to activate an object by vocalizing, banging, or other actions (e.g., bouncing) without looking at another person or vocalizing for help, but does not request, as specified above.

B8. Giving

This item describes handing objects to another person across a range of pragmatic contexts, including sharing and getting help. It does not require eye contact, but does imply independent, spontaneous release of the object.

0 = Spontaneously gives toys or objects to other people in a variety of contexts throughout the ADOS-2 evaluation, including giving toys, food, or pretend food for the purpose of sharing.

1 = More than one example of giving objects to other people for the purpose of getting help (e.g., in operating toys or opening food containers) or as part of a routine. May occur in just one context, but must be repeated without a specific prompt.

2 = Rarely or never gives objects to another person.

B9. Showing

Showing is defined as deliberately orienting or placing an object where it can be seen by another person with no identifiable purpose of getting help or participating in a routine. For full credit, this must be accompanied by eye contact, but vocalization is not required.

0 = Spontaneously shows toys or objects during the ADOS-2 evaluation by holding them up or placing them in front of others, and using eye contact with or without vocalization.

1 = Shows toys or objects in a partial or inconsistent manner (e.g., holds them up and/or places them in front of others without coordinated eye contact, looks from an object in his or her hands to another person without clearly orienting it toward that person, or shows objects as described above for a rating of 0 on one occasion only).

2 = Does not show objects to another person.

B10. Spontaneous Initiation of Joint Attention

This item codes the child's attempts to draw another person's attention to objects that neither of them is touching and are clearly out of reach. This does not include such attempts if they are for the purpose of requesting.

0 = Uses clearly integrated eye contact to direct another person's attention to an object that is out of reach by looking at the object, then at the examiner or the parent/caregiver, and then back at the object OR by using a three-point gaze shift starting with the examiner or parent/caregiver. Eye contact may be coordinated with pointing and/or vocalization. One clear example is sufficient for this rating.

1 = Partially references an object that is clearly out of reach in order to direct another person's attention. May spontaneously look at and point to the object and/or vocalize, but does not coordinate either of these with looking at another person, OR may look at an object and then look at or point to the examiner or the parent/caregiver, but not look back at the object.

2 = No approximation of spontaneous initiation of joint attention in order to direct another person's attention to an object that is out of reach.

B11. Response to Joint Attention

This item codes the child's response to the examiner's use of gaze and/or pointing to direct the child's attention to a distant object. The rating should not be affected by the child's understanding of language (i.e., he or she must follow the direction of the examiner's gaze or pointing, but does not have to understand what was said).

0 = Uses the orientation of the examiner's eyes and face alone as a cue to look toward the target, without the need for pointing. The child must follow the examiner's gaze and turn his or her face or eyes in the direction of the target after watching the examiner do so; he or she does not actually have to catch sight of the target.

1 = Follows the examiner's pointing by looking at or toward the target.

2 = Does not follow the examiner's gaze or pointing to orient toward the object, but looks at the target when activated.

3 = Does not orient to the object even when the object is activated.

B12. Quality of Social Overtures

This is a summary item that focuses on the *quality* of the child's attempts to initiate social interaction, not on the frequency of such attempts. Special attention should be given to the form of the overtures and their appropriateness to the social context. The rating should reflect the majority of social overtures, not merely the best ones.

0 = Effectively uses nonverbal and verbal means to make clear social overtures to the examiner or the parent/caregiver. The overtures must be appropriate to immediate contexts.

1 = Slightly unusual quality of social overtures. Assign this rating if overtures are restricted to personal demands or related to strong interests, but with some attempt to involve the examiner or the parent/caregiver in those interests.

2 = Overtures often lack integration into context AND/OR social quality. Assign this rating if there are some clearly inappropriate overtures, even if there are other overtures.

3 = No social overtures of any kind.

B13a. Amount of Social Overtures/Maintenance of Attention: EXAMINER

The focus of this item is on the *number* of the child's attempts to get, maintain, or direct the examiner's attention, AND/OR to direct the examiner's attention to objects or actions of interest to the child. The rating for this item may include words/vocalizations or nonverbal behaviors if they are neither related to preoccupations nor aimed at getting objects, but seem to function primarily as a method of social contact. *Do not include requests for help or objects when rating this item except for a code of 3.*

	0 = Frequent attempts to get or maintain the examiner's attention AND/OR to direct the examiner's attention to objects or actions of interest to the child.
	1 = Some attempts at getting, maintaining, or directing the examiner's attention as described above for a rating of 0, but reduced in frequency or the number of different activities in which they are used.
	2 = Makes occasional attempts to get, maintain, or direct the examiner's attention, including overtures solely for the purpose of seeking comfort.
	3 = Shows relatively little concern as to whether the examiner is paying attention to him or her unless he or she needs help (e.g., initiates social contact only when requesting).
	7 = Unusually frequent, intense, or excessive demands for attention.

B13b. Amount of Social Overtures/Maintenance of Attention: PARENT/CAREGIVER

The focus of this item is on the *number* of the child's attempts to get, maintain, or direct the parent/caregiver's attention, AND/OR to direct the parent/caregiver's attention to objects or actions of interest to the child. The rating for this item may include words/vocalizations or nonverbal behaviors if they are neither related to preoccupations nor aimed at getting objects, but seem to function primarily as a method of social contact. *Do not include requests for help or objects when rating this item except for a code of 3.*

	0 = Frequent attempts to get or maintain the parent/caregiver's attention AND/OR to direct the parent/caregiver's attention to objects or actions of interest to the child.
	1 = Some attempts at getting, maintaining, or directing the parent/caregiver's attention as described above for a rating of 0, but reduced in frequency or the number of different activities in which they are used.
	2 = Makes occasional attempts to get, maintain, or direct the parent/caregiver's attention, including overtures solely for the purpose of seeking comfort.
	3 = Shows relatively little concern as to whether the parent/caregiver is paying attention to him or her unless he or she needs help (e.g., initiates social contact only when requesting).
	7 = Unusually frequent, intense, or excessive demands for attention.
	8 = Familiar caregiver not available for ADOS-2 administration.

B14. Quality of Social Response

This is a summary item that focuses on the child's social responses throughout the ADOS-2 evaluation.

	0 = Shows a range of appropriate responses that are varied according to immediate social situations and presses.
	1 = Shows responsiveness to most social contexts, but somewhat limited, socially awkward, inappropriate, inconsistent, or consistently negative.
	2 = Odd, stereotyped responses, or responses that are restricted in range or inappropriate to the context.
	3 = Minimal or no response to the examiner's attempts to engage the child.

B15. Level of Engagement

This item codes the degree of interest in and engagement with the activities presented as part of the ADOS-2 evaluation. The child's degree of enjoyment in the activities is not coded here.

	0 = Spontaneously engaged and consistently interested in activities presented by the examiner.
	1 = Inconsistently spontaneously engaged.
	2 = Engaged only when the examiner works hard to get and keep the child's interest.
	3 = Not engaged, even when the examiner makes efforts to attract the child's interest, OR the child is engaged only during snack or games involving physical contact.

B16. Overall Quality of Rapport

The code for this item is a summary rating that reflects the examiner's overall judgment of the rapport or comfort level established with the child during the ADOS-2 evaluation. The rating should take into account the degree to which the examiner had to modify his or her own behavior to maintain the interaction successfully.

	0 = Comfortable interaction between the child and examiner that is appropriate to the context of the ADOS-2 assessment.
	1 = Interaction sometimes comfortable, but not sustained (e.g., sometimes feels awkward or stilted, or the child's behavior seems mechanical or slightly inappropriate).
	2 = One-sided or unusual interaction resulting in a consistently mildly uncomfortable session.
	3 = The child shows minimal regard for the examiner AND/OR the observation is markedly difficult or uncomfortable for a significant proportion of the time.

C Play

Code in relation to chronological age expectations, not in comparison to developmental level or estimated expressive language skills.

C1. Functional Play With Objects

This item describes appropriate use of toys or miniatures/representational items as they are intended. Exclude play that occurs in response to directions from the parent/caregiver or the examiner. Use "C2. Imagination/Creativity" to rate all play with a doll. Miniatures are representational toys (i.e., smaller versions of real objects). Putting candles into the birthday cake should not be coded here.

0 = Spontaneously plays with a variety of toys in a conventional manner, including appropriate play with several different miniatures/representational toys (e.g., telephone, truck, dishes, materials in the "Birthday Party" activity). Do not include imitations, prompted actions, or pushing the car.

1 = Some spontaneous functional play with at least one miniature/representational toy. Do not include imitations, responses to the examiner's or a parent/caregiver's direct requests (e.g., "Answer the phone"), pushing the car, or use of construction toys.

2 = Plays appropriately with cause-and-effect toys and/or construction toys only, AND/OR pushing the car. This may include imitating a demonstration or imitating more representational play with other toys.

3 = No play with toys or only stereotyped play.

C2. Imagination/Creativity

This item describes the flexible, creative use of objects in a representational manner that goes beyond the physical properties of the materials (e.g., beyond placing toy spoons on toy plates). Any use of the doll should be coded here, as specified.

0 = Spontaneous use of a doll or other object as an independent agent, OR spontaneous use of objects to represent other objects (e.g., pretends to eat the string like spaghetti).

1 = Spontaneous pretend play with a doll (e.g., feeding, hugging, or giving a drink) or other objects, but no use of a doll or other toy as an independent agent or to represent something else.

2 = Imitates pretend play as described above for a rating of 1, OR imitation with a placeholder; no spontaneous pretend play.

3 = No imitated or spontaneous pretend play.

D Stereotyped Behaviors and Restricted Interests

Code without reference to developmental level or estimated expressive language skills.

D1. Unusual Sensory Interest in Play Material/Person

Rate the child's interest in or unusual behaviors associated with sensory aspects of toys or surroundings (e.g., sniffing, repetitive feeling of texture, licking, biting, unusually strong interest in the repetition of certain sounds, unusual or prolonged visual examination).

If the child has a preoccupation that is based on a sensory interest, this may be coded here as *one* unusual sensory interest. For example, if he or she shows an interest in several sets of table legs, this is coded later in this section of the protocol under "D4. Unusually Repetitive Interests or Stereotyped Behaviors." If the child is interested in table legs and likes to look at them repeatedly, as shown by peering at them and tilting his or her head, it should be coded under "Unusually Repetitive Interests or Stereotyped Behaviors" if it is a persistent behavior, but may also be coded here because of the sensory component involved. If the child likes to look at table legs, the corners of the room, the doors on the pop-up toy, and the slats of the window blinds, but does not become overly preoccupied with any of these objects and does not move in unusual ways as he or she does so, he or she should be coded here for unusual sensory interests but not under "Unusually Repetitive Interests or Stereotyped Behaviors."

If the ADOS-2 assessment occurs in a room with a one-way mirror, looking into the mirror is not coded as an unusual sensory interest. Mouthing is also not coded in this module. Sensory aversions are also not coded here.

	0 = No unusual sensory interests or sensory-seeking behaviors.
	1 = Several possible sensory interests not as clear as specified below for a rating of 2, AND/OR only one clear occurrence of an unusual sensory interest or a sensory-seeking behavior. One "possible" sensory interest should be coded 0.
	2 = Definite interest in sensory elements of objects or of play materials OR sensory examination of himself or herself or others; two or more clear occurrences must be observed. May be observed during the same activity.
	3 = Definite unusual sensory-seeking behaviors occur during at least two different tasks or activities and may interfere with the ADOS-2 assessment.

Specify:

D2. Hand and Finger and Other Complex Mannerisms

Rate unusual and/or repetitive movements or posturing of the hands and fingers, arms, or body. Repetitive clapping is *not* coded in this module. Do not include body rocking unless it involves more than the torso. Finger tapping, nail biting, hair twisting, and thumb sucking are also not coded here. The child does not have to watch the movements of his or her fingers or hands for the movements to be coded here.

	0 = None.
	1 = Unusual and/or repetitive hand and finger mannerisms or complex mannerisms not as clear as specified below for a rating of 2.
	2 = Definite finger flicking or twisting, AND/OR hand or finger or complex mannerisms, stereotypies, or posturing. May be brief and/or rare if clear.
	3 = Mannerisms, as described above, occur frequently, during at least two different tasks or activities, and/or may interfere with the ADOS-2 assessment.

Specify:

D3. Self-Injurious Behavior

Rate behaviors that involve any kind of aggressive act to self, even if not clearly harmful.

	0 = No attempts to harm self.
	1 = Dubious or possible self-injury, and/or rare but clear self-injury (e.g., one clear example of biting at own hand or arm, pulling own hair, slapping own face, or banging own head).
	2 = More than one clear example of self-injury, such as head banging, face slapping, hair pulling, or self-biting.

D4. Unusually Repetitive Interests or Stereotyped Behaviors

Rate any unusually repetitive interests or stereotyped behaviors, including preoccupation with unusual activities or objects, such as table legs or wristwatches; repetitive nonfunctional use of toys, such as spinning wheels, lining things up, or flicking the doll's eyes for more than 2 or 3 seconds; repetitive actions, such as banging objects or putting fingers in ears; and insistence on unusual routines or ritualized behaviors, such as specific ways of touching or moving objects, or insistence on having the parent/caregiver or the examiner act in a specific way. Persistent aversive reactions that are unusual in form and/or intensity to sensory stimuli (e.g., the sound of the bubble toy, being touched) can be coded here as 1, 2, or 3, as appropriate. *If it is necessary to remove preoccupying objects from the room or lock them in a closet (i.e., to do more than put them on the floor or under a blanket partially out of sight), the code should be a 2 or 3.*

	0 = No repetitive or stereotyped behaviors during the ADOS-2 evaluation.
	1 = An interest or behavior that is repetitive or stereotyped to an unusual degree, including an intense interest in a particular toy or object, a definite interest in an unusual object or activity (odd for the child's level of motor skill), an unusually routinized activity, or a clear interest in a part of an object. This interest or behavior occurs in conjunction with several other activities and does not prevent the child from completing any ADOS-2 activities.
	2 = Clearly repetitive or stereotyped interests and/or behaviors, as described above. These behaviors may form a substantial minority of the child's interests and spontaneous behaviors and may interfere with the child's ability to complete ADOS-2 activities, but it is possible for his or her attention to be directed to other objects or activities, at least momentarily.
	3 = Repetitive or stereotyped interests and/or behaviors, as described above, form the majority of the child's interests, AND/OR attempts to direct his or her attention to other objects or activities are met with significant resistance and/or distress.

Specify unusual preoccupations, rituals, repetitive behaviors:

E Other Abnormal Behaviors

Unless stated otherwise, code these items without reference to developmental level or estimated expressive language skills.

E1. Overactivity

For this item, rate whether the child remains still and/or seated when expected to do so by the examiner, based on appropriate expectations for his or her general developmental level.

0 = Sits or stands still appropriately when expected to do so during the ADOS-2 assessment. May explore the room as expected for developmental level but is not obviously overactive.

1 = Sits or stands still when clearly expected to do so (e.g., during the symbolic imitation task, the birthday party) for activities besides the snack, but often fidgets, moves about, or gets up out of his or her seat.

2 = Fidgety; more active than other children of same developmental level.

3 = Incessantly and energetically moves around the room in a way that is difficult to interrupt; the level of activity disrupts the ADOS-2 assessment.

7 = Underactive.

E2. Tantrums, Aggression, Negative or Disruptive Behavior

This item includes any form of anger or disruption beyond communication of mild frustration or whining.

0 = Not upset, disruptive, negative, destructive, or aggressive during the ADOS-2 assessment.

1 = Displays an example of mild upset, anger, aggression, negativism, or intentionally disruptive behavior to the parent/caregiver or the examiner.

2 = More than one intentionally disruptive (e.g., swiping toys off the table) or mildly aggressive act. Loud screaming can be coded here.

3 = Shows marked or repeated negativism, temper tantrums, or more significant aggression (e.g., hitting or biting others).

E3. Anxiety

Anxiety includes initial wariness, as well as more obvious signs of worry or concern.

0 = No obvious anxiety (e.g., trembling or jumpiness).

1 = Mild signs of anxiety, especially at the beginning of the ADOS-2 session, OR marked anxiety only in response to a specific request or to one particular toy or task.

2 = Marked anxiety in response to more than one toy or task or several times during the ADOS-2 evaluation.

ADOS-2 Module 1 Algorithms

Child ID: _____ Examiner: _____

Gender: Female ☐ Male ☐ Date of Birth: _____ Date of Evaluation: _____ Chronological Age: _____

CONVERTING ITEM CODES TO ALGORITHM SCORES

- **Convert** assigned ratings of **3** to algorithm scores of **2**.
- **Convert** assigned ratings other than 0, 1, 2, or 3 (i.e., 7, 8, and 9) to algorithm scores of **0**.
- **Transfer** assigned ratings of **0**, **1**, and **2** directly to the algorithm form (do not convert).

	CHOOSING THE CORRECT ALGORITHM COLUMN	
	FEW TO NO WORDS Assigned rating of **3 or 4 on Item A1,** "Overall Level of Non-Echoed Spoken Language."	**SOME WORDS** Assigned rating of **0, 1, or 2 on Item A1,** "Overall Level of Non-Echoed Spoken Language."
Social Affect (SA)		
Communication		
Frequency of Spontaneous Vocalization Directed to Others (A-2)		
Pointing (A-7)		
Gestures (A-8)		
Reciprocal Social Interaction		
Unusual Eye Contact (B-1)		
Facial Expressions Directed to Others (B-3)		
Integration of Gaze and Other Behaviors During Social Overtures (B-4)		
Shared Enjoyment in Interaction (B-5)		
Showing (B-9)		
Spontaneous Initiation of Joint Attention (B-10)		
Response to Joint Attention (B-11)		
Quality of Social Overtures (B-12)		
SA TOTAL		
Restricted and Repetitive Behavior (RRB)		
Restricted and Repetitive Behaviors		
Intonation of Vocalizations or Verbalizations (A-3)		
Stereotyped/Idiosyncratic Use of Words or Phrases (A-5)		
Unusual Sensory Interest in Play Material/Person (D-1)		
Hand and Finger and Other Complex Mannerisms (D-2)		
Unusually Repetitive Interests or Stereotyped Behaviors (D-4)		
RRB TOTAL		
OVERALL TOTAL (SA + RRB)		

See the back of this form for guidance on how to convert the Overall Total to the ADOS-2 Classification and the ADOS-2 Comparison Score.

CLASSIFICATION/DIAGNOSIS

ADOS-2 Classification: _____

Overall Diagnosis: _____

ADOS-2 COMPARISON SCORE (See back of form for conversion table.)	Level of autism spectrum–related symptoms:
10	
9	HIGH
8	
7	
6	MODERATE
5	
4	LOW
3	
2	
1	MINIMAL-TO-NO EVIDENCE

Converting the Overall Total to the ADOS-2 Classification and ADOS-2 Comparison Score

ADOS-2 Classification

Compare the Overall Total to the cutoff scores below, according to the Module 1 algorithm type:

	FEW TO NO WORDS	SOME WORDS
autism	16	12
autism spectrum	11	8

Assign the ADOS-2 Classification:	
autism	Overall Total is equal to or greater than the *autism* cutoff: ▪ Few to No Words—Overall Total is 16 or higher ▪ Some Words—Overall Total is 12 or higher
autism spectrum	Overall Total is equal to or greater than the *autism spectrum* cutoff, but less than the *autism* cutoff: ▪ Few to No Words—Overall Total is 11 to 15 ▪ Some Words—Overall Total is 8 to 11
non-spectrum	Overall Total is less than the *autism spectrum* cutoff: ▪ Few to No Words—Overall Total is 10 or lower ▪ Some Words—Overall Total is 7 or lower

Record the ADOS-2 Classification on the front of this form in the space marked *ADOS-2 Classification*.

ADOS-2 Comparison Score

In the table below, select the column corresponding to the child's language level (i.e., the algorithm type) and chronological age. Next, locate the obtained Overall Total in that column. Follow the row with the obtained Overall Total to the far left or far right column to find the ADOS-2 Comparison Score associated with that Overall Total.

ADOS-2 Comparison Score Conversion Table for Module 1 (Pre-Verbal/Single Words)

	FEW TO NO WORDS				SOME WORDS					
COMPARISON SCORE	2 yrs	3 yrs	4–5 yrs	6–14 yrs	2 yrs	3 yrs	4 yrs	5–6 yrs	7–14 yrs	COMPARISON SCORE
10	25–28	25–28	26–28	26–28	22–28	22–28	23–28	24–28	24–28	10
9	23–24	24	24–25	25	20–21	20–21	21–22	22–23	22–23	9
8	22	23	22–23	23–24	17–19	18–19	19–20	20–21	21	8
7	20–21	21–22	20–21	20–22	14–16	15–17	16–18	17–19	19–20	7
6	16–19	16–20	16–19	16–19	12–13	12–14	12–15	12–16	12–18	6
5	14–15	15	13–15	14–15	11	10–11	10–11	11	10–11	5
4	11–13	11–14	11–12	11–13	8–10	8–9	8–9	8–10	8–9	4
3	9–10	9–10	7–10	7–10	6–7	7	5–7	5–7	6–7	3
2	7–8	7–8	4–6	4–6	4–5	5–6	3–4	3–4	3–5	2
1	0–6	0–6	0–3	0–3	0–3	0–4	0–2	0–2	0–2	1

Record the obtained Comparison Score on the front of this form in the box marked *ADOS-2 Comparison Score*. Circle the interpretive range (i.e., level of autism spectrum–related symptoms) associated with the score.

Appendix E- ADI-R- Protocol and Score Sheet

WPS Edition

Interview Protocol

ADI-R Autism Diagnostic Interview-Revised

Ann Le Couteur, M.B.B.S., Catherine Lord, Ph.D., Michael Rutter, M.D., F.R.S.

SUBJECT

Name/ID Number: _____

Date of Birth: _____ Chronological Age: _____ Gender: ☐ Male ☐ Female

INFORMANT

Name: _____

Relation to Subject: _____

INTERVIEWER

Name: _____

School/Clinic: _____ Date of Interview: _____

This Interview Protocol should be used in conjunction with the *WPS Edition ADI-R Manual* (WPS No. W-382B)

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Additional copies of this booklet (W-382A) may be purchased from WPS. Please contact us at **800.648.8857** or **www.wpspublish.com**.

W-382A

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BACKGROUND

FAMILY MEMBERS/FAMILY MEDICAL AND SOCIAL HISTORY

NOTE THROUGHOUT ANY DISCREPANCIES BETWEEN INFORMANT'S DESCRIPTION AND OBSERVER'S KNOWLEDGE FROM OTHER SOURCES, AND SUMMARIZE AT END OF INTERVIEW. ASK QUESTIONS AS APPROPRIATE FOR RELATIONSHIP BETWEEN INFORMANT AND SUBJECT.

To begin, perhaps you could give me an idea of who's who in [subject]**'s family.**

Does s/he have any brothers or sisters? Could you tell me their names and ages? Do all of them have the same birth parents? Are any of them adopted or fostered? *(If either parent previously married)* **Are any from a previous marriage? Does anyone else live in** [subject]**'s home?**

Have any of the brothers or sisters been delayed in their development? or had any special problems in development for which treatment was sought?

Did either of [subject]**'s parents have any developmental difficulties (or late walking or talking)? or special problems in development for which treatment was given? Is there anyone in** [subject]**'s extended family who has difficulties similar to those of** [subject]**?**

Names of Siblings	Date of Birth	Age	Sex	Relationship to Subject (biological, foster, adoptive, half sibling)	Developmental Difficulties
1.					
2.					
3.					
4.					
5.					
6.					

Biological mother: _____

Biological father: _____

Caregiving mother (if not birth mother): _____

Caregiving father (if not biological father): _____

SUBJECT'S EDUCATION (SCHOOL AND PRESCHOOL)

THE PURPOSE OF THESE QUESTIONS IS TO PROVIDE A FRAME OF REFERENCE FOR THE ITEMS THAT FOLLOW.

Now I'd like to ask about what sort of programs, playgroups, and schools [subject] **has attended.** Was this a regular playgroup or school? How long did s/he attend? Did s/he need any special help/remedial help? Did s/he have any special problems with reading or spelling? (GO THROUGH SCHOOLS AS APPROPRIATE FOR AGE AND OBTAIN DETAILS OF ATTAINMENTS IF APPROPRIATE.) What has s/he done since leaving school?

School	Type	Dates attended	Additional help required
1.			
2.			
3.			
4.			
5.			

PERSONALIZED TIMING

Later on in the interview, I am going to need to ask you to focus particularly on the 12-month period between [subject's] **fourth and fifth birthdays. What is going to be the easiest way for you to think about that age period?** You've just mentioned that [subject] was attending [school] at that time; is that right? Where were you living then? (GO THROUGH OTHER POSSIBLE PERSONALIZED TIMINGS, SUCH AS THE BIRTH OF SIBLINGS, MOVES OF HOUSE, EITHER PARENT STARTING OR FINISHING JOBS, FAMILY DEATHS, ETC.)

DIAGNOSIS *(no coding needed here)*

Did anyone ever say that [subject] **had a medical problem or give you a medical diagnosis for her/him? What about hearing?** (GET DETAILS AND WRITE BELOW.)

MEDICATION *(no coding needed here)*

Does [subject] **take any regular pills or medicines now?** (GET DETAILS AND WRITE BELOW.)

INTRODUCTORY QUESTIONS

THE PURPOSE OF THESE FIRST QUESTIONS IS TO PROVIDE A FRAME OF REFERENCE FOR THE ITEMS BELOW.

I'd like to start off by just getting a general picture of [subject]**. Let me just briefly ask you some questions and then we can then come back to some things in more detail once I have some sense of what** [subject] **is like. Can you tell me a little about** [subject]**?** How would you describe [subject's] behavior to me if I had to pick her/him out in a group of other children/young people the same age? What kinds of things does s/he do when left to her/his own devices? When is s/he at her/his best? What about the most difficult? **What is** [subject]'s **language like?**

1. CURRENT CONCERNS *(no coding needed here)*

Do you have any concerns about [subject]**'s behavior or development now? What are they?**
(OBTAIN DESCRIPTION AND NOTE BELOW.)

EARLY DEVELOPMENT

Can we now go back to talk about [subject]**'s early years?**

Onset of Symptoms

2. AGE (IN MONTHS) WHEN PARENTS FIRST NOTICED THAT SOMETHING WAS NOT QUITE RIGHT IN LANGUAGE, RELATIONSHIPS, OR BEHAVIOR

First, I'd like to talk about [subject]**'s early development.**

How old was [subject] **when you first wondered if there might be something not quite right with her/his development?**

Code age in months, or choose one of the below codes. Try to code an actual age rather than 996, etc. Note: If parents express age in weeks, code to nearest month. If an age range is given (e.g., 3-4 months), take **midpoint** and round up to nearest month. As far as possible, try to code an actual age rather than 996, etc.

991 = parents not concerned, although child was referred by professional

992 = parents have been worried since birth (e.g., if baby premature or very ill at birth)

996 = can't recall, but before 3 years

997 = can't recall, but 3 years or later

998 = N/A

999= N/K or not asked

3. FIRST SYMPTOMS TO AROUSE PARENTAL CONCERN *(no coding needed here)*

What was it that gave you concern at that time?
(ELICIT DETAILS OF SYMPTOMS FIRST CAUSING PARENTAL CONCERN AND NOTE BELOW.)

4. ONSET AS PERCEIVED WITH HINDSIGHT

THE PURPOSE OF THIS ITEM IS TO RECORD THE EARLIEST POINT IN THE CHILD'S DEVELOPMENT THAT ANYTHING UNUSUAL MAY HAVE Ooccurred, ACCORDING TO THE INFORMANT'S BEST JUDGMENT WITH HINDSIGHT.

Looking back with hindsight, when do you think s/he first showed any problems or difficulties in development or behavior?

Do you think that *everything* was alright before then?

Code informant's judgment. ☐

0 = problems present in first 12 months

1 = problems not present before first birthday, but were noted before second birthday

2 = problems not present before second birthday, but were noted at or before third birthday

3 = problems not present before third birthday, but were noted at or before fourth birthday

4 = problems not present before fourth birthday, but were noted at or before fifth birthday

5 = problems not present before fifth birthday, but were noted at or before sixth birthday

6 = problems not present before sixth birthday, but were noted at a later date

(Specify:_____)

7 = child always "different," but differences were not perceived by parents as any kind of abnormality

8 = no problems were noted by parents

9 = N/K or not asked

Motor Milestones

5. FIRST WALKED UNAIDED

What about walking?

At what age did [subject] **walk without holding on?**

(IF NOT WALKING BY 18 MONTHS – OR IF APPARENTLY DELAYED OR DEVIANT – ASK ABOUT OTHER MOTOR MILESTONES, SUCH AS AGE WHEN FIRST SAT UNAIDED ON A FLAT SURFACE. WRITE DETAILS BELOW.)

Note: Remember to take midpoint and round up to the nearest month. As far as possible, try to code actual age rather than using 996, etc.

(Code in months, normal < 18 months.)

995 = still not reached

996 = N/K, but apparently normal

997 = N/K, but apparently delayed

998 = N/A

999 = N/K or not asked

Toilet Training

PROBE FOR THE POSSIBILITY THAT EACH SET OF HABITS MAY HAVE BEEN SUBSEQUENTLY LOST AND RELEARNED. NOTE AGES FOR BOTH, BUT CODE RELEARNING ONLY. DO NOT CODE ISOLATED ACCIDENTS WITH AN UNDERSTANDABLE EXPLANATION, (E.G., SUBJECT UNWELL, HAD A HIGH TEMPERATURE, RESPONDING TO A CHANGE OF ENVIRONMENT, OR IN ACUTE DISTRESS.)

How has toilet training gone?

6. ACQUISITION OF BLADDER CONTROL: DAYTIME

Is [subject] **dry during the day?**

How old was s/he when this was first achieved?

When was s/he first dry for 12 months without accidents?

Code the age (in months) of last daytime bladder accident **before** clear 12-month period; Exclude soiling accidents. Code months when milestone first reached or choose one of the below codes.

993	= successfully toilet trained for a period of 12 months, but has relapsed and now regularly wets
994	= never achieved continence
995	= still not reached, i.e., continent for period of less than 12 months
996	= N/K, but apparently normal
997	= N/K, but apparently delayed
998	= N/A
999	= N/K or not asked

7. ACQUISITION OF BLADDER CONTROL: NIGHTTIME

Is [subject] **dry at night?**

How old was s/he when s/he first remained dry at night?

When was s/he first dry for 12 months without an accident?

Code the age (in months) of last nighttime bladder accident **before** clear 12-month period; or choose one of the below codes. Exclude soiling accidents. Code months when milestone first reached.

993	= successfully toilet trained for a period of 12 months, but has relapsed and now regularly wets
994	= never achieved continence
995	= still not reached, i.e., continent for period of less than 12 months
996	= N/K, but apparently normal
997	= N/K, but apparently delayed
998	= N/A
999	= N/K or not asked

8. ACQUISITION OF BOWEL CONTROL

Does [subject] **soil himself/herself at all (with her/his bowel movements)?**

How old was s/he when s/he first got full control of her/his bowels?

When was s/he first continent for 12 months without an accident?

Code the age (in months) when continence achieved (i.e., before clear 12-month period following last bowel accident); or choose one of the below codes. Code accidents involving soiling or both wetting and soiling.

993	= achieved bowel control for a period of 12 months, but has relapsed and now regularly soils
994	= never achieved continence
995	= still not reached, i.e., continent for period of less than 12 months
996	= N/K, but apparently normal
997	= N/K, but apparently delayed
998	= N/A
999	= N/K or not asked

ACQUISITION AND LOSS OF LANGUAGE/OTHER SKILLS

Now I'd like to talk about [subject]**'s language development and the kinds of things children do before they learn to talk.**

What is [subject]**'s language like now? Has s/he learned to talk yet?**

(ADAPT INITIAL PROBES TO WHAT IS ALREADY KNOWN ABOUT SUBJECT'S LEVEL OF LANGUAGE, AND OBTAIN DESCRIPTIONS TO AID THE WORDING OF LATER QUESTIONS.)

9. AGE OF FIRST SINGLE WORDS

"MEANINGFULLY" REFERS TO WORDS USED REPEATEDLY AND CONSISTENTLY FOR THE PURPOSE OF COMMUNICATION WITH REFERENCE TO A PARTICULAR CONCEPT, OBJECT, OR EVENT. DO NOT CODE "MOMMY" AND "DADDY"; INCLUDE ANY OTHER **SPONTANEOUS**, PHONOLOGICALLY CONSISTENT SOUNDS THAT APPROXIMATE REAL WORDS IN LANGUAGE OF FAMILY AND ARE USED REPEATEDLY WITH MEANING.

How old was s/he when s/he first used words meaningfully, apart from "mama" and "dada"?

What were her/his first words?

How did s/he show that s/he knew their meaning? (GET EXAMPLES.)

Did [subject] ever use these words to refer to anything else or as sounds that didn't seem to have any specific meaning?

Code age (in months) first spoke single words; or choose one of the below codes (normal ≤ 24 months). ☐☐☐

993 = had some words, then lost and not yet regained

994 = milestone not reached

996 = N/K, but apparently normal

997 = N/K, but apparently delayed

999 = N/K or not asked

10. AGE OF FIRST PHRASES (IF EVER USED)

FOR THE PURPOSES OF THIS CODE, A PHRASE MUST CONSIST OF TWO WORDS, ONE OF WHICH MUST BE A VERB. DO NOT CODE ATTRIBUTE-NOUN COMBINATIONS OR ECHOLALIC SPEECH OR PHRASES THAT MIGHT HAVE BEEN LEARNED AS A SINGLE WORD TO CONVEY A SINGLE MEANING (E.G., "SEE YOU" [MEANING GOOD-BYE]). NOTE THAT THIS DEFINITION DIFFERS FROM WHAT IS REGARDED AS VERBAL FOR ITEM 30, "OVERALL LEVEL OF LANGUAGE."

How old was s/he when s/he first said something that involved putting words together meaningfully (i.e., using two- or three-word phrases)?

What did s/he say?

What about phrases including a verb? (GET EXAMPLES.)

Code age (in months) first used phrases; or choose one of the below codes (normal ≤ 33 months). ☐☐☐

993 = had some phrases, then lost; not yet regained

994 = milestone not reached

996 = N/K, but apparently normal

997 = N/K, but apparently delayed

999 = N/K or not asked

Loss of Language Skills (Items 11–19)

THIS ITEM IS TO DETERMINE WHETHER, ONCE THE SUBJECT HAS DEVELOPED COMMUNICATIVE LANGUAGE, THERE WAS A DEFINITE PERIOD OF LOSS OF SKILLS THAT LASTED AT LEAST 3 MONTHS. USE THE FOLLOWING DEFINITIONS:

LANGUAGE BEFORE LOSS: COMMUNICATIVE USE OF AT LEAST FIVE DIFFERENT WORDS (OTHER THAN "MAMA" AND "DADA") ON A DAILY BASIS FOR AT LEAST 3 MONTHS.

LANGUAGE LOSS: LOSS FOR AT LEAST 3 MONTHS OF A LANGUAGE SKILL PREVIOUSLY ESTABLISHED, AS SPECIFIED ABOVE.

Were you ever concerned that [subject] **might have lost language skills during the first years of her/his life?**

Was there ever a time that s/he stopped speaking for some months after having learned to talk?

(IF YES) How much language did s/he have before stopping? Was s/he using at least five different words (other than "mama" or "dada") on a daily basis for as long as 3 months?

11. LOSS OF LANGUAGE SKILLS AFTER ACQUISITION

0 = No
1 = Yes

EVER ☐

If answer is yes, proceed to next question (Item 12).
If answer is no, proceed to item 20 (Page 21).

12. LEVEL OF COMMUNICATIVE LANGUAGE BEFORE LOSS

How much language did [subject] **have before losing it?**

What was s/he able to say before the change occurred?

(PROBE FOR NUMBER OF MEANINGFUL WORDS, EXTENT OF SPONTANEOUS USAGE, AND LEVEL OF COMMUNICATIVE USE.)

EVER ☐

0 = daily, spontaneous, and meaningful speech used communicatively, with at least five different words used at some point before change (and any of the other skills listed below)

1 = occasional and/or fewer than five words used spontaneously and communicatively (alone or in combination with imitative abilities)

2 = produced speech or sounds upon request (may or may not have also spontaneously imitated)

3 = spontaneous imitations of vocalization (without ever having any completely spontaneous speech), with no elicited imitation or spontaneous communicative speech

8 = no change or loss

9 = N/K or not asked

Type of Language Skills Lost (Items 13–16)

FOR THE FOLLOWING ITEMS, "LOSS" REFERS TO ABILITIES THAT THE SUBJECT HAD AND THEN LOST FOR AT LEAST 3 MONTHS

What aspects of language did [subject] **lose?**
Did s/he stop using meaningful words spontaneously?
Did s/he stop using words to communicate with other people?
What about use of grammar?
Was her/his pronunciation of words affected?

0 = no definite loss
1 = probable loss of specified skill
2 = definite loss of specified skill
8 = insufficient language to show change specified
9 = N/K or not asked

13. LOSS OF SPONTANEOUS USE OF AT LEAST FIVE MEANINGFUL WORDS — EVER ☐

14. LOSS OF COMMUNICATIVE INTENT — EVER ☐

15. LOSS OF SYNTACTICAL SKILLS (GRAMMAR) — EVER ☐

16. LOSS OF ARTICULATION (PRONUNCIATION) — EVER ☐

17. AGE WHEN MAIN LOSS OF LANGUAGE SKILLS FIRST APPARENT

How old was [subject] **when s/he first began to lose her/his language?**

Code age in months, or choose one of the following:

998 = no loss

999 = N/K or not asked

☐☐☐

18. ASSOCIATION OF LOSS OF LANGUAGE WITH PHYSICAL ILLNESS

Did [subject] **have any serious physical illness at the time that s/he began to lose language?**
(IF YES, OBTAIN DETAILS.)

EVER ☐

0 = loss of skills, but no possibly relevant association with a definite physical illness

1 = loss associated with a definite illness (e.g., high fever with ear infection), but no clear evidence of meningeal or encephalitic involvement

2 = loss associated with impaired consciousness/epileptic attacks or other definite evidence of meningeal or encephalitic involvement

8 = no loss of skills

9 = N/K or not asked

19. DURATION OF LOSS OF LANGUAGE SKILLS

How long was it before language began to come back?

How long was it before s/he reached the level s/he had been at before the loss took place?

Code in months the time from start of loss to time when previous level regained; or choose one of the following:

☐☐☐

993 = loss still present without recovery of language functions

994 = progressive deterioration continuing

998 = no loss

999 = N/K or not asked

General Loss of Skills (Items 20–28)

20. LOSS OF SKILLS (FOR AT LEAST 3 MONTHS)

SKILL LOSS: A SKILL THAT HAD BEEN ESTABLISHED AND USED ON A DAILY BASIS FOR AT LEAST 3 MONTHS, AND WAS THEN LOST SUBSTANTIALLY OR COMPLETELY FOR AT LEAST 3 MONTHS. DO **NOT** INCLUDE: A LOSS OF BLADDER OR BOWEL CONTROL IF NOT PART OF A MORE GENERAL LOSS OF SKILLS; OR VARIATIONS IN USE OF SKILLS AT TIMES OF WORSENING BEHAVIOR IF SUBJECT CLEARLY RECOVERS (I.E., IF "LOSS" IS PART OF A MORE GENERAL PATTERN OF UPS AND DOWNS). LOSS MUST BE CONSISTENT OVER A PERIOD OF AT LEAST 3 MONTHS.

We've just talked about possible loss of language skills. I'd like to go back now to ask about possible losses in other skills. Has there ever been a period when [subject] **seemed to get markedly worse or dropped further behind in her/his development?**

When was this?

What skills did [subject] **lose?**

(IF LOSS OF LANGUAGE SKILLS) **Did** [subject] **lose these other skills at the same time as losing language?**

0 = no consistent loss of skills (although behavior may vary at times)

1 = probable loss of skill, but of a degree that falls short of specified criteria

2 = account of definite loss of skills over a period of time

9 = N/K or not asked

EVER ☐

If loss, proceed to next question (Item 21).

If no loss of skills, code "0," "8," or "998" for Items 20 to 28 and then skip to Item 29 (Page 24).

Type of Skills Lost (Items 21–25)

What skills did [subject] **lose?**
Did it affect her/his ability to look after her/himself?
Did it affect her/his play?
What about coordination? walking? ability to grip or hold objects?
What about using the bathroom? school-type skills?
(IF LOSS OF LANGUAGE SKILLS) Did [subject] lose these other skills at the same time as losing language?

Code "0" if none, "1" if possible loss, "2" if definite loss

21. PURPOSIVE HAND MOVEMENTS
(ABILITY TO GRIP/HOLD OBJECTS) — EVER ☐

22. MOTOR SKILLS
(POSTURE, GAIT, COORDINATION) — EVER ☐

23. SELF-HELP SKILLS
(FEEDING, DRESS, USING THE BATHROOM ETC.) — EVER ☐

24. CONSTRUCTIVE OR IMAGINATIVE PLAY
(PUZZLES, GAMES, MAKE-BELIEVE ETC.) — EVER ☐

25. SOCIAL ENGAGEMENT AND RESPONSIVENESS
(SOCIAL RELATEDNESS, INTEREST, AND INVOLVEMENT) — EVER ☐

26. AGE WHEN MAIN LOSS OF SKILL FIRST APPARENT

How old was s/he when the loss of this skill first became apparent?

Code age in months, or choose one of the following:

998 = no loss at either "1" or "2" level of skills

999 = N/K or not asked

☐☐☐

27. ASSOCIATION OF LOSS OF SKILLS WITH PHYSICAL ILLNESS

Did [subject] **have any serious physical illness at the time this change occurred?** (IF YES, OBTAIN DETAILS.)

0 = loss of skills, but no possibly relevant association with a definite physical illness

1 = loss associated with definite illness (e.g., high fever with ear infection), but no clear evidence of meningeal or encephalitic involvement

2 = loss associated with impaired consciousness/epileptic attacks or other definite evidence of meningeal or encephalitic involvement

8 = no loss of skills

9 = N/K or not asked

EVER ☐

28. DURATION OF LOSS OF SKILLS

How long was it before [subject]**'s skills began to come back?**

How long was it before s/he reached the level s/he had been at before the loss took place?

Code in months the time from start of loss to time previous level regained; or choose one of the following:

993 = loss still present

994 = progressive deterioration continuing

998 = no loss

999 = N/K or not asked

☐☐☐

LANGUAGE AND COMMUNICATION FUNCTIONING

Now let's come back to [subject]**'s language and communication. Let me begin with what her/his understanding of language is like now.**

29. COMPREHENSION OF SIMPLE LANGUAGE

THIS IS A SUMMARY CODE THAT DEALS WITH THE SUBJECT'S UNDERSTANDING OF SPOKEN LANGUAGE WHEN THERE IS AN ABSENCE OF OTHER CUES SUCH AS THOSE THAT MIGHT BE PROVIDED BY GESTURE, POINTING, OR CONTEXT.

How much language do you think [subject] **understands if you don't gesture?**

What about when s/he can't tell from the situation what is going to happen? For example, can you send her/him into another room to get something like her/his shoes or blanket?

What about your purse or a book?

Could you ask her/him to put them somewhere, other than the usual place?

Could s/he deliver a simple message?

Could s/he follow an instruction with an "if" and a "then"?

Does s/he understand if you say "no" without gesturing or raising your voice?

How about "yes" or "okay"?

How about names of favorite foods or toys or people in your family?

Do you think s/he understands 10 words? 50?

What about at age 4 to 5?

Current ☐

0 = in response to a request can usually perform an unexpected action with an unexpected object; or could place an object, other than something to be used by self (such as boots or a toy), in an unexpected location in a different room ("Put the keys on the kitchen table")

Most abnormal 4.0–5.0 ☐

1 = in response to a request can usually get an object, other than something for self or something highly contextualized, from another room ("Get the keys from the kitchen table"), but usually cannot carry out a new action on this object or put it in a "new" place

2 = understands many words (more than 50), including "yes" and names of familiar people, toys, or foods, but does not meet criteria for "0" or "1"

3 = understands fewer than 50 words, but some comprehension of "no" and names of a few favorite objects, foods, or people, or words within familiar routines

4 = little or no comprehension of words, even in context

8 = N/A (e.g., deaf)

9 = N/K or not asked

30. OVERALL LEVEL OF LANGUAGE

THIS IS A SUMMARY CODE CONCERNING WHETHER SUBJECT USES AT LEAST THREE WORD PHRASES; THIS INCLUDES SPONTANEOUS SPEECH OR ECHOED OR STEREOTYPED SPEECH IF THEY ARE USED FUNCTIONALLY.

How much speech does [subject] **have now?**

Does s/he have phrases with at least three words that s/he uses every day?

Do they ever include verbs?

Do other people understand? If not, does s/he have single words that are used on a daily basis? How many?

CURRENT

0 = functional use of spontaneous, echoed, or stereotyped language that, on a daily basis, involves phrases of three words or more that at least sometimes include a verb and are comprehensible to other people ☐

1 = no functional use of three-word phrases in spontaneous, echoed, or stereotyped speech, but uses speech on a daily basis with at least five different words in the last month

2 = fewer than five words total or speech not used on a daily basis

If code "1" or "2," and subject never had speech at level "0" (or had lost it by age 4 to 5 years), ask next question (Item 31), then skip to Item 42 (Page 37). Code "8" for all categories in Items 32 to 41 (Pages 27 to 36).

If code "1" or "2," but did have speech at level "0" at age 4 to 5 years, do not skip Items 32 to 41. Code these "8" for "current" and as appropriate for 4 to 5 years or "ever."

31. USE OF OTHER'S BODY TO COMMUNICATE

THE EMPHASIS IS ON THE ABNORMAL USE OF ANOTHER PERSON AS A KIND OF EXTENSION OF THE SUBJECT'S ARM OR BODY. FOR EXAMPLE, THE USE OF **ANOTHER** PERSON'S HAND TO POINT, TOUCH AN OBJECT, OR PERFORM A TASK SUCH AS TURNING A DOOR KNOB TO OPEN A DOOR, UNSCREWING A BOTTLE TOP, OR MANIPULATING A ZIPPER OR BUTTONS. THIS BEHAVIOR WILL PROBABLY TAKE PLACE WITHOUT ANY PRIOR ATTEMPT TO COMMUNICATE THE NEED OR REQUEST, BY MEANS OF USING OTHER SOUNDS OR GESTURES. THUS, THE PHYSICAL CONTACT IS NOT TO INITIATE A SOCIAL APPROACH, BUT RATHER TO FACILITATE THE COMPLETION OF THE TASK.

Now let me focus on the time when [subject] **had very little speech.**

How did s/he let you know s/he wanted something then?

Did s/he ever show you what s/he wanted by taking your hand or wrist or some other part of your body?

What exactly did s/he do?

What did s/he do when you were brought to the object wanted?

Did s/he ever use your hand as if it were a tool or an extension of her/his own arm (such as pointing with your hand or getting your hand to turn a door knob)?

Did s/he look at you when doing this?

Did s/he combine taking your hand with trying to communicate with sounds or words?

When did s/he do this?

Did s/he try to communicate first by sounds or gesture?

Does s/he ever take your hand or wrist like this now? (GET DETAILS SUFFICIENT FOR CODING.)

0 = no use of other's body to communicate, except in situations where other strategies have not worked (e.g., when parent conversing with someone and subject cannot get her/his attention), or when taking someone's hand to lead them places

1 = occasional placement of other's hand on objects or use of other's hand as a tool or to point, but some combination with other modes of communication

2 = occasional placement of other's hand or use of other's hand as a tool or to demonstrate "for" the subject without integration with other modes of communication

3 = regular use of other's hand as a tool or to gesture "for" the subject

8 = little or no spontaneous communication

9 = N/K or not asked

CURRENT ☐

EVER ☐

Items 32 to 41 apply only to verbal subjects

32. ARTICULATION/PRONUNCIATION

CODE ONLY FOR SUBJECTS AGED 4 YEARS OR OLDER. ARTICULATION REFERS TO THE ENUNCIATION OF THE SOUNDS OF LANGUAGE.

Let me now come back to [subject]**'s talking now.**

What is her/his pronunciation like?

Are there any words or sounds s/he doesn't get quite right? What are they?

Do other people understand her/him easily?

What about people outside the family?

What was her/his articulation like when s/he reached her/his fifth birthday?

What errors did s/he make at age 5? (NOTE EXAMPLES.)

Could a stranger understand her/him at age 5? (GET DETAILS OF DIFFICULTIES WITH ARTICULATION.)

0 = understood by anybody (i.e., clear enunciation of most sounds, but may include a few consonant omissions or substitutions)

1 = understood better by family than others because of difficulty with some sounds, but mostly comprehensible to strangers at first encounter

2 = definite articulation difficulties such that some words are very difficult for strangers to understand until they get to know her/him

3 = strangers find speech almost impossible to understand or parents have significant difficulties understanding because of articulation

8 = N/A; no speech or subject below age 4.0 years

9 = N/K or not asked

CURRENT (4.0 or older) ☐

AT 5.0 YEARS ☐

33. STEREOTYPED UTTERANCES AND DELAYED ECHOLALIA

THESE ARE DEFINED AS THE NONHALLUCINATORY USE OF REPETITIVE SPEECH PATTERNS THAT ARE CLEARLY ODD IN TERMS OF EITHER STEREOTYPED CONTENT, OR THEIR NONSOCIAL USAGE, OR BOTH. THESE INCLUDE PHRASES THAT ARE INTERSPERSED INTO MORE NORMAL SPEECH; SELF-COMMENTARY ON THE PERSON'S OWN ACTIONS; A REPETITIVE RERUN OF EMOTIVE OR UPSETTING INTERCHANGES; OR ROUTINIZED PHRASES USED OUT OF APPROPRIATE CONTEXT. DO NOT INCLUDE THE REPETITIONS THAT OFTEN OCCUR WITH NORMALLY DEVELOPING CHILDREN AS PART OF PLAY WHEN PHRASE SPEECH IS JUST BECOMING WELL ESTABLISHED, OR FOR REASSURANCE.

Has s/he ever tended to use rather odd phrases or say the same thing over and over in almost exactly the same way? That is, either phrases s/he has heard other people use or ones s/he has made up (e.g., "It's bad to bite your wrist"; "Does this look like a traffic light?"; "Say it's alright now").

Does s/he tend to talk to her/himself in this way when doing something on her/his own, or when upset about something that has happened during the day?

Does s/he use the phrase appropriately or not to mean anything in particular or as part of a conversation with her/himself?

Can you give me some examples?

What about when s/he was younger?

Does s/he ever give a running commentary on what s/he is doing?

Did s/he ever use odd phrases more often than s/he does now?

0 = rarely or never uses stereotyped phrases

1 = speech tends/tended to be more repetitive than most subjects at the same level of complexity, but not stereotyped in an odd or unusual way; or occasional stereotyped utterances, but consistent productive language as well

2 = often uses/used stereotyped utterances with productive language as well

3 = phrases are almost exclusively stereotyped utterances

8 = N/A; no phrases (code "1" or "2" on Item 30)

9 = N/K or not asked

CURRENT ☐

EVER ☐

34. SOCIAL VERBALIZATION/CHAT

THE EMPHASIS IN DEFINING SOCIAL VERBALIZATION/CHAT IS ON WHETHER OR NOT SPEECH IS USED JUST TO BE FRIENDLY OR SOCIAL RATHER THAN TO EXPRESS NEEDS OR GIVE SOME INFORMATION. THE FOCUS OF THIS QUESTION IS SOCIAL APPROACH, NOT SOCIAL RECIPROCITY, WHICH IS DEALT WITH IN ITEM 35.

When people talk, sometimes it is to get something or find out about something, but sometimes the purpose seems mainly just to be with someone – sort of "small talk" – such as saying "It never stops raining," "The telephone is ringing again!" or "You are very busy today." Would [subject] **ever talk with you just to participate in some form of language interchange?**

What about when s/he was younger (but using phrases)?

0 = verbalizes or chats with clear social quality of talking to be friendly or to express interest, rather than to make needs known — CURRENT ☐

1 = some **social** use of speech in response to caregiver or to get attention with no other obvious motivation, but limited in frequency or range of contexts — EVER (when verbal) ☐

2 = uses some speech to alert caregiver to immediate needs or wants, but little or no purely social use of verbalization

8 = N/A (code "1" or "2" on Item 30)

9 = N/K or not asked

35. RECIPROCAL CONVERSATION (WITHIN SUBJECT'S LEVEL OF LANGUAGE)

THE EMPHASIS OF THIS ITEM IS ON THE ABILITY TO FACILITATE THE FLOW OF CONVERSATION (I.E., TO BUILD ON THE **OTHER PERSON'S** RESPONSES RATHER THAN THE SUBJECT'S ABILITY TO TALK/CHAT)

Can you have a conversation with [subject]? **That is, if you say something to her/him, without asking a direct question, what will** [subject] **usually do?**

Will s/he say something?

Will s/he ever ask you a question or build on what **you** have said in such a way that s/he adds something new to what you have said, so that the conversation will continue? In other words, will s/he converse to-and-fro on topics that you have introduced?

Can s/he also bring up appropriate topics?

What about when s/he was younger (but using phrases)?

0 = conversation flows, including both offering information and building on other person's response in a manner that leads to ongoing dialogue — CURRENT ☐

1 = occasional reciprocal conversation, but less frequent than normal or limited in flexibility or topics — EVER (when verbal) ☐

2 = little or no reciprocal conversation; others find it difficult to **build** a conversation even if there is apparent positive or social talk by subject; subject fails to follow anyone else's conversation topic; may ask or answer questions but not as part of a single interchange

3 = very little spontaneous speech

8 = N/A (code "1" or "2" on Item 30)

9 = N/K or not asked

36. INAPPROPRIATE QUESTIONS OR STATEMENTS

THE FOCUS IS ON SOCIALLY INAPPROPRIATE UTTERANCES THAT REFLECT A LACK OF UNDERSTANDING OR A DISREGARD OF THE SOCIAL IMPACT OF SUCH COMMENTS. THESE MAY CONSIST OF UTTERANCES THAT ARE INTRINSICALLY ODD (E.G., "HOW TALL WAS MR. BROWN WHEN HE WAS 2?"), OR UTTERANCES THAT ARE INAPPROPRIATE BECAUSE OF THEIR PERSONAL NATURE OR IN RELATION TO THE SITUATION. REPETITION MAY CONTRIBUTE TO THE ODDNESS BUT IT IS NOT SUFFICIENT IN ITSELF.

Are there times when [subject] **uses socially inappropriate questions or statements?**
For example, does s/he regularly ask personal questions or make personal comments at awkward times? (GET EXAMPLES.)

Was this ever a problem in the past?

0 = no or very rare use of questions/statements inappropriate to conversation or setting

1 = use of some questions/statements regardless of situation; questions or statements are slightly inappropriate and may be repetitious, but are not usually very odd or highly embarrassing

2 = frequent use of questions/statements that are odd or obviously inappropriate to the situation

8 = N/A (code "1" or "2" on Item 30)

9 = N/K or not asked

CURRENT ☐

EVER ☐

37. PRONOMINAL REVERSAL

THE EMPHASIS IS ON THE CONSISTENT ABNORMAL CONFUSION OF PRONOUNS BETWEEN FIRST AND SECOND OR THIRD PERSON. IT DOES NOT INCLUDE "I/ME" CONFUSION AS THIS IS OFTEN A SUBCULTURALLY ACCEPTABLE USAGE.

Has [subject] **ever got her/his personal pronouns the wrong way round? For example, has** [subject] **ever mixed up "you" and "I"?**

What about saying "he" or "she" instead of "I"? For example, saying "*You* want a drink" instead of "*I* want a drink" or "He is hungry" instead of "I am hungry." (NOTE EXAMPLES.)

(IF YES) When using "you" or "s/he" instead of "I," *how* does s/he say it? For example, does her/his statement have the intonation of a question?

What about when [subject] **was younger?**

0 = no confusion between 1st and 2nd or 3rd person after phrase speech with pronoun use established

1 = refers/referred to self by name instead of "I" after phrase speech established, but no persistent "you/s/he-I" confusion

2 = "you/I" or "s/he/I" confusion after phrase speech established, but "you" or "s/he" not used with intonation of a question

3 = pronominal confusion when asking a question in which "you" or "s/he" is used for "I"

7 = other types of pronominal confusion (other than "I/me"), such as "he/you"

8 = N/A (code "1" or "2" on Item 30 or no pronouns used)

9 = N/K or not asked

CURRENT ☐

EVER ☐

38. NEOLOGISMS/IDIOSYNCRATIC LANGUAGE

NEOLOGISMS MUST BE NONWORDS AND OBVIOUSLY PECULIAR (E.G., "PLIN" FOR A FREE-FALLING PIECE OF PAPER OR FABRIC, OR "MASHUDA" FOR TRIANGLES.) IDIOSYNCRATIC LANGUAGE REFERS TO REAL WORDS AND/OR PHRASES USED OR COMBINED BY THE SUBJECT IN A WAY THAT S/HE COULD NOT HAVE HEARD. THESE ARE USED TO CONVEY **SPECIFIC** MEANINGS; THEY *DO NOT* INCLUDE CONVENTIONAL METAPHORS. DIFFERENTIATE UNUSUAL OR TRULY IDIOSYNCRATIC USAGES FROM ORDINARY CHILDISH REFERENCES TO OBJECTS ACCORDING TO THEIR FUNCTION OR AS PART OF A SHARED GAME OR JOKE.

Does s/he ever use words that s/he seems to have invented or made up?

Does [subject] **ever put things in odd, indirect ways, or have idiosyncratic ways of saying things, such as saying "hot rain" for "steam" or referring to her/his grandmother by her age?**

Would s/he ever take this one step further and refer to other women as "55"? Can you give me some examples?

Did s/he ever use these sorts of odd words or phrases in the past?
(GET EXAMPLES AND PROMPT AS NECESSARY.)

0 = no use of neologisms or idiosyncratic language — CURRENT ☐

1 = occasional use of neologisms and/or idiosyncratic words and phrases used consistently over a period of time

2 = regular use of neologisms and/or idiosyncratic ways of saying things, including generalization of unusual term to reference beyond the example that may have fostered the initial idiosyncratic word or phrase — EVER ☐

8 = N/A (code "1" or "2" on Item 30)

9 = N/K or not asked

39. VERBAL RITUALS

WHEN DECIDING WHETHER VERBAL RITUALS ARE PRESENT, FOCUS ON THE DEGREE OF PREDICTABILITY OF THE CONTEXT AND SEQUENCE, AS WELL AS ON THE COMPULSIVE QUALITY OF THE SPEECH. THE EMPHASIS IS ON THE FIXED SEQUENCES OF UTTERANCES THAT ARE SAID AS IF THE SUBJECT FEELS PRESSURE TO COMPLETE THEM IN A PARTICULAR ORDER. THE SUBJECT IS IMPOSING AN ORDER ON WHAT S/HE SAYS AND MAY, IN ADDITION, POSE SIMILAR RESTRICTIONS ON THE VERBAL RESPONSES/UTTERANCES OF OTHERS. EXCLUDE VERBAL RITUALS THAT OCCUR **SOLELY** AS PART OF A BEDTIME ROUTINE.

Does s/he ever say the same thing over and over in exactly the same way or insist on you saying the same things over and over again?

Does s/he ever keep saying the same thing until you reply in a certain way?

What happens if you interrupt her/him or refuse to comply?

Was this ever a problem in the past? (GET DETAILS.)

0 = no verbal rituals

1 = tendency to say things in ritualized way or to require others to do so, but no indication that this is compulsive, and readily stops if asked to do so

2 = subject has to say one or more things in a special way; rituals may intrude on family life, may involve other family members and some distress at interruption, or may cause some disturbance or minor reorganization of family life that can be tolerated by most families

3 = as for "2," but with marked difficulty to control and marked intrusiveness on family life; family members involved to a degree that causes definite social impairment, disruption, or prevention of some family activities; serious distress at any attempted interruption

8 = N/A (code "1" or "2" on Item 30)

9 = N/K or not asked

CURRENT ☐

EVER ☐

40. INTONATION/VOLUME/RHYTHM/RATE

THIS ITEM REFERS TO UNUSUAL QUALITIES OF PROSODY OR THE PARALINGUISTIC SOUND OF THE SUBJECT'S SPEECH AS EVIDENCED IN INTONATION, VOLUME, RHYTHM, OR RATE. DO NOT CODE USE OF COLLOQUIAL PHRASES OR INVECTIVES HERE.

Is there anything unusual about the way [subject] **speaks? That is, is her/his speech of normal volume or is it consistently too loud or too quiet?**

What about the rate and rhythm of her/his speech?

What about the intonation or pitch?

Does s/he ever repeat whole sentences or monologues in exactly the same tone of voice in which s/he first heard them? (GET DETAILS.)

What about in the past?

0 = normal, appropriately varying intonation, reasonable volume, and normal rate of speech, with regular rhythm coordinated with breathing — CURRENT ☐

1 = speech that shows one or other of the abnormalities listed under "2," but not obviously peculiar and no interference with intelligibility

2 = speech that is clearly abnormal in terms of any or all of the following: (a) odd intonation or inappropriate pitch and stress; (b) markedly flat and toneless or mechanical speech; (c) consistently abnormal volume that lacks modulation; (d) inappropriate, poorly modulated rate or rhythm (either unusually slow or halting or unusually rapid or jerky) to a degree that creates **some** interference with intelligibility — EVER ☐

3 = speech that is frequently obviously peculiar or difficult to understand because of abnormalities of type specified under "2"

7 = stutter or stammer; abnormal intonation due to severe hearing impairment; or intonation abnormality due to neurological disorder causing motor dysfunction

8 = N/A (code "1" or "2" on Item 30)

9 = N/K or not asked

41. CURRENT COMMUNICATIVE SPEECH

THIS ITEM REFERS TO SEMANTIC AND GRAMMATICAL COMPLEXITY WITHIN A SENTENCE IN NONECHOED UTTERANCES. THIS IS A SUMMARY CODE TO ASSESS HOW WELL THE SUBJECT USES HER/HIS LANGUAGE TO COMMUNICATE.

How does [subject] **now use the words s/he has?**

(IT IS OFTEN HELPFUL TO ASK PARENTS/INFORMANTS TO RECALL A PARTICULAR CONVERSATION WITH THE SUBJECT, SUCH AS ONE TAKING PLACE ON THE WAY TO THE APPOINTMENT OR DURING A RECENT MEAL.)

In what sort of situation does s/he talk the most?

Does s/he call you by name or use words to direct your attention? (GET EXAMPLES OF COMMUNICATIVE USE OF WORDS.)

Does s/he ever tell you about things that are not present (e.g., about something that happened a while ago or something s/he is looking forward to)?

What about when s/he was 5 years of age?

	CURRENT	AT 5.0 YEARS
0 = speech, at whatever level attained, used frequently and communicatively in a variety of contexts, including some reference to events not present (Do not include requests here)	☐	
1 = some communicative use of words (i.e., words used regularly to communicate, with or without an abnormal element), but somewhat restricted in frequency or contexts		☐
2 = some spontaneous words and/or echolalic language, but with limited communicative use		
3 = little or no communicative language (including exclusively non-communicative echolalia), though subject has some language		
8 = N/A (code "1" or "2" on Item 30, or under 5 years of age for 5.0 year coding)		
9 = N/K or not asked		

Items 42 onwards apply to both verbal and nonverbal subjects.

42. POINTING TO EXPRESS INTEREST

THIS ITEM IS STRICTLY CONCERNED WITH UNPROMPTED POINTING THAT IS USED AS A SPONTANEOUS COMMUNICATION TO EXPRESS INTEREST OR TO SHOW SOMETHING AT A DISTANCE, RATHER THAN AS A MEANS OF OBTAINING SOME OBJECT. POINTING MUST BE SOCIAL AND IT MUST BE INITIATED BY THE SUBJECT. FURTHERMORE, THE POINTING MUST BE AT OBJECTS THAT ARE WITHIN SIGHT BUT THAT ARE SOME DISTANCE AWAY. POINTING AT BOOKS, OR POINTING AS A LEARNED RESPONSE TO QUESTIONS, IS EXPLICITLY EXCLUDED FROM THIS ITEM. ALSO EXCLUDED IS POINTING THAT IS USED AS A MEANS OF OBTAINING SOME OBJECT. IN ORDER FOR THE POINTING TO BE CODED "0" IT MUST INVOLVE COORDINATED EYE GAZE WITH THE OTHER PERSON, AS DESCRIBED BELOW.

Does [subject] **ever spontaneously point at things around her/him?**

With a finger or sort of a hand extended, like reaching?

In what circumstances?

Does s/he ever point at things at a distance, such as out a window at home or in a car or bus?

If I wanted to get you to look at something, I might first look at it, then look at you, then point and look at the object again, then look back at you to see if you understood. Can [subject] do this?

What about when s/he was 4 to 5 years old?

0 = spontaneously points at objects at a distance with finger to express interest, using coordinated eye gaze in order to communicate

1 = makes some limited attempt to express interest by pointing, but with limited flexibility and/or lack of coordination (e.g., uses arm or points with finger, but without consistent coordination with eye gaze)

2 = little or no spontaneous unprompted attempts to point to express interest in objects at a distance

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

43. NODDING

THIS ITEM IS INTENDED TO DETERMINE IF THE SUBJECT CURRENTLY USES OR HAS EVER USED THE CONVENTIONAL GESTURE OF HEAD NODDING TO COMMUNICATE "YES." NODDING SHOULD HAVE OCCURRED IN SEVERAL DIFFERENT SITUATIONS BUT MAY HAVE DECREASED IN FREQUENCY AS THE SUBJECT LEARNED TO SPEAK.

Does [subject] **nod her/his head to mean "yes"?**

What about when s/he was 4 to 5 years old?
(GET DETAILS.)

0 = consistently nods spontaneously
1 = sometimes nods spontaneously
2 = never nods spontaneously
8 = N/A
9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

44. HEAD SHAKING

THIS ITEM IS INTENDED TO DETERMINE IF THE SUBJECT CURRENTLY USES OR HAS EVER USED THE CONVENTIONAL GESTURE OF HEAD SHAKING TO COMMUNICATE "NO." HEAD SHAKING SHOULD HAVE OCCURRED IN SEVERAL DIFFERENT SITUATIONS, BUT MAY HAVE DECREASED IN FREQUENCY AS THE SUBJECT LEARNED TO SPEAK.

Does [subject] **shake her/his head to mean "no"?**

What about when s/he was 4 to 5 years old?
(GET DETAILS.)

0 = consistently shakes head spontaneously
1 = sometimes shakes head spontaneously
2 = never shakes head spontaneously
8 = N/A
9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

45. CONVENTIONAL/INSTRUMENTAL GESTURES

INSTRUMENTAL GESTURES ARE SPONTANEOUS, CULTURALLY APPROPRIATE, DELIBERATE HAND OR ARM MOVEMENTS THAT CONVEY A MESSAGE BY THEIR FORM AS SOCIAL SIGNALS. EXCLUDE PURELY EMOTIONAL SIGNALS (SUCH AS HANDS TO FACE IN EMBARRASSMENT OR SHRINKING WITH FEAR); DEMONSTRATIONS; AND INSTANCES OF TOUCHING OR PULLING SOMEONE TO GAIN THEIR ATTENTION OR SHOW THEM SOMETHING. ALSO EXCLUDE MANNERISMS SUCH AS TOUCHING THE FACE OR SCRATCHING. ALL GESTURES MUST BE/HAVE BEEN USED OVER A PERIOD OF 3 OR MORE MONTHS TO BE CODED. OFTEN IT IS USEFUL IN HELPING INFORMANTS TO REMEMBER GESTURES TO FOCUS ON HOW THE SUBJECT DIRECTED THEIR ATTENTION OR USED GESTURE WHEN OTHER MODES OF COMMUNICATION WERE NOT CLEAR OR SUCCESSFUL.

Does [subject] **wave good-bye?**

When does this happen?

Does s/he ever use other common gestures, such as blowing a kiss, clapping for a job well done, putting a finger to her/his lips to mean "be quiet," or shaking a finger for "bad"?

Does s/he ever use gestures, other than pointing or holding arms up to be lifted, to let you know what s/he wants?

Does s/he use gestures when s/he is trying to get you to help her/him or to get your attention (for example, beckoning to someone, or putting out a hand with palm extended to ask that you give her/him something)?

What about when s/he was 4 to 5 years old?

Note: Subjects who have been taught signing and who use instrumental signs only in the teaching context should be coded "2." However, if the taught signs are used spontaneously with some variety and creativity for instrumental purposes, code "0" or "1" as appropriate.

- 0 = appropriate and spontaneous use of a variety of conventional or instrumental gestures
- 1 = spontaneous use of conventional or instrumental gestures, but limited in range or contexts
- 2 = inconsistent spontaneous use, or use of elicited or well-rehearsed simple conventional or instrumental gestures only
- 3 = no use of conventional or instrumental gestures
- 8 = N/A
- 9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

46. ATTENTION TO VOICE

For subjects aged 5.0 years or older, probe only for the 4.0- to 5.0-year period.

THE FOCUS IS ON WHETHER THE SUBJECT SHOWS AN ORIENTING RESPONSE WHEN SPOKEN TO AND NOT WHETHER S/HE COMPLIES WITH WHAT IS SAID. THE ORIENTING RESPONSE SHOULD CONSIST OF AN AUTOMATIC LOOKING TO THE SOUND, TOGETHER WITH AN APPROPRIATE FACIAL EXPRESSION. THIS SHOULD OCCUR WITHOUT THE NEED FOR EXTRA STEPS SUCH AS CALLING THE SUBJECT'S NAME OR STANDING VERY CLOSE TO HIM/HER.

If you come into a room and start talking to [subject] **without calling her/his name, what does s/he do? I mean when you say something neutral rather than when you're trying to get her/him to do something. Does s/he look up and pay attention to you?**

How does s/he respond? How about to other people?

Do you need to say her/his name or catch her/his eye first or could you just say something that s/he might not even be that interested in, such as "Oh no, it's raining," or "My goodness, what a lot of toys!"

What did [subject] **do when s/he was 4 to 5 years old?** (GET DETAILS.)

0 = usually looks up and pays attention when spoken to in a positive manner in contexts **other than** to do something that s/he may not want to do

1 = does not consistently appear to pay attention (e.g., might look up briefly, but little sustained attention), but sometimes responds to what is said or responds on occasion only to firm, loud voice

2 = usually does not look up or pay attention when spoken to, and does not respond to what is said; **or** responds to her/his name only or when her/his attention is caught very deliberately

3 = rarely responds, although hearing normal

8 = N/A

9 = N/K or not asked

CURRENT (UNDER 5.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

47. SPONTANEOUS IMITATION OF ACTIONS

For subject's aged 10.0 years or older, probe only for the 4.0- to 5.0-year period.

THE EMPHASIS IS ON THE SPONTANEOUS IMITATION OF A VARIED RANGE OF NONTAUGHT, INDIVIDUAL BEHAVIORS, ACTIONS, OR CHARACTERISTICS OF ANOTHER PERSON. EXCLUDE IMITATION OF TV/FILM CHARACTERS.

Does [subject] **imitate you or other people in the family?**

How about when you are *not* trying to get her/him to do so?

Does s/he copy something you have done, but using a "pretend" object (such as mowing the lawn with some toy vehicle)?

Is the imitation only at the time you are doing whatever it is, or does the copying form part of her/his play at *other* times?

How varied are the things s/he imitates? Does the imitation ever involve some *personal* characteristic, such as the way you walk or gesture or the way you hold something? (GET EXAMPLES.)

What about when s/he was 4 to 5 years old?

Do not code elicited or vocal imitation here.

0 = spontaneous imitation of a varied range of non-taught actions, at least some of which are incorporated into play outside the context of the observed behavior of the imitated person

1 = some indication of spontaneous imitation that goes beyond copying a frequent use of an object, but not of sufficient flexibility or number to meet the criteria for "0"

2 = spontaneous imitation limited to a few familiar routines that are not incorporated into play; including frequent appropriate use of an object probably learned through imitation (e.g., mowing lawn with a toy mower)

3 = very rare or no spontaneous imitation

8 = N/A

9 = N/K or not asked

CURRENT (UNDER 10.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

48. IMAGINATIVE PLAY

For subjects aged 10.0 years or older, probe only for the 4.0- to 5.0-year period.

IMAGINATION IS DEFINED AS PRETEND PLAY THAT IMPLIES THE FORMATION OF MENTAL IMAGES OF THINGS NOT PRESENT. THE FOCUS HERE IS ON THE CHILD'S CREATIVE AND VARIED USE OF ACTIONS OR OBJECTS IN PLAY TO REPRESENT HER/HIS OWN IDEAS.

Does [subject] **play any pretend games?**

Does s/he play with toy tea sets or dolls or action figures or cars? (GET EXAMPLES.)

Does s/he drink the tea/push the car/kiss the stuffed animal?

Has s/he ever given the doll a drink or the action figure a ride in the car?

Has s/he ever used the doll/action figure as the initiator–so that the doll pours and serves the tea or the action figure walks to the car and gets in it?

Does s/he ever talk to her/his dolls or animals?
Does s/he ever make them talk or make noises?

Does this type of play vary from day to day?

Has s/he ever made up a sort of story or sequence (e.g., with the toy cars racing each other, being parked in a garage, or going to Granny's house)?

What about at age 4 to 5? (GET EXAMPLES.)

0 = variety of pretend play, including use of dolls/animals/toys as self-initiating agents

1 = some pretend play, including actions directed to dolls or cars, etc., but limited in variety or frequency

2 = occasional, spontaneous pretend actions or highly repetitive pretend play (which may be frequent), or only play that has been taught by others

3 = no pretend play

8 = N/A

9 = N/K or not asked

CURRENT (UNDER 10.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

49. IMAGINATIVE PLAY WITH PEERS

For subjects aged 10.0 years or older, probe only for the 4.0- to 5.0-year period.

THE FOCUS HERE IS ON THE SPONTANEOUS, CREATIVE SHARING OF IMAGINATION AMONG CHILDREN, INCORPORATING BOTH THE SUBJECT'S IDEAS AND THOSE OF OTHER CHILDREN. THE LEVEL OF IMAGINATION MAY BE SIMPLE SO LONG AS IT IS SOCIALLY INTERACTIVE, SPONTANEOUS, AND VARIED. IF THE SUBJECT'S ONLY PLAY IS WITH SIBLINGS, BE PARTICULARLY CAREFUL TO DIFFERENTIATE WELL-PRACTISED ROUTINES FROM SPONTANEOUS, FLEXIBLE PLAY. ALSO DIFFERENTIATE PLAY THAT IS HIGHLY STRUCTURED "FOR" THE SUBJECT BY THE SIBLING FROM PLAY IN WHICH S/HE SHOWS SOME INITIATIVE.

Does [subject] **ever play imaginative games with someone else?**

Do they seem to understand what each other is pretending? How can you tell? Can you give me an example?

Does [subject] ever take the lead in this play? Or does s/he mostly follow the other person's ideas?

What about at age 4 to 5?

0 = imaginative, cooperative play with other children in which the subject both takes the lead and follows another child in spontaneous, pretend activities

1 = some participation in pretend play with another child, but not truly reciprocal and/or pretending is very limited in variety

2 = some play with other children, but little or no pretending

3 = no play with other children or no pretend play even on own

8 = N/A

9 = N/K or not asked

CURRENT (OVER 4.0 AND UNDER 10.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

SOCIAL DEVELOPMENT AND PLAY

Thank you. That has given me a clear idea about her/his communication and imaginative play. Now can we talk about how s/he got on with people when s/he was little?

50. DIRECT GAZE

INCLUDES BOTH THE SUBJECT'S USE OF DIRECT EYE GAZE TO COMMUNICATE AND HER/HIS RESPONSE TO OTHERS' ATTEMPTS TO CATCH HER/HIS EYE.

For subjects UNDER 5.0 years:

Does [subject] **look you directly in the face when doing things with you or talking with you?**

Can you catch her/his eye?

Does s/he sometimes watch you as you walk into the room?

Does s/he look back and forth to your face as other children would?

What about with others?

0 = normal reciprocal direct gaze used to communicate across a range of situations and people

1 = definite direct gaze, but only of brief duration or not consistent during social interactions

2 = uncertain/occasional direct gaze, or gaze rarely used during social interactions

3 = unusual or odd use of gaze

8 = N/A

9 = N/K or not asked

CURRENT (UNDER 5.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

For subjects OVER 5.0 years:

When [subject] **was 4 to 5 years of age, did s/he look at you directly in the face when doing things with you or talking with you?**

Could you catch her/his eye?

Did s/he sometimes watch you as you walked into the room?

Would s/he have looked back and forth to your face as other children would?

What about with others?

51. SOCIAL SMILING

DEFINED AS SPONTANEOUS SMILING DIRECTED AT A VARIETY OF PEOPLE, INCLUDING SMILING BACK AT SOMEONE SMILING AT HER/HIM, SMILING DURING AN APPROACH, AND SMILING IN RESPONSE TO WHAT SOMEONE DOES OR SAYS TO HER/HIM.

When [subject] **is approaching someone to get her/him to do something or to talk to her/him, does** [subject] **smile in greeting?**

What about when s/he sees you for the first time when you've been out? Or when meeting someone s/he knows?

If s/he is not smiling first, what does s/he do if someone else smiles at her/him? Or when someone says something nice to her/him?

What about at age 4 to 5 years old?

0 = regularly predictable, reciprocal, social smiles in response to the smiles of a variety of people besides parent/caregiver

1 = some evidence of reciprocal social smiling, but not sufficient to code "0"

2 = some evidence of smiling while looking at people, but generally not reciprocal; code here if smiles only to parent/caregiver, smiles only upon request, or smiles in odd situations or odd ways

3 = little or no smiling at people, though may smile at other things

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

52. SHOWING AND DIRECTING ATTENTION

THE PURPOSE OF THIS ITEM IS TO DETERMINE WHETHER, HOW, AND IN WHAT CIRCUMSTANCES THE SUBJECT DIRECTS OTHERS' ATTENTION TO TOYS OR OBJECTS IN WHICH S/HE IS INTERESTED. THE FOCUS IS ON SPONTANEOUS DIRECTING OF ATTENTION PURELY TO SHARE INTEREST.

Does s/he ever show you things that interest her/him? For example, would s/he bring a new toy for you to see or call your attention to something s/he is playing with or making? What sorts of things are these?

Does this ever happen for things that aren't part of her/his special interests and aren't things s/he needs you for?

What about when [subject] **was 4 to 5 years old?**

0 = regular showing of objects by bringing things to parent/caregiver and directing her/his attention, with no manifest motive other than sharing

1 = possible showing as described above, but not sufficiently frequent or of purely communicative quality to meet criteria for "0"

2 = some bringing things to parent/caregiver and/or showing, but associated with preoccupations, food, or need for help

3 = rare or no social approaches of this type

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

53. OFFERING TO SHARE

THIS ITEM CONCERNS UNPROMPTED, NONROUTINE OFFERS TO SHARE A RANGE OF DIFFERENT OBJECTS WITH OTHER PEOPLE.

Does [subject] **ever offer to share things, that is, food or toys or favorite objects, with you?**

How about with other children?

Does s/he do this on her/his own or do you need to suggest it?

How often would this happen?

What about when [subject] **was 4 to 5 years old?**
(BE SURE TO DIFFERENTIATE CLEAR, SPONTANEOUS OFFERS TO SHARE FROM RESPONSES TO PROMPTING AND RELINQUISHING THINGS IF ANOTHER CHILD TRIES TO TAKE THEM. PROBES FOR OLDER CHILDREN OR ADULTS COULD INCLUDE SHARING A PEN, PENCIL, CRAYONS, NAPKINS, SPACE ON A BENCH OR COUCH, A BLANKET; OR GETTING A CUP OF TEA OR A DRINK.)

0 = frequent, spontaneous, and varied offers to share different sorts of objects (e.g., toys, comforters) with other people

1 = some spontaneous offers to share, but limited in number of contexts or frequency (must be more than food)

2 = will sometimes share if requested, but not spontaneously, or spontaneous sharing of food only

3 = no sharing

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

54. SEEKING TO SHARE ENJOYMENT WITH OTHERS

THE AIM OF THIS ITEM IS TO DETERMINE WHETHER THE SUBJECT ATTEMPTS TO SHARE HER/HIS ENJOYMENT OF THINGS THAT GIVE HER/HIM PLEASURE WITH OTHERS, WITH NO OTHER APPARENT MOTIVE OTHER THAN SHARING.

What kinds of things might make [subject] **excited and happy?**

How does s/he show these feelings?

Does [subject] **ever seem to want you to share in her/his enjoyment of something?**

Has s/he tried to share these feelings with you?

For example, if s/he has built something or sees something s/he particularly likes, will s/he let you know about her/his excitement by smiling or talking or making noises?

What about when [subject] **was 4 to 5 years old?**

0 = frequent attempts across a variety of contexts to direct several other people's attention to things that s/he enjoys or has done well (must be with more than one parent)

1 = some attempts to share enjoyment, but limited in number or variety or spontaneity, or lacking clear quality of shared pleasure

2 = few or no attempts to share enjoyment

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

55. OFFERING COMFORT

DEFINED AS A SPONTANEOUS UNPROMPTED GESTURE, TOUCH, VOCALIZATION, OR OFFER OF AN OBJECT (E.G., BLANKET). IT ALSO INCLUDES CHANGE IN FACIAL EXPRESSION DIRECTED TO SOMEONE WHO IS SAD, ILL, OR HURT, IN AN ATTEMPT TO HELP HER/HIM FEEL BETTER.

Does [subject] **ever try to comfort you if you are sad, hurt, or ill?**

What does s/he do if you are crying or if you have hurt yourself?

Would her/his facial expression change as s/he does this?

What about with her/his brother or sister?

Does s/he show comfort in more than one situation?

Do people have to show that they are upset in an exaggerated fashion to elicit comfort?

What about when s/he was 4 to 5 years old?

Code only if the subject spontaneously initiates offers of comfort.

CURRENT ☐

0 = flexibly and spontaneously offers comfort in a range of circumstances and ways, for example, by gesture, touching, or vocalization, or offers of objects (e.g., blanket); must include change in facial expression

MOST ABNORMAL 4.0–5.0 ☐

1 = has partial response (e.g., stands nearby and looks concerned) or indirect physical approach (e.g., comes to sit in lap, but with no clear attempt to comfort); or offers comfort in response to exaggerated expression (e.g., to pretend crying) or in one routine situation (e.g., to baby sister when she's hungry)

2 = rarely offers comfort or only in odd ways

3 = never offers comfort to others

8 = N/A

9 = N/K or not asked

56. QUALITY OF SOCIAL OVERTURES

THE FOCUS OF THIS ITEM IS ON THE **QUALITY** OF SOCIAL INTENTIONALITY WHEN SEEKING HELP, NOT ON THE NUMBER OF CONTEXTS IN WHICH SUCH APPROACHES OCCUR. CODE "0" ONLY IF SUBJECT CONSISTENTLY, DURING HIGHLY MOTIVATED APPROACHES (SUCH AS ASKING FOR HELP), MAKES SOME SORT OF VOCALIZATION THAT IS INTEGRATED WITH HER/HIS OTHER BEHAVIORS, INCLUDING EYE GAZE, AND DIRECTS HER/HIS ATTENTION TO THE OBJECT AND THE OTHER PERSON. CODE **TYPICAL**, RATHER THAN BEST, MOTIVATED OVERTURES.

When s/he wants something or wants help, how does s/he try to get your attention?

Does s/he point, give objects to you, or come and get you when s/he needs help?

Does s/he look at the object or you?

Does s/he ever use gestures or movements with sounds or words to get your attention?

If you don't understand at first, what does [subject] do?

Does s/he look at you and then talk or make a sound?

What about when s/he was 4 to 5 years old? (GET EXAMPLES.)

Does s/he show interest in other people or any other activities?

How does s/he show her/his interest, or get other people's attention? How often would s/he do this?

Code according to **majority** of overtures rather than best ones.

- 0 = consistently uses coordinated eye gaze with accompanying vocalization in typical situations when motivated to communicate
- 1 = may use eye gaze or vocalization, but these are weakly integrated
- 2 = rarely shows well-coordinated, focused social intentionality involving eye gaze or vocalization, or shows this in odd ways
- 3 = shows no coordination of eye gaze and vocalization
- 8 = N/A
- 9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

57. RANGE OF FACIAL EXPRESSIONS USED TO COMMUNICATE

THE FOCUS HERE IS ON FACIAL EXPRESSIONS USED TO COMMUNICATE, NOT JUST THOSE ASSOCIATED WITH THE EXPERIENCE OF EMOTIONS. A NORMAL RANGE OF EMOTIONS, EVEN IN A VERY YOUNG CHILD, WOULD BE EXPECTED TO INCLUDE SEVERAL MORE SUBTLE FACIAL EXPRESSIONS USED COMMUNICATIVELY, INCLUDING SURPRISE, GUILT, DISGUST, INTEREST, AMUSEMENT, AND EMBARRASSMENT, AS WELL AS JOY, ANGER, FEAR, AND PAIN.

Does [subject] **show a normal range of facial expression? For example, does s/he frown or pout or look embarrassed as well as laugh or cry?**

Can s/he look guilty...or surprised...or amused?

Can you tell by her/his face when s/he is afraid or disgusted?

Does s/he have the same range of facial expressions as other children?

What about when s/he was 4 to 5 years old?
(GET EXAMPLES.)

0 = full range of facial expression

1 = somewhat limited facial expression; may be rather stilted, exaggerated, in manner

2 = markedly limited range of facial expressions or tendency to have just one facial expression (e.g., happy) for all circumstances

3 = facial expression showing little or no indication of emotion of any kind

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

58. INAPPROPRIATE FACIAL EXPRESSIONS

INAPPROPRIATE FACIAL EXPRESSIONS ARE THOSE THAT INDICATE EMOTIONS INCONGRUENT WITH THE SITUATION, SUCH AS LAUGHING WHEN SOMEONE IS UPSET OR HURT, OR LAUGHING OR CRYING FOR NO DISCERNABLE REASON.

Does [subject]**'s facial expression usually seem appropriate to the particular situation as far as you can tell?**

Does s/he ever laugh or smile in situations that do not seem funny to most people or when you do not understand what it is s/he finds amusing?

Did this ever occur in the past? (NOTE EXAMPLES.)

0 = facial expressions almost always appropriate to mood, situation, and context

1 = facial expressions slightly or occasionally inappropriate or odd

2 = facial expressions obviously inappropriate in several different situations (SPECIFY)

8 = N/A (almost no variation in facial expression, appropriate or inappropriate, as in coding of "3" in Item 57)

9 = N/K or not asked

CURRENT ☐

EVER ☐

59. APPROPRIATENESS OF SOCIAL RESPONSES

THE FOCUS OF THIS ITEM IS ON HOW THE SUBJECT RESPONDS WHEN ADULTS OTHER THAN PARENTS ATTEMPT TO INTERACT WITH HER/HIM IN EVERYDAY, BUT NONROUTINE SITUATIONS.

Now can we turn to how [subject] **responds to what other people say or do?**

Does s/he consistently respond to the approaches of others in familiar situations?

How does s/he respond if a friend of yours whom s/he doesn't know well approaches and speaks to her/him?

What about someone s/he really likes?

How does s/he respond if someone unfamiliar (such as at church or in a shop) appropriately talks to her/him or tries to attract her/his attention?

Does s/he look directly at her/him?

Does s/he smile or show pleasure?

Would s/he show other reactions, such as interest or tentativeness? (GET EXAMPLES. PROBE TO DETERMINE CONSISTENCY AND CIRCUMSTANCES. IF THE CHILD SOUNDS SHY, SEEK FURTHER EXAMPLES OF PEOPLE WHO ARE MORE FAMILIAR.)

What about when s/he was 4 to 5 years of age?

0 = appropriate response to overtures by familiar and unfamiliar adults

1 = some clear positive responses and interactions, but not consistent

2 = responds to parents/caregiver and others in familiar settings, but responses are stereotyped, inappropriate, or very limited

3 = little or no interest in or response to people, except parents/caregiver or very familiar significant others

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

Now I'd like to talk about the way [subject] **plays and the kinds of things s/he is interested in.**

FAVORITE ACTIVITIES/TOYS

If [subject] **could choose anything s/he likes to do, what would be her/his favorite activities? How about favorite toys or any other kinds of objects?** (ASK FOR INFORMATION ABOUT THE MAIN ACTIVITIES AND TOYS, AND RECORD THEM INTO THE SEPARATE COLUMNS BELOW.)

Favorite Activities	Favorite Toys/Objects

60. INITIATION OF APPROPRIATE ACTIVITIES

THIS ITEM CONCERNS HOW THE SUBJECT SPONTANEOUSLY KEEPS HIMSELF/HERSELF OCCUPIED AND INVOLVED IN A RANGE OF NONODD AND NONREPETITIVE ACTIVITIES WHEN NOT SUPERVISED OR DIRECTED.

How good is [subject] **at organizing her/his own play or activities without your help?**

That is, does s/he find things to do without your directing her/him?

What kind of things does s/he do if left to her/his own devices? (GET EXAMPLES.)

What about when s/he was 4 to 5 years old?

0 = spontaneously takes up a range of appropriate play activities, without prompting or organization by other people

1 = spontaneously initiates only a limited range of appropriate activities

2 = engages in passive, but otherwise appropriate, activity, such as watching TV or listening to the radio

3 = engages in no active or constructive play, or engages only in repetitive activities or motor stereotypes

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

ITEMS 61 TO 64:
For children under 4.0 years, only the "current" coding is applicable.
For those aged 10.0 years or older, code only "most abnormal 4.0–5.0 years."

61. IMITATIVE SOCIAL PLAY

THE FOCUS OF THIS ITEM IS ON THE CHILD'S RECIPROCAL PARTICIPATION AS BOTH LEADER AND FOLLOWER IN EARLY SOCIAL GAMES THAT REQUIRE IMITATION AND COORDINATION OF SIMPLE ACTIONS. DO NOT COUNT BALL GAMES.

As a young child, did [subject] **enter into the spirit of social games such as "Here We Go 'Round the Mulberry Bush" or "Ring A Ring O'Roses?**

That is, did s/he spontaneously join in and try to initiate the various actions?

What about teasing games such as "I'm going to get you!" or having your fingers walking toward her/him?

What about with other familiar adults?

How did s/he join in the game?

Can s/he play peek-a-boo? How do you play it?

How about pat-a-cake? Simon says?

What about at age 4 to 5?

Code play with an adult or another child.

- 0 = normal social play, including clear evidence that the child initiates and responds to simple infant social games and can take both parts
- 1 = some to-and-fro (i.e., reciprocal) social play, but limited in amount, duration, or contexts in which shown (e.g., only plays peekaboo or pat-a-cake with parents/caregiver)
- 2 = little to-and-fro social play (e.g., plays peekaboo or pat-a-cake in a limited way only, but not reciprocal)
- 3 = no evidence of to-and-fro social play
- 8 = N/A
- 9 = N/K or not asked

CURRENT (UNDER 10.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

62. INTEREST IN CHILDREN

For subjects aged 10.0 years or older, probe only for the 4.0- to 5.0-year period.

THE FOCUS HERE IS ON THE SUBJECT'S INTEREST IN WATCHING AND INTERACTING WITH OTHER CHILDREN OF THE SAME AGE.

What does [subject] **think about other children of approximately the same age whom s/he does not know? Is s/he interested in them?**

What does s/he do when another child comes to your house or s/he sees a child in another familiar situation (e.g. church, playgroup)?

What about when [subject] **was 4 to 5 years old?**

Code in relation to children of approximately the same age whom the subject does not know. Do not code interest in babies here.

- 0 = often watches other children and sometimes makes a clear effort to approach them or get their attention
- 1 = usually watches other children or indicates interest in them to parent/caregiver in some way (e.g., by pointing, vocalizing, or trying to imitate what they are doing, but no attempt to seek them out); or approaches other children without trying to get their attention
- 2 = occasionally watches other children, but almost never tries to approach them, or to direct parent's/caregiver's attention to them, or copy them
- 3 = shows no, or almost no, interest in other children
- 8 = N/A
- 9 = N/K or not asked

CURRENT (UNDER 10.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

63. RESPONSE TO APPROACHES OF OTHER CHILDREN

For subjects aged 10.0 years or older, probe only for the 4.0- to 5.0-year period.

THE AIM HERE IS TO DETERMINE HOW THE SUBJECT RESPONDS WHEN OTHER CHILDREN APPROACH HER/HIM AND WHETHER THIS RESPONSE CONSTITUTES AN EFFORT TO KEEP AN INTERACTION GOING.

What about if another child approaches her/him?

Does s/he behave differently with [sibling] or with a child s/he has seen many times before?

Does the other child's age make a difference?

Does s/he ever actively avoid other children?

What about at age 4 to 5?

Code in relation to peers and older children; do not include responses to babies.

0 = generally responsive to other children's approaches, although may be hesitant initially if other children are too rough or intrusive; sometimes makes a clear effort to keep an interaction going with a child other than a sibling by gesturing, vocalizing, offering an object, etc.

1 = sometimes responsive to other children's approaches, but response is limited, somewhat unpredictable, or only to a sibling or a very familiar child

2 = rarely or never responds to the approach of even a familiar child (although may show interest in nonapproaching children or babies)

3 = consistently and persistently avoids approaches of other children

8 = N/A

9 = N/K or not asked

CURRENT (UNDER 10.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

64. GROUP PLAY WITH PEERS

For subjects aged 10.0 years or older, probe only for the 4.0- to 5.0-year period.

THE FOCUS IS ON THE SUBJECT'S PARTICIPATION IN GROUPS OF OTHER CHILDREN IN SPONTANEOUS GAMES OR ACTIVITIES. COOPERATION MUST INVOLVE THE SUBJECT ATTENDING TO HER/HIS PEERS AND MODIFYING HER/HIS BEHAVIOR IN A WAY THAT CLEARLY DEMONSTRATES SPONTANEOUS, FLEXIBLE, INTERACTIVE PLAY. CHASING AND BALL GAMES SHOULD BE INCLUDED ONLY IF SPONTANEOUS, FLEXIBLE, AND INTERACTIVE. NOTE PREVIOUS COMMENTS REGARDING CARE IN INTERPRETING PLAY WITH SIBLINGS.

How does [subject] **play with others of her/his age when there are more than two together?**

What is their play like?

Is [subject] different with children or others outside your immediate family?

Does [subject] play cooperatively in games that need some form of joining in–such as musical games or hide-and-seek or ball games? (GIVE EXAMPLES AS APPROPRIATE FOR MENTAL AGE LEVEL.)

Would s/he initiate such games? Or actively seek to join in?

Can s/he take different parts in these games (like being chased or doing the chasing, or hiding and looking for the other person)?

What about when [subject] **was 4 to 5 years old?**

0 = actively seeks and plays cooperatively in several different groups (three or more subjects) in a variety of activities or situations

1 = some cooperative play, but of insufficient initiative, flexibility, frequency, or variety to code "0"

2 = enjoys "parallel" active play (such as jumping in turn on a trampoline or falling down with others during Ring A Ring O'Roses), but little or no cooperative play

3 = seeks no play that involves participation in groups of other children, though may chase or play catch

8 = N/A

9 = N/K or not asked

CURRENT (OVER 4.0 AND UNDER 10.0) ☐

MOST ABNORMAL 4.0–5.0 ☐

65. FRIENDSHIPS

For subjects aged 5.0 years and older only.

FOR THE PURPOSE OF THIS ITEM, FRIENDSHIP IS DEFINED AS A SELECTIVE, RECIPROCAL RELATIONSHIP BETWEEN TWO PERSONS OF APPROXIMATELY THE SAME AGE WHO SEEK EACH OTHER'S COMPANY AND SHARE ACTIVITIES AND INTERESTS.

Does s/he have any particular friends or a best friend?
In what way does s/he show that they are her/his friends?

Do you know the names of any of her/his friends?

Does s/he see any of them outside of school, like around the neighborhood or in another social setting (e.g., clubs)?

Does s/he ever go out with them such as to the cinema/theatre/concerts? Do they share interests? (PROBE AS APPROPRIATE AND NOTE EXAMPLES.)

Are her/his relationships with others normal? (IF NOT) In what way are they abnormal? (FOCUS ON SUBJECT'S DEVELOPMENTAL LEVEL– I.E., MENTAL AGE, NOT CHRONOLOGICAL AGE.)

Was it the same in the past, or did s/he have fewer/more friends when s/he was younger?

0 = one or more relationships with person **in approximately own age group** with whom subject shares non-stereotyped activities of personal variety; whom subject sees outside prearranged group (such as club); and with whom there is definite reciprocity and mutual responsiveness

1 = one or more relationships that involve some personal shared activities outside a prearranged situation, with some initiative taken by subject, but limited in terms of restricted interests (e.g., model railways) or less than normal responsiveness/reciprocity

2 = people with whom subject has some kind of personal relationship involving seeking of contact, but **only** in group situation (such as club, church, etc.) or in school or at work

3 = no **peer** relationships that involve selectivity and sharing

8 = N/A (subject is outside the specified age range, or there has been an **unusually serious** lack of opportunity for peer contact)

9 = N/K or not asked

CURRENT (5.0 OR OLDER) ☐

MOST ABNORMAL 10.0–15.0 ☐

66. SOCIAL DISINHIBITION

For subjects aged 4.0 or older only.

SOCIAL DISINHIBITION REFERS TO BEHAVIOR THAT IS NOT APPROPRIATELY MODULATED ACCORDING TO THE SOCIAL EXPECTATIONS IN THE SUBJECT'S SOCIOCULTURAL ENVIRONMENT. SUCH DISINHIBITION MAY ARISE FROM A VARIETY OF CAUSES, BUT THE AIM HERE IS TO ASK ABOUT THAT WHICH ARISES FROM A LACK OF AWARENESS OF SOCIAL CUES. CODE INAPPROPRIATE QUESTIONS OR STATEMENTS IN ITEM 36, NOT HERE.

As they grow up, children ordinarily learn that they need to behave differently in different social situations. For example, they are usually more shy or reserved with people that they do not know very well or in certain situations such as church.

Does [subject] **vary in her/his behavior according to whom s/he is with or where s/he is?**

Is s/he ever cheeky or rude, or even inappropriately friendly to strangers?

Does s/he seem aware of social cues or social rules?

Is s/he more socially naive than other children/people (that is, unable to understand what one should say or do in particular social situations)?

Does s/he ever approach or touch strangers inappropriately?

What does s/he do if you visit a friend's home? (GET EXAMPLES.)

Was this ever a problem (after [subject] **turned 4), in a way that it would not have been for other children that age?**

All codings should be as judged by interviewer on basis of descriptions obtained and **not** on informant's inference.

CURRENT (4.0 AND ABOVE) ☐

MOST ABNORMAL 4.0–5.0 ☐

0 = normal social inhibition

1 = occasional cheekiness or disinhibition more than others at same developmental level, but not to the extent of embarrassment: somewhat socially naive or imperceptive for developmental level

2 = definite lack of appreciation of social cues, contexts, or requirements: definitely lacks normal social inhibitions and sometimes behaves in socially embarrassing ways; fails to modulate behavior according to social context

3 = marked social disinhibition: appears unaware of social cues and social requirements so that behavior frequently embarrassing or inappropriate

8 = N/A

9 = N/K or not asked

INTERESTS AND BEHAVIORS

FOR ITEMS 67 TO 78, "INTERFERENCE WITH" REFERS TO DIFFICULTIES FOR THE FAMILY, AND "SOCIAL IMPAIRMENT" REFERS TO SUBJECT'S OWN LIMITATION OR HANDICAP AS A RESULT OF THE AMOUNT OF TIME SPENT IN ABNORMAL ACTIVITY. ALL BEHAVIORS MUST HAVE OCCURRED OVER A 3-MONTH PERIOD TO BE CODED. IT IS IMPORTANT TO ENSURE THAT EXAMPLES FOR "CURRENT" AND "EVER" CODINGS ARE OBTAINED, WHERE SPECIFIED.

CODING INFORMATION FOR ITEMS 67 TO 78:

Code 2 involves some disturbance or reorganization of family life that can be tolerated by most families OR involves some limited interference with subject participating in other activities.

Code 3 requires major disruption or prevention of some family activities OR disruption or prevention of activities by the subject.

67. UNUSUAL PREOCCUPATIONS

AN UNUSUAL PREOCCUPATION IS DEFINED AS AN INTEREST THAT IS ODD OR PECULIAR IN QUALITY—THAT IS UNUSUAL IN ITS INTENSITY AND LACK OF SOCIAL FEATURES—AND WHICH IS REPETITIVE OR STEREOTYPED IN ONE OR MORE OF ITS FEATURES OR ELEMENTS.

Does [subject] **have any unusual or peculiar interests– I mean ones that preoccupy her/him even when the focus of interest is not physically present and might seem odd to other people? For example, is s/he unusually interested in things like metal objects, lights, street signs, or toilets?**

How much does s/he talk about them?

Does this interest influence how s/he behaves? How long has it lasted?

Does this interfere with her/his other activities or with family life?

Are there things that you do differently as a family because of this interest?

How much of a problem is it for the family?

Was there ever anything like this in the past?

Unusual preoccupations must have gone on for at least 3 months to be coded.

CURRENT ☐

0 = no unusual preoccupations

1 = unusual preoccupation that does not interfere with significant activities of family life or does not cause social impairment of the subject

EVER ☐

2 = definite, repetitive preoccupation that intrudes into family life, but does not disrupt it significantly; or definite, repetitive preoccupation that does not cause substantial interference with social functioning, but which does constrain or intrude upon subject's other activities

3 = definite preoccupation that causes substantial interference or social impairment and severely limits the subject's other activities

9 = N/K or not asked

68. CIRCUMSCRIBED INTERESTS

For subjects aged 3.0 years or older only.

A CIRCUMSCRIBED INTEREST IS DEFINED AS A PURSUIT THAT DIFFERS FROM ORDINARY HOBBIES IN ITS INTENSITY; ITS CIRCUMSCRIBED NATURE (I.E., IT MAY INVOLVE A HIGH LEVEL OF EXPERTISE, BUT THIS REMAINS UNUSUALLY FOCUSED AND HAS NOT DEVELOPED INTO A BROADER CONTEXT OF KNOWLEDGE); ITS NONSOCIAL QUALITY (IT MAY BE SHARED WITH ANOTHER INDIVIDUAL WITH A SIMILAR CIRCUMSCRIBED INTEREST BUT NOT AS PART OF A SPECIALIZED CLUB OR ASSOCIATION); AND ITS RELATIVE NONPROGRESSION OR DEVELOPMENT OVER TIME (THAT IS, THE INTEREST PERSISTS, BUT DOES NOT FORM THE BASIS OF A BUILDING UP OF SHARED OR USED EXPERTISE). IT DIFFERS FROM AN "UNUSUAL PREOCCUPATION"(ITEM 67) IN THAT IT LACKS PECULIAR OR ODD CONTENT. CIRCUMSCRIBED INTERESTS ARE UNUSUAL IN THEIR QUALITIES (AS ABOVE) BUT NOT IN THEIR CONTENT.

Does [subject] **have any special hobbies/interests that are unusual in their intensity?**

How long has s/he had this interest?

In what way is it unusual?

Has it developed or changed at all over time?

Does s/he share the interest with other people? In what way?

Does it (the interest) seem at all encompassing in its intensity?

What happens if you interrupt her/him?

Does it interfere with her/his doing things?

Have there been any special interests in the past? (GET DETAILS.)

Circumscribed interests must have gone on for at least 3 months to be coded.

0 = no circumscribed interests

1 = special interest of unusual degree, but not definitely intrusive into or constraining of the subject's or family's other activities

2 = definite circumscribed interest that does not cause substantial interference with social functioning, but which does constrain or intrude upon subject's or family's other activities

3 = definite circumscribed interest that causes clear-cut social impairment

8 = N/A (age below 3.0 years)

9 = N/K or not asked

CURRENT (3.0 OR OLDER) ☐

EVER (3.0 OR OLDER) ☐

69. REPETITIVE USE OF OBJECTS OR INTEREST IN PARTS OF OBJECTS

THIS ITEM INVOLVES ACTIONS OF A STEREOTYPED OR REPETITIVE NATURE THAT ARE NONFUNCTIONAL AND THAT INVOLVE A FOCUS EITHER ON PARTS OF OBJECTS OR ON A USAGE OF AN OBJECT THAT IS CLEARLY SEPARATE FROM THAT WHICH IS ORDINARILY ACCEPTED.

How does s/he play with her/his toys or things around the house? (GET EXAMPLES.)

Will s/he play with the whole toy or does s/he seem to be more interested in a certain part of the toy (e.g., spinning the wheels of a car or opening and shutting its door), rather than using it as it was intended?

Are there particular kinds of objects s/he really likes?

Does s/he ever collect or gather certain sorts of objects?

What does s/he do with them?

Does s/he ever line things up or do the same thing over and over with them, such as drop things from the same distance?

Do these activities change over time or are they exactly the same?

Has s/he ever used objects in these ways in the past?

Repetitive use of objects or interests in parts of objects must have gone on for at least 3 months to be coded.

CURRENT ☐

EVER ☐

0 = little or no repetitive use of objects

1 = some repetitive use of objects (e.g., shaking strings or spinning things), or interest in parts (e.g., turning wheels and dials) or very specific types of objects (e.g., collecting bits of paper), in conjunction with several other activities but not causing social impairment

2 = play linked to highly stereotypic use of objects or attention to specific parts or types of objects, but which does not constrain or intrude upon subject's other activities

3 = play linked to highly stereotypic use of objects to an extent that prevents or seriously interferes with other activities

7 = an interest in "infant" toys, such as music boxes or rattles, but play is with a variety of objects and not in a highly stereotypic fashion

8 = N/A (no play with objects)

9 = N/K or not asked

70. COMPULSIONS/RITUALS

THE EMPHASIS OF THIS ITEM IS ON FIXED SEQUENCES THAT ARE PERFORMED AS IF THE SUBJECT FEELS PRESSURE TO COMPLETE THEM IN A PARTICULAR ORDER. **COMPULSIONS** MAY ALSO INCLUDE HAVING TO PLACE PARTICULAR OBJECTS IN EXACT POSITIONS OR RELATIONSHIPS IN SPACE, SUCH AS OPENING ALL DOORS TO A CERTAIN ANGLE OR TURNING ALL LIGHTS OFF. A COMPULSION WITH LIGHTS DIFFERS FROM REPETITIVE USE OF OBJECTS (CODED IN ITEM 69) IN THAT THE SUBJECT INSISTS THAT SEVERAL LIGHTS MUST REMAIN OFF, RATHER THAN CARRYING OUT A REPETITIVE ACTION OF FLICKING LIGHTS OFF AND ON.

RITUALS DIFFER FROM DIFFICULTIES WITH CHANGES AS DESCRIBED IN ITEM 74 IN THAT THEY HAVE SEQUENCE; IN ADDITION, IN A RITUAL OR COMPULSION THE SUBJECT IS IMPOSING AN ORDER ON EVENTS, RATHER THAN RESPONDING TO A PERCEIVED CHANGE. THUS, A SUBJECT WHO NEEDS TO LAY HER/HIS NAPKIN OUT FLAT AND PLACE HER/HIS SPOON ON IT BEFORE S/HE WILL EAT, COULD BE CODED AS HAVING A RITUAL, WHEREAS A SUBJECT WHO IS UPSET IF S/HE IS GIVEN A DIFFERENT NAPKIN WOULD BE CODED ONLY UNDER "DIFFICULTIES WITH MINOR CHANGES IN SUBJECT'S OWN ROUTINES OR PERSONAL ENVIRONMENT" (ITEM 74).

BEDTIME ROUTINES ARE EXPLICITLY EXCLUDED FROM THIS ITEM BECAUSE THEY OCCUR SO COMMONLY IN NORMALLY DEVELOPING CHILDREN.

Are there things that [subject] **seems to have to do in a very particular way or order; that is, rituals that s/he has to do or has to have you do?**

Like touching particular things or putting things in special places before going on to do something else?

How does s/he react if s/he is unable to complete the whole sequence of her/his activity or is disrupted during the course of her/his actions? (GET DETAILS AND EXAMPLES.)

Was this ever a problem in the past? (PROBE AS APPROPRIATE, USING PROMPTS OR A BRIEF DEMONSTRATION IF NECESSARY.)

Compulsions/rituals must have gone on for at least 3 months to be coded.

CURRENT ☐

0 = no compulsions/rituals

1 = some activities with unusually fixed sequences, but no activity that appears compulsive in quality

EVER ☐

2 = one or more activities that subject has to perform in a special way; subject appears to be under pressure or becomes anxious if activity disrupted, or family goes to unusual lengths to avoid interrupting ritual or to make sure subject is forewarned if it is necessary to interrupt her/him; compulsive quality present, but little interference with family life or social impairment

3 = one or more activities that subject has to perform in a special way; subject appears to be under **marked** pressure or becomes extremely anxious or distressed if activity disrupted; degree of compulsive quality intrudes upon family life or causes definite social impairment to subject

9 = N/K or not asked

71. UNUSUAL SENSORY INTERESTS

UNUSUAL SENSORY INTERESTS ARE DEFINED AS UNUSUALLY STRONG SEEKING OF STIMULATIONS FROM THE BASIC SENSATIONS OF SIGHT, TOUCH, SOUND, TASTE, OR SMELL THAT ARE DISSOCIATED FROM MEANING. THE FOCUS IS ON THE EXTENT TO WHICH THE ABNORMAL INTEREST DISTURBS OR REPLACES "NORMAL USE" OF THE OBJECT.

Does s/he seem particularly interested in the sight, feel, sound, taste, or smell of things or people? For example, does s/he tend to sniff toys, objects, or people inappropriately?

Or is s/he unusually concerned with the feel or texture of things?

Or does s/he tend to peer at or look at things for long periods of time?

Or does s/he touch things to her/his lips or tongue to see how they feel?

How long has s/he been interested in this? (GET EXAMPLES, SPECIFYING THE SENSE AND CIRCUMSTANCES WHERE SHOWN.)

Has there ever been a time when s/he showed an unusual interest in sensations?

Unusual sensory interests must have gone on for at least 3 months to be coded.

0 = has no unusual sensory interests

1 = shows one or two unusual interests regularly

2 = has unusual sensory interest that takes up a major amount of time or prevents or limits alternative use of that material in its ordinary function

9 = N/K or not asked

CURRENT ☐

EVER ☐

72. UNDUE GENERAL SENSITIVITY TO NOISE

THE FOCUS NEEDS TO BE THE PREDICTABLE, GENERALLY INCREASED SENSITIVITY TO EVERYDAY SOUNDS, SUCH AS HOUSEHOLD APPLIANCES OR TRAFFIC, RATHER THAN A REACTION TO A SUDDEN, HARSH, OR UNEXPECTED NOISE SUCH AS THUNDER OR A LOUDSPEAKER. DO NOT INCLUDE IDIOSYNCRATIC RESPONSES TO HIGHLY SPECIFIC SOUNDS (THESE ARE COVERED BY ITEM 73).

Has s/he ever seemed oversensitive to noise?

Has s/he ever deliberately and regularly put her/his hands over her/his ears in response to ordinary sounds?

Does s/he do this now?

To what kinds of sounds?

Have you ever had to adjust what you do because [subject] was so upset by noises?

To code for general sensitivity to noise, more than one occurrence is required, however clearly it is remembered (must have gone on for at least 3 months to be coded).

CURRENT ☐

0 = no general sensitivity to noise

1 = slight sensitivity to noise: somewhat sensitive to loud sounds such as the vacuum cleaner, motorbikes, or other appliances

EVER ☐

2 = definite sensitivity to noises that are not distressing to most other people, the sensitivity being accompanied by a clear behavioral change (such as avoidance, hands over ears, or crying)

3 = definite sensitivity to noises to the extent that subject's distress/disturbance in relation to certain noises interferes with family or household routines

9 = N/K or not asked

73. ABNORMAL, IDIOSYNCRATIC, NEGATIVE RESPONSE TO SPECIFIC SENSORY STIMULI

TO MEET THE CRITERIA FOR CODING, THE SUBJECT'S RESPONSE MUST BE PREDICTABLE; BE SPECIFIC TO SOME IDENTIFIABLE AND PARTICULAR SENSORY STIMULUS (OR GROUP OF STIMULI); BE IDIOSYNCRATIC; AND INVOLVE SOME FORM OF NEGATIVE, EMOTIONAL REACTION OTHER THAN FEAR (OFTEN IT INVOLVES ANGER OR MARKED IRRITATION). THUS, GENERAL DISTRESS IN RELATION TO VERY LOUD NOISES IS EXCLUDED, AS ARE NEGATIVE REACTIONS TO ENVIRONMENTAL CHANGE (SEE ITEMS 72, 74, AND 75).

Does [subject] **ever get unusually upset or irritated by particular sounds such as people coughing or a baby crying?** (TAKE CARE TO DIFFERENTIATE FROM A FEAR REACTION.)

What does s/he do?

How does s/he show that s/he is upset?

Do you think s/he is afraid or is it more like anger or irritation?

Is it just one particular sort of sound?

Does [subject] **ever react in an unusual, but predictable, way to other sensations (such as tastes or smells or the sight or feel of things)? For example, does s/he react to the sight of something like earrings or men with beards?**

How long has this gone on?

Was this ever a problem in the past? (GET EXAMPLES.)

Abnormal, idiosyncratic, negative response to specific sensory stimuli must have gone on for at least 3 months to be coded.

CURRENT ☐

EVER ☐

0 = no predictable, abnormal, idiosyncratic, negative response to specific sensory stimuli

1 = predictable, abnormal, idiosyncratic, negative response to one or more specific stimuli, but reaction mild or controllable so does not give rise to avoidance or to any interference with ordinary life

2 = predictable, abnormal, idiosyncratic, negative response to one or more specific stimuli; some intrusion into ordinary activities so there are occasional tantrums/disturbances or attempts by family to avoid subject being exposed to specific stimulus; however, no substantial interference with general pattern of family life

3 = predictable, abnormal, idiosyncratic, negative response to one or more specific stimuli that causes substantial interference with family life or totally, or almost totally, prevents some activity

9 = N/K or not asked

74. DIFFICULTIES WITH MINOR CHANGES IN SUBJECT'S OWN ROUTINES OR PERSONAL ENVIRONMENT

THIS ITEM CONCERNS MARKED NEGATIVE REACTIONS TO A VARIETY OF MINOR CHANGES IN HOW, WHERE, OR WHEN THE SUBJECT CARRIES OUT DAILY ACTIVITIES. THESE CHANGES MUST BE MINOR. DO NOT INCLUDE MOVING HOUSE, CHANGING SCHOOL, OR ANY OTHER MAJOR TRANSITION THAT WOULD BE EXPECTED TO AFFECT ANY SUBJECT. THE EMPHASIS FOR THIS ITEM IS ON AN UNUSUAL DEGREE OF UPSET OR INSISTENCE ON MAINTAINING THE ORIGINAL CONDITION IF A MINOR ASPECT OF THE **SUBJECT'S** ROUTINE IS CHANGED.

Is [subject] **bothered by minor changes in her/his routine? Or in the way her/his personal things are arranged?** For example, does it bother her/him to switch from one pair of mittens or gloves to another or from winter to summer clothing (e.g., long sleeves to short sleeves)?

How about changes in schedule?

Does it make a difference to [subject] if, for instance, you bathe her/him or s/he takes a bath 15 minutes earlier or later than usual, or s/he gets dressed before breakfast or after, if this broke her/his routine? What does happen?

Do *minor* changes in eating routines, such as where the salt and pepper are on the table or where food is placed on her/his plate, cause any difficulty?

Was this ever a problem in the past?
(PROBE FOR DETAILS AND NOTE EXAMPLES.)

Difficulties with minor changes in subject's own routines or personal environment must have gone on for at least 3 months to be coded.

CURRENT ☐

EVER ☐

0 = no difficulties with minor changes in own subject's own routines

1 = unusually negative reaction to minor changes in subject's own routines, but with no serious distress and little or no interference in family life

2 = definite, unusual reactions to minor changes in subject's own routines, causing resistance or distress/or family going to unusual lengths to avoid changing minor aspects of subject's routines or to prepare subject for minor changes; but no substantial interference in family life

3 = definite, unusual, and marked resistance to minor changes in subject's own routines, with substantial interference with or impairment of family activities

9 = N/K or not asked

75. RESISTANCE TO TRIVIAL CHANGES IN THE ENVIRONMENT *(NOT DIRECTLY AFFECTING THE SUBJECT)*

THIS ITEM CONCERNS THE SUBJECT'S MARKED DIFFICULTY WITH MINOR OR TRIVIAL CHANGES IN ASPECTS OF THE ENVIRONMENT THAT HAVE NO DIRECT EFFECT ON HER/HIM, FOR EXAMPLE, THE POSITION OF ORNAMENTS, THE ORIENTATION OF THE TELEPHONE, OR CLOTHES WORN BY PEOPLE OTHER THAN SUBJECT. THE EMPHASIS IS ON THE **SUBJECT'S** UNUSUALLY NEGATIVE REACTION TO THESE TRIVIAL CHANGES.

How does [subject] **react to changes about the house, or to changes in small details of her/his environment or surroundings?** For example, how does s/he react to a change in someone else's daily routine, how the furniture is arranged, or what you wear (e.g., if you wear glasses or a hat)?

Does s/he get distressed?

What about when s/he was younger?

Was this ever a problem in the past?

(IF THIS IS/WAS A PROBLEM, PROBE FOR DETAILS AND NOTE EXAMPLES.)

Resistance to trivial changes in the environment must have gone on for at least 3 months to be coded.

CURRENT ☐

EVER ☐

0 = none

1 = unusually negative reaction to trivial changes in the environment, but with no serious distress and little or no interference in family life

2 = definite, unusual reactions to trivial changes in the environment, causing marked distress or causing family to go to unusual lengths to avoid trivial changes in the environment or to prepare subject for such trivial changes; but no substantial interference in family life

3 = definite, unusual, and marked resistance to trivial changes in the environment, with substantial interference with or impairment of family activities

9 = N/K or not asked

76. UNUSUAL ATTACHMENT TO OBJECTS

AN ATTACHMENT IS DEFINED AS AN UNUSUAL INTEREST AND DEPENDENCE ON A PARTICULAR OBJECT THAT THE SUBJECT CARRIES AROUND WITH HER/HIM. THE FOCUS HERE IS ON ATTACHMENTS TO UNUSUAL OBJECTS, I.E., NOT THE SOFT, CUDDLY BLANKETS OR STUFFED TOYS USED BY MOST CHILDREN. THE STRENGTH OF THE ATTACHMENT IS DETERMINED BY HOW DIFFICULT IT IS FOR THE SUBJECT TO SEPARATE FROM THE OBJECT AND WHETHER ITS POSSESSION INTRUDES INTO THE SUBJECT'S OR FAMILY'S LIFE. THE BEHAVIOR OF AN UNUSUAL ATTACHMENT MUST HAVE LASTED 3 MONTHS, BUT THIS MAY OR MAY NOT HAVE INVOLVED THE SAME OBJECT THROUGHOUT.

Does [subject] **have anything to which s/he is particularly attached and that s/he likes to carry around with her/him?**

What is it like?

Is it something like a teddy or blanket, or is it something more unusual, like a piece of pipe, a clothes peg, or a stone? (GET EXAMPLES.)

What does s/he do with it?

If asked to put it down, will s/he do so?

Does s/he take it to bed?

What happens if it is taken away or if it gets mislaid?

What about when s/he was younger?

Has s/he ever been particularly attached to anything?

Unusual attachments to objects must have gone on for at least 3 months to be coded.

CURRENT ☐

EVER ☐

0 = no attachment or attachment only to cuddly object used as comforter

1 = some attachment to slightly unusual object, such as piece of paper or soft brush, or several similar interchangeable objects, but puts down if asked to do so and can tolerate separation from it; no interference with activities

2 = attachment to an unusual object causes significant distress on separation or causes caregivers to try to ensure object always readily available for subject because of anticipated distress; occasional interference with activities

3 = unusual attachment so intrusive that it prevents many everyday activities

6 = attachment to soother/comforter or blanket or other usual object beyond age 5 or with such intensity that interferes with social functioning or activities (if has also had an unusual attachment, code that instead)

7 = series of short-lasting (1–3 days) attachments to unusual objects or groups of objects, replaced by new attachment to different kind of unusual object also for short time

9 = N/K or not asked

77. HAND AND FINGER MANNERISMS

HAND AND FINGER MANNERISMS OF THE TYPE COVERED BY THIS ITEM TYPICALLY INVOLVE RAPID, VOLUNTARY, REPETITIOUS MOVEMENTS OF THE FINGERS AND HANDS, OFTEN BUT NOT ALWAYS WITHIN THE LINE OF THE SUBJECT'S VISION. DO **NOT** INCLUDE NAIL BITING, HAIR TWISTING, OR THUMB SUCKING. CLAPPING IS **NOT** A HAND MANNERISM, NOR ARE THE NONSPECIFIC OVERFLOW MOVEMENTS SEEN IN INFANTS AND TODDLERS WHEN THEY ARE EXCITED. IF HAND AND FINGER MANNERISMS ONLY OCCUR DURING WHOLE BODY MOVEMENTS, CODE ON ITEM 78 ONLY. DO NOT INCLUDE ROCKING IN EITHER CODE.

Does [subject] **have any mannerisms or odd ways of moving her/his hands or fingers? Such as twisting or flicking her/his fingers in front of her/his eyes?**

Do they interfere with getting [subject] to do other things? In what way?

What happens if you try to get her/him to stop?

Are there any particular circumstances in which s/he does this more than in others? (GET DETAILS.)

Did s/he ever show any of these types of mannerisms or odd movements in the past? (NOTE EXAMPLES.)

Hand and finger mannerisms must have gone on for at least 3 months to be coded.

CURRENT ☐

EVER ☐

0 = no hand and finger mannerisms

1 = occasional hand and finger mannerisms only or type not as clearly specified as for rating of "2"

2 = definite, frequent hand mannerisms or finger flicking/twisting, but no interference with other activities or distress if interrupted

3 = marked mannerisms of type specified; associated with social impairment or distress when interrupted or infrequent interruption due to others' concern about subject's reaction

8 = N/A (e.g., physically disabled)

9 = N/K or not asked

78. OTHER COMPLEX MANNERISMS OR STEREOTYPED BODY MOVEMENTS *(DO NOT INCLUDE ISOLATED ROCKING)*

THE FOCUS HERE IS ON COMPLEX, STEREOTYPIC, VOLUNTARY, WHOLE-BODY MOVEMENTS, SUCH AS ARM WAVING WHILE ROCKING UP ONTO TIPTOES.

Does [subject] **have any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down?**

Do they interfere at all with getting [subject] to do other things? In what way?

What happens if you try to get her/him to stop? (GET DETAILS.)

In the past, did s/he have any of these movements? (NOTE EXAMPLES. ISOLATED ROCKING IS EXCLUDED BUT COMPLICATED MANNERISMS THAT INVOLVE ROCKING ONLY AS ONE COMPONENT MAY BE APPLICABLE.)

Complex mannerisms or stereotyped body movements must have lasted 3 months to be coded.

CURRENT ☐

EVER ☐

0 = no complex mannerisms or stereotyped body movements

1 = only occasional complex mannerisms or stereotyped body movements

2 = definite, frequent other mannerisms or stereotypies, but will stop without distress if interrupted

3 = marked mannerisms associated with social impairment

8 = N/A

9 = N/K or not asked

79. MIDLINE HAND MOVEMENTS

THESE MOVEMENTS ARE THOSE THAT OCCUR IN THE MIDDLE OF THE SUBJECT'S BODY AND USUALLY INVOLVE BOTH HANDS MOVING IN SIMILAR WAYS IN A HAND WRINGING OR HAND WASHING MOVEMENT.

Does s/he have any particular ways of moving her/his hands in front of her/his body, for example, hand wringing or turning the hands from side to side together as if washing them?

Midline hand movements must have lasted 3 months to be coded.

0 = no midline hand movements

1 = only occasional midline hand movements or type not as clearly specified as for a rating of "2"

2 = definite abnormal wringing hand movements mainly in the midline

8 = N/A

9 = N/K or not asked

CURRENT ☐

EVER ☐

GENERAL BEHAVIORS

80. GAIT

THE FOCUS IS ON UNUSUAL WAYS OF WALKING–PARTICULARLY TIPTOEING OR BOUNCING–THAT ARE NOT CLEARLY ASSOCIATED WITH PHYSICAL HANDICAP.

Is there anything unusual about the way [subject] **walks** (e.g., bouncing, exaggeration of toe-heel, up on toes)**?** (GET DESCRIPTION.)

Do you think other people notice it?

Has there ever been anything unusual?

How did s/he walk when s/he was 4 to 5 years old?

Do not code broad-based, immature or clumsy gait.

0 = normal gait

1 = somewhat unusual gait

2 = definitely odd gait (e.g., toe-walking or abnormal bouncing)

3 = gait sufficiently odd to be noticed by others outside family or teachers

7 = gait apparently due to a neurological condition or to severe developmental motor impairment

8 = N/A

9 = N/K or not asked

CURRENT ☐

MOST ABNORMAL 4.0–5.0 ☐

81. AGGRESSION TOWARD CAREGIVERS OR FAMILY MEMBERS

THIS ITEM IS CONCERNED WITH EPISODES OF AGGRESSION WITHIN THE FAMILY, INCLUDING WITH CAREGIVERS, OF SUFFICIENT SEVERITY AND/OR FREQUENCY TO CONSTITUTE A SIGNIFICANT CAUSE FOR CONCERN.

Have there been times when [subject] **has been aggressive toward other people within the family (or other caregivers)?**

Has s/he ever hit or bitten anyone?

What about when s/he was younger? (GET DETAILS OF CIRCUMSTANCES AND OF AGGRESSIVE ACTS.)

What does s/he do?

What are the circumstances?

What seems to start the aggression?

Has s/he ever really hurt someone? What happened?

Has s/he ever used any kind of implement like a stick or a knife?

How long do the aggressive episodes last (a few minutes or several hours)? How often do they occur?

0 = no aggression or only rare episodes; rare aggressiveness, not a significant problem

1 = mild aggressiveness only (threatening without physical contact; or behavior that might represent just unduly rough play **or** momentary, provoked lashing out)

2 = definite physical aggression involving hitting or biting but no use of implements

3 = violence that involves the use of implements

9 = N/K or not asked

CURRENT ☐

EVER ☐

82. AGGRESSION TOWARD NONCAREGIVERS OR NONFAMILY MEMBERS

THIS ITEM CONSTITUTES A DIRECT PARALLEL TO ITEM 81 AND IS DIFFERENT ONLY IN SO FAR AS THE AGGRESSION IS DIRECTED TO INDIVIDUALS WHO ARE NOT CAREGIVERS OR MEMBERS OF THE FAMILY. IT INCLUDES AGGRESSION TOWARD BOTH PEERS AND ADULTS.

What about aggression toward people outside the family, as at school or in shops or on buses?

Has s/he ever behaved in ways that might lead other people to think that s/he was going to be aggressive?

Has there ever been a concern that s/he might harm or hurt other people?

What about when s/he was younger?
(GET DETAILS OF CIRCUMSTANCES AND OF AGGRESSIVE ACTS.)

What does s/he do?

What are the circumstances?

What seems to start the aggression?

Has s/he ever really hurt someone? What happened?

Has s/he ever used any kind of implement like a stick or knife?

How long did/do the aggressive episodes last (a few minutes or several hours)?

How often did/do they occur?

0 = aggression rare, not a significant problem

1 = mild aggressiveness only (threatening without physical contact; or behavior that might represent just unduly rough play **or** momentary provoked lashing out)

2 = definite physical aggression involving hitting or biting but no use of implements

3 = violence that involves the use of implements

9 = N/K or not asked

CURRENT ☐

EVER ☐

83. SELF-INJURY

SELF-INJURY IS A DELIBERATE SELF-DIRECTED AGGRESSIVE ACT (E.G., BITING THE WRIST, BANGING THE HEAD) THAT RESULTS IN TISSUE DAMAGE AND OCCURS OVER A PERIOD OF AT LEAST 3 MONTHS.

Does [subject] ever injure himself/herself deliberately, such as by biting her/his arm or banging her/his head or anything else like this? (GET DETAILS.)

Was this ever a problem in the past?

Self-injury must occur over a period of 3 months to be coded.

0 = no self-injury

1 = slight self-injury (e.g., occasionally bites own hand/arm when annoyed, pulls hair, or slaps face); no substantial tissue damage

2 = self-injury definitely present (e.g., actual bruises or calluses, repeated head banging, hair pulling, biting associated with definite tissue damage; do not count picking of spots)

3 = definite self-injury with serious damage (e.g., skull fracture, eye injury, etc.)

9 = N/K or not asked

CURRENT ☐

EVER ☐

84. HYPERVENTILATION

HYPERVENTILATION INVOLVES EPISODES OF RAPID, DEEP, REPETITIVE BREATHING IN SITUATIONS OTHER THAN THOSE THAT ELICIT PANIC.

Does [subject] **ever breathe in deeply with repeated rapid breaths?**

Does s/he ever sound as if s/he is gasping for air over and over within a period of a few seconds?

0 = no hyperventilating
1 = occasional hyperventilating
2 = frequent hyperventilating
9 = N/K or not asked

CURRENT ☐

EVER ☐

85. FAINTS/FITS/BLACKOUTS

THE FOCUS IS ON EPISODES INVOLVING AN UNEXPLAINED CHANGE IN LEVEL OF CONSCIOUSNESS WITH OR WITHOUT FALLING OR JERKING MOVEMENTS OF THE LIMBS.

Has [subject] **ever fainted or had a fit/seizure/convulsion?**

Has s/he ever had medicine to control fits?

(IF YES, PROBE FOR FURTHER DETAILS ABOUT THE "EPISODES," INCLUDING AGE OF ONSET, FREQUENCY, A CLEAR DESCRIPTION, AND WHETHER THEY REQUIRED INVESTIGATION AND TREATMENT, INCLUDING PAST AND CURRENT MEDICATION AND/OR HOSPITAL ADMISSION.)

0 = no attacks

1 = history of attacks that might be epileptic, but diagnosis not established

2 = definite diagnosis of epilepsy

7 = febrile convulsions only, with no continuing daily medication outside the period of fever

9 = N/K or not asked

CURRENT ☐

EVER ☐

86. AGE WHEN ABNORMALITY FIRST EVIDENT

IF IT IS ALREADY CLEAR THAT BEHAVIOR ABNORMAL BY AGE 3 YEARS, QUESTION ONLY ON EARLIER AGES IN ORDER TO ASSESS PROBABLE TIME THAT ABNORMALITIES FIRST EVIDENT. IF ACCOUNT SO FAR SUGGESTS SUBJECT NORMAL UP TO 3 YEARS, FOCUS FIRST ON AGE 3 YEARS IN ORDER TO DETERMINE IF DEVELOPMENT DEFINITELY NORMAL AT THAT AGE, AND THEN EXPLORE EARLIER AGES. THIS CODING IS MADE ON THE INTERVIWER'S JUDGEMENT USING ALL AVAILABLE INFORMATION FROM THE INTERVIEW.

When we started talking about [subject], I asked you when you thought that s/he first showed any difficulties in development or behavior. You said that you thought [day/month/year]. (REFER BACK TO ITEM 2) **I'd like now just to check back on those early years.**

Could you tell what [subject] **was like about the time of her/his third birthday?**

What was her/his play like?

What toys did s/he play with?

Any pretend games?

How was her/his talking then?

What about looking after herself/himself? Feeding? Toileting? Dressing?

What were her/his relationships with other children like?

Working back again just to check: what about at age 1 year and at age 2 years?

0 = development in the first 3 years of life clearly normal in quality and within normal limits for social, adaptational, language, self-help, and motor milestones; no behavioral problems of a type that might indicate developmental delay or deviance ☐

1 = development possibly within normal limits during first 3 years, but uncertainty because of either the quality of behavior or the level of skills

2 = development probably abnormal by the age of 3 years, as indicated by developmental delay or deviance, but not of a degree or type that is definitely incompatible with normality

3 = development definitely abnormal in the first 3 years but quality of behavior/social relationships/ communications not unambiguously autistic at that age

4 = development definitely abnormal in the first 3 years and quality of behavior/social relationships/ communications strongly indicative of autism at that age

9 = N/K or not asked

87. INTERVIEWER'S JUDGMENT ON AGE WHEN DEVELOPMENTAL ABNORMALITIES PROBABLY FIRST MANIFEST

☐☐☐
Code in months

Special Isolated Skills (Items 88–93)

For Items 88 to 93, probe as appropriate to the subject's level of functioning and get details of level and pattern of skills, as well as extent that skill involves meaning and interpretation and can be applied in day-to-day situations. Describe in detail. Code for "current" and "ever."

Does [subject] **have any unusually marked special skills? Are there any things that s/he seems to be *very good* at, either currently or at any time in the past?** (GET DETAILS AND EXAMPLES.) **Are these skills related to one of her/his special interests or unusual preoccupations?**

Is [subject] particularly good with shapes–as in puzzles or jigsaws? Has this *ever* been a particular ability?

What about her/his memory? Was it ever exceptional?

Does s/he have particular musical skills? How about in the past?

Is s/he unusually good at drawing? Was s/he in the past?

How about reading? In the past?

What about computations? In the past?

Throughout this section, the focus should be on a particular skill or ability. Once a decision has been made about the presence or absence of a skill, the next assessment needs to be in relation to how this skill compares with the subject's overall level of functioning and how this would compare with the general population. For example, a child with mental retardation who could multiply three-figure numbers in his/her head but could not apply this skill would get a code of "2." For Item 93, "computational ability," if s/he could apply the skill in real-life situations, s/he would get a code of "7." If his/her computational skill was average by population norms, but well above his/her mental age, this would be coded "1."

Code special skills on next page.

SPECIAL ISOLATED SKILLS

0 = no outstanding skills/knowledge in relation to overall level of ability, whether high or low

1 = isolated skill/knowledge that is definitely out of keeping with subject's general level of ability, but not above general population norms

2 = isolated skill/knowledge that is definitely above the subject's general level of ability and above the general population's normal level, but is not used functionally or meaningfully to any marked extent (e.g., a preschool child who can read without comprehension or a calendrical calculator would be coded here)

7 = isolated skill/knowledge that is above the subject's general level and above the normal population's level of ability and is used meaningfully (i.e., genuine talent or ability used adaptively, such as performing music for others' enjoyment or participating in age-appropriate children's hobbies such as model-building or computer programming); subject is recognized by peers as having exceptional skill

8 = N/A (e.g., reading in a nonverbal subject)

9 = N/K or not asked

	CURRENT	EVER
88. VISUOSPATIAL ABILITY (IN PUZZLES, JIGSAWS, SHAPES, PATTERNS, ETC.)	☐	☐
89. MEMORY SKILL (ACCURATE MEMORY FOR DETAIL, AS OF DATES OR TIMETABLES)	☐	☐
90. MUSICAL ABILITY (RECOGNITION, COMPOSITION, ABSOLUTE PITCH, OR PERFORMANCE)	☐	☐
91. DRAWING SKILL (UNUSUALLY SKILLED USE OF PERSPECTIVE OR CREATIVE APPROACH)	☐	☐
92. READING ABILITY (E.G., EARLY SIGHT READING)	☐	☐
93. COMPUTATIONAL ABILITY (E.G., MENTAL ARITHMETIC)	☐	☐

C: Restricted, Repetitive, and Stereotyped Patterns of Behavior

Copy each code into the box for algorithm type and subject age level.

Algorithm type	Current Behavior Algorithm			Diagnostic Algorithm	
Age	2.0 to 3.11	4.0 to 9.11	10.0 or older*	2.0 to 3.11	4.0 or older
Code	Current			Ever	

C1: Encompassing preoccupation or circumscribed pattern of interest

Convert to Scores

67 Unusual Preoccupations

68 Circumscribed Interests *(score if 3 years or older)*

Total C1

C2: Apparently compulsive adherence to nonfunctional routines or rituals

39 Verbal Rituals *(score only if Item 30 = 0)*

70 Compulsions/Rituals

Total C2

C3: Stereotyped and repetitive motor mannerisms

77 Hand and Finger Mannerisms

78 Other Complex Mannerisms or Stereotyped Body Movements

Record the higher of the two scores

Total C3

C4: Preoccupation with parts of objects or nonfunctional elements of material

69 Repetitive Use of Objects or Interest in Parts of Objects

71 Unusual Sensory Interests

Record the higher of the two scores

Total C4

*Current Behavior Algorithm for 10.0 or older should be scored only for verbal subjects (Item 30 = 0). For this age group, no Current Behavior Algorithm is available for nonverbal subjects (Item 30 = 1 or 2).

Total C
C1 + C2 + C3 + C4
(cutoff = 3, diagnostic only)

D: Abnormality of Development Evident at or Before 36 Months

Diagnostic Algorithms only.

		Code	Score
2	Age Parents First Noticed *(if <36 months, score 1)*		
9	Age of First Single Words *(if >24 months, score 1)*		
10	Age of First Phrases *(if >33 months, score 1)*		
86	Age When Abnormality First Evident *(if coded 3 or 4, score 1)*		
87	Interviewer's Judgment on Age When Abnormalities First Manifest *(if <36 months, score 1)*		

Total D
(cutoff = 1, diagnostic only)

CONCLUDING COMMENTS (NO CODING REQUIRED)

OVERALL ASSESSMENT

Are there any other aspects of [subject]**'s behavior that particularly concern you?** (PROBE ONLY IF POSSIBLY RELEVANT TO ANY OF SPECIFIED CODINGS OR TO DIFFERENTIAL DIAGNOSIS OF AUTISM.)

Is there anything else you would like to tell me about that we haven't covered?

INTERVIEWER'S IMPRESSIONS AND CIRCUMSTANCES OF INTERVIEW
(DESCRIBE. NOTE WHETHER AUDIO/VIDEO RECORDING MADE.)

SUMMARY OF DISCREPANCIES BETWEEN INFORMANT DESCRIPTION AND OBSERVER INFORMATION

NOTES

ADI-R Autism Diagnostic Interview–Revised

Ann Le Couteur, M.B.B.S., Catherine Lord, Ph.D., Michael Rutter, M.D., F.R.S.

WPS Test with Confidence

Comprehensive Algorithm Form

Subject

Name of Subject/ID:

Date of Birth: / / **Chronological Age:** **Gender:** Female Male

Respondent

Name:

Relation to Subject:

Clinician

Name:

School/Clinic:

Date of Interview: / /

Mark the algorithm used.

Current Behavior Algorithm

- 2 Years, 0 Months to 3 Years, 11 Months
- 4 Years, 0 Months to 9 Years, 11 Months
- 10 Years, 0 Months or Older (Verbal Subjects only; Item 30 = 0)

Diagnostic Algorithm

- 2 Years, 0 Months to 3 Years, 11 Months
- 4 Years, 0 Months or Older

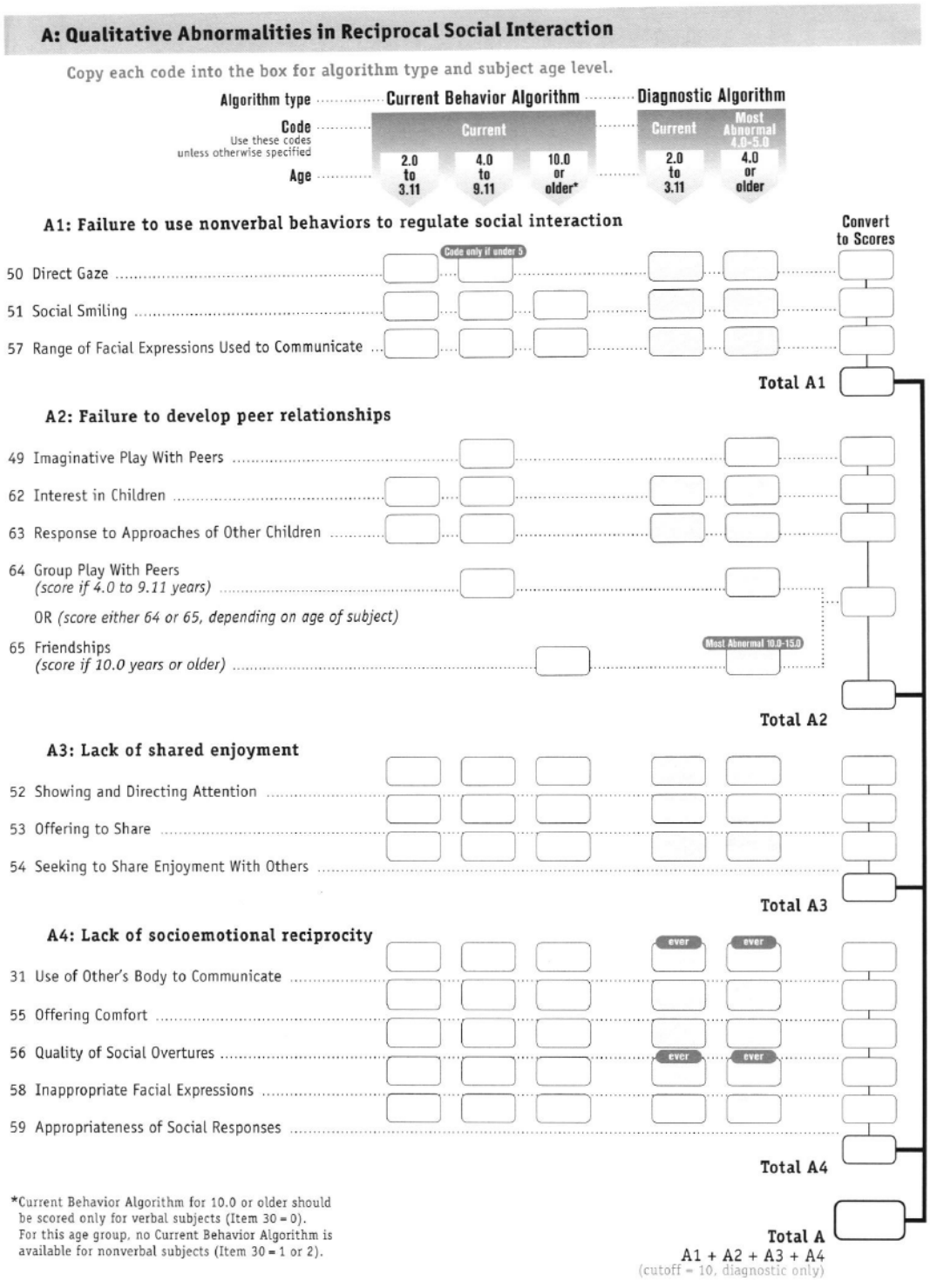
Item Code to Algorithm Score Conversion

Code	*0*	*1*	*2*	*3*	*7*	*8*	*9*
Score	0	1	2	2	0	0	0

Score Summary

										Diagnostic Algorithm cutoffs*
A1		+ A2		+ A3		+ A4		=	**Total A**	cutoff = 10
B1		+ B4		+ B2(V)		+ B3(V)		=	Verbal **Total B**	cutoff = 8
B1		+ B4						=	Nonverbal **Total B**	cutoff = 7
C1		+ C2		+ C3		+ C4		=	**Total C**	cutoff = 3
									Total D	cutoff = 1

*Cutoffs are for Diagnostic Algorithms only. The Current Behavior Algorithms do not have cutoffs.


A: Qualitative Abnormalities in Reciprocal Social Interaction
Copy each code into the box for algorithm type and subject age level.
Algorithm type
Current Behavior Algorithm
Diagnostic Algorithm
Code
Use these codes unless otherwise specified
Current
Current
Most Abnormal 4.0-5.0
Age
2.0 to 3.11
4.0 to 9.11
10.0 or older*
2.0 to 3.11
4.0 or older
A1: Failure to use nonverbal behaviors to regulate social interaction
Convert to Scores
Code only if under 5
50 Direct Gaze
51 Social Smiling
57 Range of Facial Expressions Used to Communicate
Total A1
A2: Failure to develop peer relationships
49 Imaginative Play With Peers
62 Interest in Children
63 Response to Approaches of Other Children
64 Group Play With Peers
(score if 4.0 to 9.11 years)
OR (score either 64 or 65, depending on age of subject)
65 Friendships
(score if 10.0 years or older)
Most Abnormal 10.0-15.0
Total A2
A3: Lack of shared enjoyment
52 Showing and Directing Attention
53 Offering to Share
54 Seeking to Share Enjoyment With Others
Total A3
A4: Lack of socioemotional reciprocity
ever
ever
31 Use of Other's Body to Communicate
55 Offering Comfort
56 Quality of Social Overtures
ever
ever
58 Inappropriate Facial Expressions
59 Appropriateness of Social Responses
Total A4
*Current Behavior Algorithm for 10.0 or older should be scored only for verbal subjects (Item 30 = 0). For this age group, no Current Behavior Algorithm is available for nonverbal subjects (Item 30 = 1 or 2).
Total A
A1 + A2 + A3 + A4
(cutoff = 10, diagnostic only)

VITA

Amy Mathews Creel obtained a Bachelors of General Studies Degree at Louisiana State University in May, 1991 and a Masters of Arts Degree in Counseling from Louisiana Tech University in May 1995. After working over fifteen years in the mental health field in both state government and private non-profit organizations, Amy Creel enrolled in the Doctorate in Philosophy program in School Psychology at Stephen F. Austin State University in January 2011. Field placements worked during the doctorate program include urban and rural school districts in Northwest Louisiana, a regional children's evaluation clinic, and a private psychology practice under the supervision of a licensed psychologist.

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APA Style

This thesis was typed by Amy Creel