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Functional Impairment in PDD-NOS: Predicting Outcome at a Two-Year Follow-up

By

Lena Janine Freeman

A Dissertation Submitted to the Faculty of Graduate Studies and Research through the Department of Psychology in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy at the University of Windsor

Windsor, Ontario, Canada

2004

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#### ABSTRACT

Examined the early history characteristics and symptom patterns of children with an initial diagnosis of either Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) or Autistic Disorder, and identified predictors of changing functional ability. Participants were 59 children (48 male, 11 female) who were first assessed at 3 to 4 years of age, and re-assessed two years later (M = 26.00 months, SD = 12.43). Based on the results of the follow-up assessment three groups were identified: children with a stable diagnosis of PDD-NOS (Stable PDD-NOS), a stable diagnosis of autism (Stable Autism), and those whose diagnosis changed from PDD-NOS to autism (Change). Overall, the Stable PDD-NOS group demonstrated a significantly better outcome than the Stable Autism group in all areas examined, including early history characteristics, symptom severity, and measures of functional ability. In contrast, the performance of the Change group was more variable and suggested a relative decline over time (i.e., an increase in symptom severity and a decline in functional ability). In terms of early history, the Change group appeared to experience greater impairments and more atypical behaviors than did the Stable PDD-NOS group. Results suggest that early history characteristics and patterns of PDD symptoms are predictive of later outcome for children initially diagnosed with PDD-NOS. Implications for research and practice are discussed.

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### DEDICATION

Many people contributed to the success of this project and deserve acknowledgement; my supervisor, Dr. Sylvia Voelker for her excellent direction and her willingness to supervise from afar; and my committee members, Dr. Elizabeth Starr, Dr. Julie Hakim-Larson, and Dr. Noel Williams, for their suggestions for improvement and attention to detail. In addition, the staff at the Windsor Regional Children's Centre willingly contributed their time and effort, in order to help facilitate data collection. My family and friends were a constant source of enthusiastic encouragement, and provided me with on-going support. A heartfelt thank-you goes to Ken, for his attentive listening skills, frequent computer tech support, and most importantly, for his unwavering commitment to this project, despite the necessary delays in our outdoor adventures.

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#### CHAPTER I

#### INTRODUCTION

Overview

A PDD-NOS diagnosis is the least reliable and least researched of the pervasive developmental disorders (PDD), even though a large proportion of children with a PDD are classified as having PDD-NOS (Buitelaar, & van der Gaag, 1998; Mahoney et al., 1998; Mayes, Volkmar, Hooks, & Cicchetti 1993; Myhr, 1998; Stone et al., 1999). PDD-NOS lacks explicit diagnostic criteria and identifies a heterogeneous group that is diagnosed by default (i.e., does not meet criteria for the other, more explicitly defined PDD diagnoses). Not surprisingly, the developmental course of children diagnosed with PDD-NOS varies, with some children maintaining a stable course, and others experiencing an increase or a decrease in symptom severity. Those who improve may no longer meet criteria for a PDD diagnosis, whereas those who experience an increase in symptom severity may ultimately meet all criteria for an autism diagnosis.

It is likely that children who move from a PDD-NOS diagnosis to an autism diagnosis experience a relative decrease in functional ability over time. The term functional ability refers to a child's global level of impairment and is an indicator of a child's ability to perform daily activities independently (Dadds, Stein, & Silver, 1995). Indicators of functional ability for children with PDD include adaptive and cognitive ability level, symptom presentation, developmental progression, as well as early history characteristics (e.g., age at recognition and presence of atypical behaviours prior to age 3). There is a limited body of literature focused specifically on PDD-NOS; however, the impairments associated with PDD-NOS are similar to those seen in autism. In fact, PDD-

NOS is often referred to as a mild variant of autism (Charman & Baird, 2002; Towbin, 1997). There is limited research on which to base expectations about the performance of a PDD-NOS sample. However, given the close relationship between PDD-NOS and autism, inferences about the functional ability of PDD-NOS can be derived from the current understanding of the functional skills associated with autism.

The goal of the present study was to identify predictors of outcome (i.e., functional ability) for children initially diagnosed with PDD-NOS using explicit criteria (Luteijn et al., 2000). There are three possible functional outcomes for children initially diagnosed with PDD-NOS: a stable course, a decrease in functional ability, or an increase in functional ability. A decline in skill level indicates a greater clinical need, and as a result, the focus of the present study was on children who experience an apparent decline in functional ability over time. Based on the literature, it was anticipated that the early history characteristics (e.g., developmental milestones, number of atypical behaviors prior to age three), the developmental progression of PDD symptoms, and specific PDD symptom patterns would distinguish between children with a stable PDD-NOS presentation and children whose changing symptom presentation warranted a shift to a diagnosis of autism (Coplan, 2000; Scambler, Rogers, & Wehner, 2001; Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1998).

To provide a context for the present study, a description of the current conceptualization of PDD-NOS is provided. Factors contributing to the poor stability and reliability of PDD-NOS are presented, followed by a summary of functional ability research on autism, PDD-NOS, samples of combined PDDs, and Autism Spectrum Disorder (ASD). Recent literature on the continuum relationship between PDD-NOS and

autism is reviewed, including studies that compare PDD-NOS and autism groups on diagnostic measures. Finally, specific limitations to PDD-NOS research are identified, such as the heterogeneity of the population, and potential solutions are suggested.

The terminology used to identify pervasive developmental disorders is changing. Previously, PDD was commonly used to identify research samples that included Autistic Disorder, Asperger's Disorder, and PDD-NOS. However, these three conditions are currently included under the rubric Autism Spectrum Disorder (ASD), in both research and clinical settings. It is likely that ASD will replace PDD in the DSM-V (C. Lord, personal communication, 2000). Both terms are frequently seen in the autism literature. Changes in the definition and inclusion criteria for Pervasive Developmental Disorder are imminent. However, for the purpose of clarity, the term PDD will be used throughout this paper to refer to samples that include autism, Asperger's Disorder, and PDD-NOS. When the original author used the term ASD, it will be used in lieu of PDD.

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

PDD-NOS is one of a family of five pervasive developmental disorders that also includes autism, Asperger's disorder, Childhood Disintegrative Disorder (CDD), and Rett's syndrome. The five conditions share three core diagnostic features: impaired social interaction, deficits in verbal and non-verbal communication, and stereotyped interests / repetitive behaviours (Vig & Jedresyk, 1999). However, autism, Asperger's Disorder and PDD-NOS appear more closely related than Childhood Disintegrative Disorder and Rett's syndrome. The latter two disorders share a behavioural phenotype with autism, but are distinct in either etiology (i.e., Rett's syndrome) or developmental course (i.e., Childhood Disintegrative Disorder).

PDD-NOS differs from autism and Asperger's Disorder in several key areas. First, PDD-NOS is the least reliable diagnosis and the least researched of the pervasive developmental disorders, even though a large majority of children with PDD are classified as having PDD-NOS (Buitelaar, & van der Gaag, 1998; Eaves & Ho, 1996; Mahoney, Szatmari, MacLean, Bryson, Bartolucci, Walter, Jones, & Zwaigenbaum, 1998; Mayes, Volkmar, Hooks, & Cicchetti 1993; Myhr, 1998; Stone, Lee, Ashford, Brissie, Hepburn, Coonrod, & Weiss, 1999). Second, PDD-NOS is defined differently than the other PDDs, as it lacks explicitly stated diagnostic criteria. The diagnostic criteria for Autistic Disorder are clearly stated (Appendix A), whereas the criteria for PDD-NOS in the DSM-IV are less explicit:

A severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific PDD, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" – presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these. (APA, 1994, p. 77)

The purpose of a Not Otherwise Specified (NOS) designation is to classify conditions that demonstrate some, but not all, of the symptoms associated with the prototypical disorder of the category. The PDD-NOS designation represents a range of impairment, from symptoms that are mild or limited in frequency, to full symptom presentation in two domains and subthreshold symptoms in the third. PDD-NOS closely

resembles autism, and is negatively defined as being "not autism" (Buitelaar et al., 1999; Myhr, 1998).

Because the diagnostic criteria for PDD-NOS are not explicitly stated, the diagnostic label has come to represent a heterogeneous group, one that demonstrates a broad spectrum of behavioural features (Buitelaar et al., 1999; Myhr, 1998). Making a PDD-NOS diagnosis relies heavily on the interpretation and judgment of individual clinicians or researchers, which in turn leads to a broad range of defining criteria. The more commonly used definitions suggest that PDD-NOS is a sub-threshold variant of autism, meaning that the three core impairments are present, but are not severe enough to warrant an autism diagnosis (Buitelaar, & van der Gaag, 1998; Buitelaar et al., 1999). Other frequently used inclusion criteria suggest that PDD-NOS represents an incomplete symptom pattern (i.e., impairment in both the social and communication domains, but not in the repetitive/stereotyped interests domain, or impairment in the social and stereotyped/repetitive behaviour domains, but not the communication domain) (Buitelaar, & van der Gaag, 1998; Robertson, Tanguay, L'Ecuyer, Sims, & Waltrip, 1999).

PDD-NOS is generally believed to have a higher prevalence rate than autism, although no statistics are available on the specific prevalence rate of PDD-NOS (Mayes, Volkmar, Hooks, & Cicchetti, 1993; Towbin, 1997; Volkmar, Klin, & Cohen, 1997). One estimate suggested that the ratio of non-autism PDDs (i.e., PDD-NOS, Asperger's disorder, Rett's disorder and CDD) to autism was 7:1 (Myhr, 1998). Given that Rett's disorder and CDD are rare disorders, it was assumed that PDD-NOS and Asperger's disorder represented the majority of the non-autism PDDs (Myhr, 1998). Despite the estimated higher frequency of PDD-NOS, relatively little is known about this condition

in comparison to autism. Autism is a well researched, easily recognized condition with clearly defined characteristics and boundaries (Buitelaar, & van der Gaag, 1998; Buitelaar, et al., 1999; Mayes et al., 1993). In contrast, PDD-NOS is rarely the focus of empirical investigations, and little is known about its associated behaviours, features, or functional impairments. The lack of explicit diagnostic criteria for PDD-NOS limits the potential for empirical investigations, which in turn, limits knowledge of the disorder (Mayes et al., 1993). PDD-NOS is known to be the least understood, and least stable of the PDD diagnoses (Buitelaar, & van der Gaag, 1998; Eaves & Ho, 1996; Mahoney et al., 1998). There is a greater likelihood for change in PDD-NOS than in autism, which emphasizes the need for further research into this condition (Charman & Baird, 2002; Moore & Goodson, 2003; Stone et al., 1999).

# Limited Reliability and Stability of PDD-NOS

The stability of a diagnosis can be described in both quantitative (i.e., the stability of symptom count and associated diagnostic label) and qualitative (i.e., the stability of functional impairment that results from the condition) terms. The reliability of a diagnosis indicates whether the condition is consistently recognized over time and across clinicians. The relatively poor reliability of PDD-NOS and possible contributing factors will be addressed and the relatively poor stability of PDD-NOS in comparison to autism will be reviewed.

*Reliability of PDD-NOS.* Clinicians and researchers consistently and reliably make the distinction between PDDs and non-PDDs (Mahoney et al., 1998; Stone et al., 1999). However, making the distinction between PDD subgroups is less accurate, ranging from fair (i.e., PDD-NOS) to excellent (i.e., autism) (Myhr, 1998; Waterhouse et al., 1996).

Autism is the most readily identifiable of the PDDs, whereas PDD-NOS is the most difficult to distinguish (Myhr, 1998; Waterhouse et al., 1996). In fact, PDD-NOS is the least reliable diagnosis of the Pervasive Developmental Disorders (Buitelaar, & van der Gaag, 1998).

Compared to autism, PDD-NOS is not as easily identified, and clinicians are more likely to disagree on the diagnosis. The reliability of the PDD criteria was evaluated by Mahoney et al. (1998), by comparing 143 children with diagnoses of autism (n = 93), Asperger's syndrome (n = 11), atypical autism (i.e., PDD-NOS, n = 22), and non-PDD diagnoses (i.e., language disorders, n = 17). The distinction between PDD and non-PDD diagnoses was strong, with inter-rater reliability ranging from good to excellent. In comparison, the inter-rater reliability between PDD subtypes was variable; autism and Asperger syndrome demonstrated good reliability (Autism: Cohen's kappa coefficient = .56; Asperger's syndrome: Cohen's kappa coefficient = .53) whereas the reliability of atypical autism or PDD-NOS was much lower (Cohen's kappa coefficient = .29).

The reliability of PDD diagnoses in children under age 3 showed a similar degree of variability across PDD subtypes, with PDD-NOS being the least reliable (Stone et al., 1999). The Stone et al. (1999) study included a moderately sized sample (n = 65) of young children (chronological age M = 31.4 months) referred for an evaluation of social and/or language delays. The children had not been diagnosed prior to the initial assessment through the study. At the first assessment, clinicians rated the children's behaviour and indicated the presence or absence of an Autism Spectrum Disorder (i.e., autism or PDD-NOS). When differentiating between ASD and a non-ASD, inter-rater reliability was high (Cohen's kappa coefficient = .67). In comparison, inter-rater

reliability for differentiating between autism and PDD-NOS was low (Cohen's kappa coefficient = .28).

In sum, there is a high rate of disagreement in making a PDD-NOS diagnosis (Charman, 1999; Mahoney et al., 1998). PDD-NOS is not easily identified and the inclusion criteria vary across clinicians and researchers (Mahoney et al., 1998; Myhr, 1998). In comparison to the other pervasive developmental disorders (i.e., Autism or Asperger's syndrome), a diagnosis of PDD-NOS is less likely to be given consistently across clinicians, and is less likely to be given at re-assessment (Eaves & Ho, 1996; Mahoney et al., 1998; Stone et al., 1999).

Stability of PDD-NOS. In addition to being the least reliably diagnosed PDD condition, PDD-NOS is also the least stable (Mahoney et al., 1998). In comparison to autism, a PDD-NOS diagnosis is significantly less stable and is more likely to change between assessments (Charman & Baird, 2002; Moore & Goodson, 2003; Stone et al., 1999). The symptom presentation and functional ability level associated with PDD-NOS is likely to change over time.

Follow-up investigations indicate three possible outcomes for PDD-NOS: a rediagnosis of PDD-NOS, movement off the PDD spectrum, or movement further along the PDD spectrum to a diagnosis of autism. The proportion of children that retain the diagnosis of PDD-NOS versus the number that moved either up or down the PDD spectrum varies across follow-up investigations.

Diagnostic follow-up studies provide useful information about the direction of change seen in PDD-NOS samples. The diagnostic outcome of a small sample of children with PDD-NOS (n = 3) was evaluated as part of an investigation of early ASD stability

(Moore & Goodson, 2003). The diagnosis of PDD-NOS was retained by one child, while the diagnosis of the other two children shifted to autism. Of the children initially diagnosed with autism (n = 16), 88 percent retained the diagnosis at follow-up, while a small percentage (i.e., 12%) showed an improvement in PDD-related symptoms, resulting in a diagnosis of PDD-NOS. Moore and Goodson (2003) noted that the children who showed an increase in social deficits tended to be more impaired overall at the initial assessment, and that there tended to be an increase in repetitive/stereotyped behaviours over time in all children on the PDD spectrum.

In another follow-up study, Eaves and Ho (2003) evaluated the reliability of early diagnosis (i.e., at age 2  $\frac{1}{2}$ ) in a sample of children with autism and PDD-NOS. Of the 9 children initially diagnosed with PDD-NOS, 22 percent (n = 2) retained the diagnosis, 22 percent (n = 2) shifted off the PDD spectrum, and 56 percent (n = 5) shifted to a diagnosis of autism. In comparison, 91 percent of the 34 children initially diagnosed with autism retained the diagnosis at follow-up (n = 31), and only six percent (n = 2) showed an improvement in symptoms, shifting to a diagnosis of PDD-NOS.

Stone et al. (1999) evaluated the accuracy of early diagnoses (i.e., in children under 3 years). Identifying the proportions of PDD-NOS diagnoses that were stable versus those that changed was not the focus of the study. However, the results provided an estimate of those with PDD-NOS whose functional ability appears to improve, and those whose functional ability appears to decline. When comparing initial and follow-up diagnoses made by the same clinician, close to half (42%) of the 12 children initially diagnosed with PDD-NOS retained the diagnosis at follow-up. One-quarter of those initially diagnosed with PDD-NOS shifted to autism (n = 3/12), and 30 percent moved off the

ASD spectrum (n = 4/12). When comparing initial diagnoses made by the primary clinician and follow-up diagnoses made by a second clinician, the same number of children retained the initial diagnosis of PDD-NOS (i.e., n = 5/12). However, half of the children shifted to a diagnosis of autism and only one child shifted from PDD-NOS to off the spectrum. The children who shifted off the spectrum tended to demonstrate language-related impairments at follow-up (Stone et al., 1999).

Given the small sample sizes frequently seen in the PDD-NOS follow-up studies (i.e., n = 3, 9, or 12), it is difficult to accurately identify the proportions of PDD-NOS diagnoses that are stable versus those that change. Based on these studies, between 20 and 40 percent of children initially diagnosed with PDD-NOS retained the diagnosis, and between 20 and 30 percent showed an improvement in PDD-related symptoms. The number of children whose symptoms increased ranged from 25 to almost 70 percent.

Currently, there are no follow-up investigations that focus specifically on the outcome of children who are initially diagnosed with PDD-NOS and later move off the PDD spectrum. However, several investigations include children who were initially diagnosed with autism and later improved (i.e., shifted to a diagnosis of PDD-NOS) (see Eaves & Ho, 2003; Gonzalez, Alpert, Shay, Campbell, & Small, 1993; Stone et al., 1999). The autism group that shifts to PDD-NOS tends to be relatively high functioning at initial assessment (i.e., demonstrate a high level of cognitive ability and mild or infrequent ASD symptoms) (Eaves & Ho, 2003; Gonzalez et al., 1993). This group is also relatively less impaired socially at follow-up than at the initial diagnosis (Stone et al., 1999). In sum, it appears that children who shift from a diagnosis of autism to a milder variant of the disorder (i.e., PDD-NOS) tend to demonstrate relatively high cognitive and

social skills at the initial assessment. It may be that similar patterns of functioning are seen in children who shift off the PDD spectrum from an initial diagnosis of PDD-NOS.

There is more information available on the PDD-NOS group that experiences a decline in functional skills at follow-up (i.e., shifts from PDD-NOS to autism). For example, it is known that the social deficits and repetitive/stereotyped behaviours tend to increase in this group (Moore & Goodson, 2003; Stone et al., 1999). Further, children whose diagnoses shift from PDD-NOS to autism appear to be more impaired overall at the first assessment, compared to those with a stable PDD-NOS diagnosis (Eaves & Ho, 2003; Moore & Goodson, 2003).

In sum, the reliability and stability of a PDD-NOS diagnosis is less than optimal. Of the three possible outcomes for PDD-NOS, the present study focuses on the group that appears to decline in functional ability (i.e., first diagnosed with PDD-NOS and then with autism at follow-up). There are three potential explanations for the apparent decrease in functional ability. First, this group may experience a regression or actual decline in skill level. Second, the change in functional skill level may reflect a delay or plateau in skill development, relative to their peers with a stable diagnosis of PDD-NOS. Third, diagnostic measures may be less sensitive to impairments in very young children or those with significant developmental delays. As a result, the PDD symptoms of children who experience significant delays very early in development may not be detected until followup, when the children are older or more developmentally mature.

Factors Contributing to the Instability of a PDD-NOS Diagnosis

Each of the three potential explanations for the shift from PDD-NOS to autism is evaluated next. The majority of the literature on these topics focuses on autism or combined PDD samples (i.e., autism, Asperger's Disorder, and PDD-NOS), and not on PDD-NOS specifically. As a result, implications for PDD-NOS will be drawn from the results for the broader PDD samples. The sensitivity of PDD diagnostic measures for young and developmentally delayed children is examined, followed by a review of the relationship between regression and PDD symptom presentation, as well as developmental delay and PDD symptom presentation

Sensitivity of PDD Diagnostic Measures. The apparent decrease in functional ability may be related to the limited sensitivity of diagnostic measures. For the children whose diagnoses shifted from PDD-NOS to autism, it was assumed that their symptoms were exacerbated or changed over time. However, this group of children often demonstrates significant developmental delays, and the perceived changes in symptom presentation may be the fault of the diagnostic measure. For example, if the current diagnostic criteria have limited sensitivity when applied to very young or developmentally delayed children, it is possible that the children will not be accurately diagnosed at their first assessment. Then, when the children are re-assessed (i.e., at an age or developmental level more applicable to the diagnostic measure) their symptom pattern appears to change, and their diagnosis shifts from PDD-NOS to autism.

For the most part, the current diagnostic criteria and, by extension, the current diagnostic measures are applicable to young children and children with cognitive impairments (Lord, 1995). However, some limitations do exist. The applicability of the current PDD diagnostic criteria is somewhat limited for children who are very young (prior to the preschool years) or those who experience significant developmental delays (Lord, 1995; Stone et al., 1999). For example, both the DSM-IV and ICD-10 include

criteria that relate to deficits in verbal communication skills, and a very young or developmentally delayed child may be pre-verbal and unable to demonstrate these deficits. In fact, the more complex verbal communication criteria of the DSM-IV and ICD-10 are often not seen in children under age 3, or in children with significant developmental delays (Stone et al., 1999). Very young or preverbal children rarely have the ability level necessary to demonstrate deficits in conversational skills or atypical speech patterns (Charman & Baird, 2002; Rogers 2001; Siegel, 1991; Stone et al., 1999; Vig & Jedrysek, 1999). Similarly, items related to peer relationships and play skills are difficult to assess in very young children, as these skills emerge later in development (Cox et al., 1999; Howlin & Asgharian, 1999; Vig & Jedrysek, 1999;Young et al., 2003). As a result, diagnostic measures are somewhat limited in their applicability to very young children (under age 3).

The limited sensitivity of the diagnostic criteria and associated diagnostic measures may explain, in part, the apparent decrease in functional ability demonstrated by some children with PDD-NOS (i.e., those who shift from PDD-NOS to autism). It is possible that the skills and PDD-related symptoms of this group do not change substantially over time. Rather, the measures are more sensitive to the types of deficits seen in older or more cognitively-able children. In addition, making a diagnosis in a very young child or a child with extremely low cognitive skills presents a challenge to clinicians (Lord, 1995; Vig & Jedrysek, 1999). Clinicians may be more likely to give provisional diagnoses to this group (Baron-Cohen, 1992; Gray & Tonge, 2002; Robins, et al., 2001), and anticipate a clarification of impairments as the child develops. However, despite the limitations of the current diagnostic criteria, it is possible to make a reliable and stable

diagnosis of autism prior to the preschool years (Lord, 1995). Clinicians experienced with the developmental progression of PDD symptoms and the impact of developmental delay on PDD symptom expression are able to make a diagnosis of autism in children as young as age 18 months (Charman & Baird, 2002; Lord, 1995). Features other than verbal communication deficits in preverbal and very young children are readily apparent to experienced clinicians. For example, children later diagnosed with autism often demonstrate specific social and non-verbal communication deficits, which are detectable prior to age three (Baranek, 1999; Baron-Cohen, Allen, & Gillberg, 1992; Baron-Cohen, Cox, Baird, Swettenham, Nightingale, Morgan, Drew, & Charman, 1996; Osterling & Dawson, 1994; Robertson et al., 1999). Examinations of first birthday home videos consistently find social impairments and other PDD-related deficits in the children later diagnosed with autism (Adrien et al., 1991; Adrien et al., 1993; Baranak, 1999; Osterling & Dawson, 1994). For example, impairments were noted in social interaction (e.g., limited eye contact, preference for being alone); sensory responses (e.g., abnormal response to sounds); motor behaviours (e.g., hand flapping, self-stimulatory behaviours); and emotional responses (e.g., limited range of facial expressions, limited smiling) (Adrien et al., 1991; Adrien et al., 1993; Osterling & Dawson, 1994).

In sum, diagnosing pervasive developmental disorders in children who are very young or who experience developmental delays presents a challenge to clinicians. Current diagnostic criteria have limited applicability for these children; however, recent research suggests that it is possible to diagnose autism reliably by age 2 (Lord, 1995). Knowledge of early PDD symptom presentation, familiarity with the developmental progression of PDD related behaviours, as well as an understanding of the relationship

between cognitive level and PDD symptoms are essential in making an accurate diagnosis in young children, or children with cognitive impairment (Baranek, 1999; Klin, Lang, Cicchetti, & Volkmar, 2000; Klinger & Renner, 2000). Therefore, a developmental delay or a very young age at initial assessment should not prevent an experienced clinician from identifying PDD-NOS. Therefore, test sensitivity is not a likely contributing factor to the instability of a PDD-NOS diagnosis.

Regression in PDD-NOS. A regression (i.e., a loss of previously acquired skills) can result in an increase in PDD symptoms. Two types of regression are documented in the PDD/ASD literature: (1) a significant, global regression that characterizes Childhood Disintegrative Disorder (Charman & Baird, 2002) and (2) a skill-specific regression that is seen in a subset of children with ASD, usually in the communication domain (Charman & Baird, 2002).

Childhood Disintegrative Disorder is not a likely cause for the decline in functional ability seen in the subset of children with PDD-NOS whose diagnosis shifts to autism. CDD is a rare diagnosis, with epidemiological surveys suggesting it occurs in less than 7 out of every 1,000,000 births (Fombonne, 2002). Further, the developmental course of CDD differs from that of PDD-NOS. Children with CDD follow a typical developmental course for the first 24 months. After age two, these children experience a period of global regression affecting multiple skill areas (Charman & Baird, 2002; Fombonne, 2002). The outcome for CDD is a diagnosis of mental retardation and autism. In comparison, delays and atypical development are apparent prior to age two in children whose diagnosis shifts from PDD-NOS to autism (De Giacomo & Fombonne, 1998; Gray & Tonge, 2001).

It is possible that children whose diagnosis shifts from PDD-NOS to autism experience a limited or skill-specific regression. Approximately 15 to 30 percent of children with ASD lose specific skills prior to age 2 (Charman & Baird, 2002). Skillspecific regressions are typically reported in the communication domain, rather than in social skills or repetitive/stereotyped behaviours (Bernabei & Camianoni, 2001; Charman & Baird, 2002; Davidovitch, Glick, Holtzman, Tirosh, & Safir, 2000, 2000; Kurita, 2001; Lord & Risi, 1998; Young et al., 2003). Parents of these children typically report a loss of meaningful, single-word speech between the ages 18 to 24 months (Kurita, 2001).

Children with PDD who lose early communication skills demonstrate a less promising outcome than those with stable skill development. Communication skill loss in early development is associated with cognitive delays in children with ASD (Burack & Volkmar, 1992). As well, those with a communication skill regression often experience greater deficits in the social-communication domain than do other children with ASD (Stella, Mundy, & Tuchman, 1999). Given these findings, a selective skill regression may account for the functional skill decrease seen in some children with an unstable diagnosis of PDD-NOS. However, selective skill loss usually occurs prior to age 2, and children with an unstable diagnosis of PDD-NOS usually do not show a change in symptom pattern until preschool or early school age. Therefore, selective skill regression cannot account for the functional skill decrease seen in all children whose diagnosis shifts from PDD-NOS to autism.

Developmental Progression of PDD Characteristics. Developmental progression refers to the changes seen in behaviours, skills, and abilities as a child matures and gains experience. A typically-developing child follows a sequential course of skill

development. For example, language acquisition begins with babbling and follows a series of stages to reach the level of meaningful language. In comparison, the early development of children with ASD follows an atypical course and progresses at a slower rate (Boelte & Poustka, 2000). Developmental progression also influences PDD symptom expression. PDD symptoms that emerge early usually suggest a delay or an absence in skill development, such as limited social interaction or delayed language acquisition (Scambler et al., 2001). PDD symptoms related to atypical skill development, such as stereotyped behaviours and echolalia often appear later, indicating that PDD symptom presentation changes with maturation (Scambler et al., 2001). Changes in symptom presentation can be accounted for by developmental progression (i.e., a change in the appearance of symptoms or behaviours due to maturation) or an exacerbation of existing symptoms (i.e., an increase in number or severity of symptoms). Both factors may account for the changing symptom presentation seen in PDD-NOS.

Developmental changes are evident in all three PDD domains (Bailey et al., 1996; Coplan, 2000; Gillberg et al., 1990; Lord & Volkmar, 2002; Vig & Jedrysek, 1999; Vostanis, Smith, Chung, & Corbett, 1994). Numerous studies indicate that PDD symptom presentation changes as children develop (Bailey et al., 1996; Gillberg et al., 1990; Vig & Jedrysek, 1999). For example, symptoms of autism were found to be more recognizable in older children than in younger children (Adrien et al, 1993; Lord, 1995). In addition, an increase in symptom severity is also associated with maturation, as parents of older children tend to report more severe symptoms of ASD than do parents of younger children (Stone & Hogan, 1993). Understanding the developmental progression

of PDD characteristics will provide insight into the changing functional abilities of PDD-NOS.

Developmental progression of social impairments. Social interaction skills develop in an atypical manner and at a slower rate in ASD groups compared to non-ASD groups of the same developmental level (Carpenter, Pennington, & Rogers, 2002). Social skill deficits change and become more apparent as children mature. Basic social deficits, such as difficulty focusing attention in social situations and limited social smiles, are often noted during a child's first 24 months (Charman & Baird, 2002; Lord, 1995). Impairments in more complex social skills are often not recognized until after age 24 months (Lord, 1995). By preschool age, delays and impairments in imitation skills are readily apparent in children with ASD compared to developmentally-matched groups (Marcus & Stone, 1993). At preschool and early school ages, children with autism begin to demonstrate a tendency to ignore others, show limited eye contact, have a restricted range of facial expressions, and also show deficits in shared enjoyment (Charman & Baird, 2002; Lord, 1995).

The presentation of PDD social deficits changes with maturation. In addition, the severity of social impairments becomes more apparent as children get older, with the full extent of social deficits becoming clear after the preschool or early school years (Charman & Baird, 2002; Marcus & Stone, 1993). Experienced clinicians can often detect social deficits in very young children (Charman & Baird, 2002). However, older children with ASD often demonstrate a broader range of social deficits than younger children (Lord, 1995). Parents of young children may be less likely to recognize the extent of their child's impairment until the child is in a setting such as preschool or

daycare, where their atypical development is more obvious relative to their peers (Lord, 1995; Marcus & Stone, 1993).

Developmental progression of communication impairments. Impairments in the communication domain are clearly influenced by developmental progression, (Wilkinson, 1998). Delays and atypical development of communication skills are among the first concerns reported by parents of children with ASD (Marcus & Stone, 1993; Young et al., 2003). However, a certain level of verbal ability is required, in order to demonstrate many of the communication deficits associated with PDD, such as echolalia and atypical language use (Gray & Tonge, 2001). As a result, communication impairment may be less apparent in pre-verbal, non-verbal, or very young children, than in older, more developmentally mature children.

Young children with PDD demonstrate non-verbal communication deficits (e.g., difficulty understanding gestures and emotions, as well as limited imitation and imagination skills) earlier than impairments in verbal communication skills (Charman & Baird, 2002). Older children are more likely to demonstrate the complex language-based diagnostic criteria, such as those that relate to peer interactions and the understanding of conversation roles, than are very young or pre-verbal children (Siegel, 1991). As children with PDD mature and acquire communication skills the scope of their impairments in this area becomes more obvious (Young et al., 2003).

Developmental progression of repetitive and stereotyped behaviours. While stereotyped behaviours and motor mannerisms are not exclusive to PDD/ASD (i.e., they are also seen in mental retardation), individuals with ASD demonstrate these behaviours more frequently than other children, and often to a more severe degree (Bodfish, Symons,

Parker, & Lewis, 2000). There is a clear developmental progression in the type of repetitive/stereotyped behaviours demonstrated by children with ASD. For example, motor mannerisms (e.g., hand flapping), repetitive behaviours (e.g., spinning objects), and unusual sensory behaviours are commonly seen in very young children with ASD (Klinger & Renner, 2000; Lord et al., 1993; Eaves & Ho, 1996; Marcus & Stone, 1993; Robins et al., 2001). These behaviours tend to decrease over time, as they are seen less frequently in older children (Klinger & Renner, 2000).

Perseverative behaviours and the more complex repetitive behaviours (e.g., insistence on routine and sameness, difficulty adjusting to changes, and highly focused interest) tend to appear between the preschool and early school years, and are rarely seen in very young children with ASD (Dahlgren & Gillberg, 1989; Klinger & Renner, 2000; Ohta, Nagai, Hara, & Sasaki, 1987; Tager-Flusberg, Joseph, & Folstein, 2000). The complex stereotyped behaviours and focused interests seen in preschool and school age children are infrequently reported in children under age 36 months (Charman & Baird, 2002; Gray & Tonge, 2001; Szatmari, 2000; Robins, Fein, Barton, & Green, 2001).

A certain level of cognitive ability and organizational skill must be attained in order to execute the more complex stereotyped and perseverative behaviours (Gray & Tonge, 2001; Szatmari, 2000). It is likely that younger children, or children who are less cognitively able, do not yet demonstrate the level of cognitive sophistication needed to execute these behaviours (Robins et al., 2001). As a result, the perseverative and repetitive behaviours are more likely to appear at later ages and stages of development (Gray & Tonge, 2001).

In sum, PDD-related symptoms are clearly influenced by development, as symptom presentation changes as children mature. The impairments and delays associated with ASD are, for the most part, more recognizable in older (i.e., school age) children than in preschool age children or toddlers (Adrien et al, 1993; Lord, 1995; Stone & Hogan, 1993). Specifically, some social and communication impairments are not readily apparent until a child is in a structured environment with peers, such as preschool or daycare (Robins et al., 2001). Likewise, restricted and/or highly focused interests are often not reported in very young children, and are more apparent in older children (Charman & Baird, 2002; Griffith et al., 1999; Vig & Jedrysek, 1999). Developmental progression may have a role in the changing PDD symptom presentation seen in children whose initial diagnosis of PDD-NOS shifts to autism. Symptom severity also appears to change as children with PDD mature. An increase in symptom severity may also have an impact on the diagnostic outcome of young children initially diagnosed with PDD-NOS.

*Summary*. Three possible explanations for the shift from PDD-NOS to autism were evaluated; limited sensitivity of diagnostic measures, and changes in symptom pattern due to either regression or developmental progression. Limitations of current diagnostic tools were ruled out as a possible contributing factor. Based on the literature, diagnostic criteria and assessment tools are somewhat limited when applied to very young or delayed children. However, research indicates that clinical experience can ameliorate these limitations, making diagnoses in young or developmentally delayed children reliable. Both selective regression and developmental progression may have contributing roles in the changing symptom pattern and decrease in functional ability that is associated with a shift from PDD-NOS to autism. Understanding the early developmental course

and pattern of PDD symptoms associated with the subset of PDD-NOS that is later diagnosed with autism will help to explain the apparent changes in functional ability. *Changes in Functional Ability: Predicting Outcome for PDD-NOS* 

For children with PDD-NOS, functional outcome is influenced by cognitive level, symptom presentation (i.e., pattern of symptoms and degree of impairment), and developmental progression. These features, particularly those connected to early functional skill level, may help identify outcome predictors for children with an unstable diagnosis of PDD-NOS. It is likely that functional skill level at outcome is associated with the degree of impairment in early development (i.e., more PDD symptoms, lower adaptive skills, and atypical behaviours prior to age 3 are associated with greater functional impairment), which implies that children with unstable PDD-NOS will exhibit greater impairment in early development than will children with stable PDD-NOS.

The following sections examine factors that contribute to functional ability. The association between PDD symptom patterns and outcome is presented first. Next, the relationship between adaptive ability and outcome in PDD is described. Adaptive skill level provides an indicator of functional level that is independent of diagnostic criteria. Level of cognitive functioning is also associated with outcome in PDD, and the relationship is summarized next. Finally, characteristics that indicate early functional ability, such as early signs of atypical behaviour, developmental milestones, and initial concerns of parents are presented. Much of the research presented focuses on autism or the broader PDD/ASD, rather than PDD-NOS specifically. However, given the close association between PDD-NOS and autism, the results of these studies can provide

information about the association between these characteristics and the outcome of PDD-NOS.

PDD symptoms and outcome. PDD encompasses a broad range of symptom patterns and degrees of impairment; from mildly impaired with few symptoms, to severe impairment with many symptoms (Coplan, 2000; Klin, Lang, Cicchetti, & Volkmar, 2000). Qualitatively, the functional ability of all individuals with PDD is significantly impaired compared to typically developing children. However, the degree of functional impairment experienced by children with PDD varies with the pattern and severity of PDD symptoms.

Early PDD symptom patterns can be associated with functional outcome. For example, the severity of social impairment in ASD is strongly associated with long-term functional ability (Lord & Risi, 1998). Mild social deficits indicate stronger functional skills, whereas severe deficits are associated with poorer functional skills (Lord & Risi, 1998). Similarly, a relatively mild deficit in the communication domain is associated with higher functional ability than a moderate or severe communication deficit (Lord & Risi, 1998). Impairments in language development, particularly the failure to develop language, are strongly associated with impaired functional outcome later in life for children with ASD (Bryson & Smith, 1998; Nordin & Gillberg, 1998; Lord & Risi, 1998; Gillbert & Steffenburg, 1987).

Functional outcome is frequently associated with early communication deficits in particular. For example, speech development over the long-term is less likely if language skills are not acquired by age 5 (Wilkinson, 1998). Similarly, the early acquisition of fundamental communication skills, such as joint-attention, is associated with a better

outcome over the long-term (Wilkinson, 1998). For a child with PDD, the presence of a language delay is also associated with outcome. For example, significant differences were observed in a comparison of two ASD groups (i.e., each group included autism, Asperger's syndrome, and PDD-NOS), one with a language delay and one without (Eisenmajer et al., 1998). The language delay group demonstrated poorer outcome, and greater deficits in the social aspects of communication (e.g., eye contact, imitation, and initiating activities) than the non-language delay group (Eisenmajer et al., 1998). The language delay group (Eisenmajer et al., 1998). The language delay group (Eisenmajer et al., 1998). The language delay group (Eisenmajer et al., 1998).

Further, the association between early symptom patterns and outcome applies to PDD-NOS samples specifically. PDD-NOS groups often demonstrate one of two dominant symptom patterns: impairment in the social and communication domains with mild or no stereotyped/repetitive behaviours, or a combination of social deficits and repetitive/stereotyped behaviours with limited or no communication impairments (Buitelaar, & van der Gaag, 1998; Robertson et al., 1999). The relative severity of the two affected areas is associated with later functional ability in PDD-NOS. For example, the PDD-NOS groups that demonstrate mild impairments in the social domain, together with moderate to severe impairments in the repetitive/stereotyped behaviours domain experience a better long-term outcome, than those with the reverse symptom pattern (i.e., severe social impairments and mild stereotyped/repetitive behaviours) (Lord & Risi, 1998). In addition, children who experience a shift in diagnosis from PDD-NOS to autism often show an increase in both the social and repetitive/stereotyped behaviour domains (Moore & Goodson, 2003; Stone et al., 1999).

To summarize, early PDD symptom patterns are associated with functional ability level and outcome. The association between symptom severity early in development and long term outcome is clear; greater severity in early childhood is indicative of greater impairment later on. The connection between symptom patterns and outcome for PDD-NOS is also apparent. Greater impairment in the social domain, in comparison to the other domains, is associated with poorer outcome for PDD-NOS. Together these results suggest that the pattern and severity of early PDD symptoms are important indicators of PDD-NOS outcome.

Adaptive functioning in PDD. A child's ability to manage daily activities (or adaptive ability) is a good indicator of functional ability and outcome in PDD. Adaptive level is a measure of independence in daily situations, including skills related to self-care such as getting dressed, feeding oneself, and communicating one's needs. An adaptive ability profile exists for children with autism (e.g., Kraijer, 2000); however, the pattern and stability of adaptive skills in children with PDD-NOS is less well known.

The Vineland Adaptive Behavior Scales (VABS) (Sparrow, Balla, & Cicchetti, 1984) is a commonly used measure of adaptive ability. The VABS measures four skill domains, including communication, social skills, self-care, and motor ability, and also provides an overall ability score (the Adaptive Behavior Composite or ABC). The VABS is well established in the PDD literature as a measure of adaptive ability in children with autism (Stone, Ousley, Hepburn, Hogan, & Brown, 1999; Szatmari, Archer, Fisman, Streiner, & Wilson, 1995).

Children with autism frequently demonstrate the same Vineland profile, with significant overall impairments, as well as a pattern of relative impairments between the

domain scores (Carter, Volkmar, Sparrow et al., 1998; Rodrigue et al., 1991; Schatz, & Hamdan-Allen, 1995). More specifically, children with autism typically obtain their lowest score in the socialization domain, followed by a lesser degree of impairment in the communication domain, and relatively mild delays in the daily living skills domain (Carter et al., 1998; Rodrigue et al., 1991; Schatz, & Hamdan-Allen, 1995; Stone et al., 1999). Further, children with autism tend to gain adaptive skills at a slower rate than typically developing children, and as a result, their adaptive scores appear to decrease over time (Fisch, Simensen, & Schroer, 2002; Lord & Schopler, 1989a). However, the score decrease reflects a delay in skill acquisition, rather than regression (Fisch et al., 2002).

Two additional features also characterize the PDD adaptive ability profile. First, skill development within adaptive domains is variable, significantly more so than for comparison groups matched on chronological and mental ages (Carter, Volkmar, Sparrow et al., 1998; Rodrigue et al., 1991; Schatz, & Hamdan-Allen, 1995; Stone et al., 1999). Second, there is a discrepancy between the level of cognitive functioning and adaptive skill level in children with autism. Adaptive ability and cognitive ability are usually closely associated (Kraijer, 2000; Liss, Harel, & Fein et al., 2001). However, for autism groups, adaptive scores tend to be lower than cognitive test scores (Bryson & Smith, 1998; Carpentieri & Morgan, 1996; Vig & Jedrysek, 1995). Further, as intelligence scores increase, less improvement is seen in the adaptive scores of children with autism than in children with other developmental delays, such as mental retardation (Schatz, & Hamdan-Allen, 1995).

In surn, a unique adaptive behaviour profile exists for autism. The pattern includes relative weaknesses between adaptive domains (i.e., social skills < communication skills < daily living skills). In addition, the severity of adaptive deficits is greater than anticipated based on the degree of cognitive impairment. Finally, significant variability is also noted within skill areas, particularly within the domain of socialization.

There is limited research on the adaptive skill profile associated with PDD-NOS (Buitelaar et al., 1999; Mayes et al., 1993). The PDD-NOS adaptive profile suggests less impairment and greater stability over time than the autism profile. In comparison to autism, PDD-NOS samples tend to demonstrate higher domain and summary scores, as well as relatively stable adaptive profiles (Gillham, Carter, Volkmar, & Sparrow, 2000). Comparisons between autism spectrum disorders suggest that PDD-NOS groups are less likely to show a decrease in adaptive scores over time than autism groups (Eaves & Ho, 2003). Children with PDD-NOS demonstrate the same core deficits in social and communication development as do children with autism, albeit to a milder degree. This suggests that the adaptive ability profile of children with PDD-NOS will be similar to that of children with autism, but with less overall impairment.

Cognitive functioning in PDD. A range of cognitive abilities, from mental retardation to above average skills, is seen in autism spectrum disorder (Vig & Jedrysek, 1999). Approximately 75 percent of individuals with ASD demonstrate cognitive skills significantly below average, with IQ scores of less than 70 (Fombonne, 1997; Gray & Tonge, 2001; Joseph, Tager-Flusberg, & Lord, 2002; Lord & Volkmar, 2002; Wolf-Schein, 1996). The cognitive ability profile associated with PDD-NOS is not well known;

however, it is likely that a wide range of IQ scores is associated with PDD-NOS, similar to the range seen in autism.

Cognitive functioning is closely associated with several aspects of outcome for a child with PDD. For example, cognitive ability level can influence the age at which ASD is identified, as a comorbid diagnosis of ASD and mental retardation is frequently identified earlier than a diagnosis of ASD alone (Baron-Cohen et al., 1992; De Giacomo & Fombonne, 1998; Lord, 1995; Vostanis et al., 1994). Further, the stability of PDD symptom expression is associated with cognitive functioning. Stevens et al. (2000) found that ASD symptoms in children with low cognitive skills were stable between preschool age and school age. In contrast, significant improvements in ASD-related symptoms were seen in a group of children matched on degree of ASD impairment, but with higher cognitive scores (Stevens et al., 2000).

Cognitive ability is also associated with symptom expression in children with ASD (Stevens et al., 2000). In particular, repetitive and stereotyped behaviours are closely associated with degree of cognitive impairment. For example, low functioning groups with ASD demonstrate motor mannerisms and sensory sensitivities more frequently than high functioning groups (Vig & Jedrysek, 1999; Waterhouse et al., 1996). In contrast, perseverative behaviours (i.e., difficulty with change and insistence on routines) are more likely to be seen in high functioning groups than in low functioning groups (Van Bourgondien, Marcus & Schopler, 1992; Waterhouse et al., 1996). It is hypothesized that certain perseverative behaviours require a relatively advanced level of cognitive ability, and as such, are more likely to occur at higher levels of cognitive development (Van Bourgondien et al., 1992; Waterhouse et al., 1996).
To a certain extent, cognitive ability level in PDD is associated with changes in global functional ability. Greater functional impairment is seen in children with moderate to severe cognitive deficits than in children with mild or no cognitive deficits (Bryson & Smith, 1998). For example, a low IQ score (i.e., below 50) at preschool age is associated with low functional ability at school age in children with PDD (Gillbert & Steffenburg, 1987). Further, low IQ scores (i.e., less than 50) at school age are also associated with severe social impairments later in life (Nordin & Gillberg, 1998).

Cognitive ability levels are more stable in school-age children than preschool-age children with PDD (Freeman, Ritvo, Needleman, & Yokota, 1985). Cognitive ability also tends to remain stable in children with ASD and mental retardation (Coplan, 2000). In contrast, improvements in cognitive ability scores are seen in children with mild cognitive impairments or average intelligence (Coplan, 2000; Freeman et al., 1985).

Together, these results support a strong association between cognitive ability and functional ability in PDD. Both symptom expression and developmental course are influenced by degree of cognitive impairment for individuals with PDD. It is likely that these patterns are also seen in PDD-NOS; cognitive deficits are associated with functional impairments in PDD-NOS and influence symptom presentation.

Early history characteristics and outcome in PDD. Early history characteristics include a range of behaviours and features that are apparent prior to a child's diagnosis. These include signs of delayed development (e.g., in achieving milestones), early atypical behaviours, as well as whether the child needed any extra supports or services to assist with development. Information about a child's early history plays an important role in the understanding and diagnosis of PDD. Currently, PDD/ASD diagnoses are based on

behavioural observations and parent report of a child's early development (Klin, Lang, Cicchetti, & Volkmar, 2000). Early history features can help in making diagnostic decisions (e.g., differentiating between ASD subtypes and non-ASD conditions) (Volkmar, 1998). A child's early development is also indicative of later outcome and functional skill level. For example, the age at which concerns are first recognized and reported by parents may suggest the severity of a child's impairment. The nature of the parents' concerns, such as atypical development (i.e., the presence of unusual behaviours or the absence of typical behaviours) and delayed development also indicate a child's functional skill level. Further, the types of services a child needs to assist with developmental delays, also indicate functional ability. The association between a child's early development and later outcome will now be reviewed.

A child's age at onset (i.e., age at which a child's atypical development was recognized, usually by parents) and age at diagnosis (i.e., the age at which a child was formally assessed and received a diagnosis) are pertinent early history characteristics. Both reference points provide useful information about a child's functional abilities. However, because parent recall and availability of resources influence age at onset and age at diagnosis, caution is needed in associating both with functional ability.

In terms of origin, ASD is generally viewed as a neurological condition with contributing genetic factors (Lord & Volkmar, 2002; Minshew, Johnson, & Luna, 2001; Tanguay, 2000), which suggests that it begins very early in development, either pre- or peri-natally. In terms of age at onset, most parents recall experiencing concern about their child's development between the ages of 12 to 24 months (De Giacomo & Fombonne,

1998; Gray & Tonge, 2001; Siegel, Pliner, Eschler, & Elliott, 1988; Vostanis et al., 1994; Vostanis et al., 1998; Young, Brewer, & Pattison, 2003).

Parents' ability to recognize and recall their child's early history is essential in determining age of onset, but the limitations of retrospective recall are well documented (Klin et al., 2000). Both parent education and practical experience are associated with the ability to recognize delays or atypical development in childhood (Baron-Cohen, Allen, & Gillberg, 1992). Familiarity with typical early childhood development is associated with earlier recognition of delays. Experienced parents (i.e., those with older children) are more likely to report concerns when their children are younger, than are parents whose child with ASD is their firstborn (De Giacomo & Fombonne, 1998; Siegel et al., 1988). Further, parents' acceptance of their child's difficulties is another influencing factor and determines the age at which parents acknowledge and report their concerns (De Giacomo & Fombonne, 1998).

Despite the limitations associated with retrospective recall, age of onset in PDD is a useful indicator of a child's potential functional ability. A high level of functional impairment is likely to be recognized earlier than a mild degree of impairment. In fact, children with autism are frequently identified at younger ages than children with PDD-NOS (Buitelaar, Van der Gaag, Klin, & Volkmar, 1999). It is probable that children who experience significant delays in adaptive skills and developmental progression, as well as a broad range of PDD symptoms, will be identified by parents earlier than children with mild to moderate delays and mild symptoms.

Initial diagnosis of PDD usually occurs months after parents first recognize developmental concerns. The length of time between the age at onset (or parent

recognition) and the initial diagnosis of ASD often ranges between 24 to 36 months (Vostanis et al., 1994; Young et al., 2003). Children with ASD, particularly autism, are usually diagnosed between the ages of 36 and 48 months (De Giacomo & Fombonne, 1998; Gillberg, Nordin, & Ehlers, 1996; Gray & Tonge, 2001). Children who experience a significant degree of functional impairment tend to present to clinicians at earlier ages than do children with mild functional impairment. For example, children with PDD-NOS are often diagnosed at later ages than are children with autism (Baron-Cohen, Allen, & Gillberg, 1992; Chakrabarti & Fombonne, 2001; Prior et al., 1998). Age at initial diagnosis provides useful information about a child's early functional ability; the age at which a child receives a diagnostic assessment reflects the severity of symptom presentation, as well as the degree to which the daily life of the child and the child's family is affected by PDD. However, there are several external factors that also influence age at diagnosis.

The availability of resources and diagnostic tools both influence the age at which a child is first assessed. For example, specialized clinicians are often required in order to determine an ASD diagnosis (Vostanis et al., 1994). Waiting lists or limited funding can restrict the availability of these appointments. In addition, current diagnostic tools are somewhat limited in their applicability to very young children (i.e., children under age 36 months), and therefore clinicians are more likely to give a provisional diagnosis to a young child than to a preschool- or school-age child (Baron-Cohen, Allen, & Gillberg, 1992; Gray & Tonge, 2001; Robins, Fein, Barton, & Green, 2001).

Delayed development is frequently reported in the early history of children with PDD. In comparison to typically developing children, the achievement of developmental

milestones (e.g., early motor, social, and language skills) is often delayed or follows an atypical progression in children with ASD (Charman & Baird, 2002). A typically developing child progresses through a series of developmental stages and attains a particular skill within a target age range. For example, a typically developing child usually learns to walk around age 12 months, and prior to walking, the child develops the prerequisite skills of sitting, crawling, and cruising. Similarly, communication and social skills both progress through a series of stages leading up to language development and joint social interaction. Typically, children begin to babble during infancy, use one-word utterances by age 12 months, and start combining two words prior to 24 months (Cox, 1993). Socially, infants begin to imitate by 12 months and demonstrate awareness of peers and engage in games during their first year, with symbolic representation occurring by 24 months (Cox, 1993).

For the most part, children with ASD meet motor milestones (e.g., sitting, crawling, and walking) within the expected time limit (Cox, 1993; Eaves & Ho, 2003). However, approximately one-third experience delays in motor skill development (Prior et al., 1998; Siegel, Pliner, Eschler, & Elliott, 1988). Both the language and social skills of children with ASD are frequently delayed and follow an atypical pattern of development (Carpenter, Pennington, & Roger, 2002; Cox, 1993; Siegel et al., 1988). Developmental milestones provide an early indication of a child's functional ability level. Delays or atypical patterns in milestone achievement can be an early indicator of impairment later in development. For example, children with ASD who demonstrated delayed milestones were diagnosed earlier than children who achieved their milestones within the expected age ranges (De Giacomo & Fombonne, 1998).

In addition to developmental delays, parents' early concerns also include their child's atypical behaviours. Children with PDD demonstrate atypical behaviours in their early history. In the years prior to a diagnostic assessment, children with PDD demonstrate both an absence of expected behaviours, as well as the addition of unusual or atypical behaviours. Initial concerns reported by parents included limited play skills, limited social interactions, as well as difficulty communicating (Bernabei, Camaioni, & Levi, 1998; Vostanis, Smith, Chung, & Corbett, 1994; Vostanis, Smith, Corbett, et al., 1998).

Parents of children with ASD recall experiencing concerns about their children's early development, particularly in the social and communication domains (Charman & Baird, 2002). Parents report the absence of certain social behaviours (e.g., no social smile, limited facial expressiveness) around the time of the child's first birthday (Charman & Baird, 2002; Young et al., 2003). By the child's second birthday parents report noticing atypical behaviours, such as aloofness, limited eye contact, and limited use of non-verbal communication (Charman & Baird, 2002). Parents report recognizing language impairments after age two when speech was clearly delayed (Young et al., 2003). Stereotyped/repetitive behaviours were usually the latest to emerge as an area of concern, typically reported by age 20 to 30 months (Young et al., 2003).

The nature of support and services needed by a child with PDD also reflects functional ability. A child's early educational and service needs reflect the child's level of functional ability. However, the association between services and functional ability level needs to be interpreted with caution. The nature of community and educational resources are influenced by factors other than a child's level of impairment, such as funding and

resource availability. For example, services vary across educational settings and the funding for support varies by geographical and political locations. Further, many settings are unable to provide resources to a child without a diagnosis, and there are often waiting lists for assessment. The types of services available in preschool and elementary school, and to some extent in structured daycares include behaviour interventions, classroom support (i.e., integrated, segregated, and partially integrated classrooms), resource and learning assistance, classroom aides, as well as other services such as speech and language therapy, occupational and physical therapy. Early functional ability is partially reflected by eligibility for special services.

Early history characteristics provide an indicator of a child's functional ability prior to diagnosis. Information about a child's early history (i.e., age at onset, delayed and atypical development, and eligibility for special services) is important in diagnostic decisions and reflects early functional skill levels. A general pattern emerges from the studies reviewed; significant early delays, atypical development, and a need for special services early in a child's history are all associated with functional impairments later in development. The majority of PDD early history research focuses on autism or combined PDD samples (Vostanis, Smith, Chung, & Corbett, 1994; Rogers & Di Lalla, 1990). As a result, the early development of children with PDD-NOS is not well documented. However, it is anticipated that functional impairment is also indicative of a history of significant delays and atypical development for children with PDD-NOS.

Early symptom patterns, adaptive and cognitive skills are associated with later functional ability level in PDD. In addition, early history characteristics related to functional ability (i.e., age at onset, developmental progression, atypical behaviours) are

also associated with outcome in PDD samples. While these factors are clearly associated with outcome in autism or PDD groups, their relationship with PDD-NOS specifically is less well-defined. The literature on PDD-NOS is sparse, and it is necessary to make extrapolations about the nature of PDD-NOS from its relationship to autism, which is better understood.

## PDD-NOS in Relation to Autism

Currently, PDD-NOS and autism are categorized as distinct entities that share impairments in three behavioural areas. However, there is limited evidence to support categorical distinctions between PDD-NOS and autism (Myhr, 1998). For both clinical and research purposes, there is a movement toward a broader definition of autism and related disorders, one that emphasizes the similarities between the conditions, rather than distinctions (Bryson & Smith, 1998). The DSM-V will likely represent autism, Asperger's syndrome and PDD-NOS as existing on a continuum, as part of "Autism Spectrum Disorder" (Lord, 2001, personal communication; Lord & Volkmar, 2002; Tager-Flusberg, Joseph, & Folstein, 2001). The severity of symptoms and level of functional ability will determine the relative positions of PDD-NOS and autism.

Through a review of ten years of PDD research, Tanguay (2000) determined that the literature supports a spectrum perspective for autism, Asperger's syndrome, and PDD-NOS. Further, the three conditions reflect different degrees of impairment, rather than clear distinctions. A spectrum perspective captures the complex nature of PDD; it emphasizes the shared nature of symptoms and possible common etiology, as well as reflects the range of ability levels and symptom patterns (Tager-Flusberg et al., 2001). However, the spectrum needs to be multi-dimensional in order to incorporate the many

factors that characterize PDD such as symptom severity, adaptive and cognitive skills, as well as developmental progression (Szatmari, 2000).

Subtype research. PDD subtype research and cluster analyses provide empirical support for a continuum or spectrum perspective. The subtype literature, including cluster analysis studies, strongly supports a dimensional or continuum perspective, particularly between PDD-NOS and autism. PDD-NOS and autism share similar patterns of impairment and differ primarily in the degree of disability (Mahoney et al., 1998) with PDD-NOS at the mild end of the continuum, demonstrating less severe symptoms and a higher level of functioning relative to autism (Lord et al., 2000).

A clear pattern of the relationship between PDD-NOS and autism emerges from cluster-analysis and empirically based studies. In a recent review of the PDD subtype literature (including 7 PDD subtype studies and 8 cluster analysis studies) a pattern emerged suggesting that the PDDs represent a continuum of impairment (Myhr, 1998). In each study, the PDD (usually autism, Asperger's disorder, and PDD-NOS) represented different degrees of functional ability; with the High Functioning end of the continuum demonstrating fewer autistic symptoms and higher cognitive and adaptive abilities, and the Low Functioning end showing more autistic symptoms, as well as lower cognitive and adaptive abilities (Myhr,1998). In this description PDD-NOS would occupy the "high functioning" end of the continuum, with autism at the "low functioning" end.

Many cluster analysis studies use PDD-related behaviours and cognitive ability in an attempt to identify homogeneous subgroups. Two patterns are consistently seen across studies; a two-cluster solution that reflects overall level of impairment (e.g., high and low functioning groups) or a three-cluster solution related to degree of symptom severity

(e.g., autism, Asperger's syndrome, and PDD-NOS) (Myhr, 1998; Prior et al., 1998; Sevin, Matson, Coe, Love, Matese, & Benavidez, 1995). Both patterns suggest a continuous or spectrum relationship within the PDD.

In one such study (Prior et al., 1998), the goal was to determine whether subgroups existed within a sample of high-functioning individuals (i.e., IQ within normal range) representing a variety of PDD conditions, including autism (n = 48), Asperger's disorder (n = 69), PDD-NOS (n = 7) and children with autistic-like features (n = 11). The cluster analysis was based on current PDD symptom patterns (e.g., frequency and severity) and developmental history variables (e.g., developmental milestones, onset of disorder, treatment, etc.). Consistent with the patterns outlined previously, this cluster analysis yielded three subgroups that differed on the basis of symptom severity and overall impairment. The three groups closely resembled the PDD subtypes of autism, Asperger's syndrome, and PDD-NOS. In terms of symptoms, the autism-like group was the most severely impaired and the PDD-NOS-like group was the least affected of the three (Prior et al., 1998). The Asperger's syndrome-like group demonstrated a moderate degree of impairment (Prior et al., 1998). With regard to developmental progression, the autismlike group was most likely to experience milestone delays, particularly in the areas of motor skills and language development, whereas the other two groups showed fewer or no delays in milestones (Prior et al., 1998).

The three clusters seen in the Prior et al (1998) study are similar in that they share the characteristic features of PDD (i.e., impairments in the social and communication domains), and differ in the degree to which they are affected. This type of relationship

supports the continuum perspective, with the PDD disorders of autism and PDD-NOS representing the two anchors of the continuum.

A second cluster analysis study (Sevin et al., 1995) also supports the continuum perspective as a means for representing the PDDs. The sample included individuals diagnosed with a PDD, and represented a broad range of ages (i.e., between 2 and 22 years) and cognitive ability levels (i.e., severe mental retardation through average intelligence). Each group in the four-cluster solution represented a different level of overall functioning (i.e., based on a combination of cognitive ability and PDD symptom severity) (Sevin et al., 1995). The highest functioning group most closely resembled PDD-NOS, with the least number of PDD symptoms and the highest overall level of functioning. The lowest functioning group was similar to autism; it was the most severely impaired and demonstrated the most symptoms of PDD. The middle two groups represented mild and moderate autism, differing from each other in the number of stereotyped behaviours and sensory abnormalities. This four-cluster solution suggests that the continuum of impairment seen in PDD at normal cognitive ability (Prior et al., 1998) may also be seen across a range of developmental and cognitive levels.

Despite the number of subtype studies, unique PDD subtypes are difficult to identify (Klinger & Renner, 2000; Lord & Volkmar, 2002). The differences between subtypes appear to reflect differences in cognitive ability, symptom severity, and functional ability (Myhr, 1998). It may be that the groups are more similar than they are different, and therefore, represent a spectrum of impairments and ability. These results consistently support the transition from PDD to "Autism Spectrum Disorder" (Sevin et al., 1995).

PDD-NOS on the PDD spectrum. Empirical evidence of the relationship between PDD-NOS and autism specifically is limited. However, the research that exists supports a continuum-relationship between the two. PDD-NOS is often differentiated from autism merely by the number of PDD symptoms, with those having PDD-NOS demonstrating fewer symptoms than autism (Szatmari, 2000). Evaluations of diagnostic tools provide useful information about the relationship between PDD-NOS and autism. Although PDD-NOS is not the target of these investigations, a PDD-NOS sample is often included. For example, PDD-NOS was compared to Asperger's Syndrome and autism during an evaluation of the social communication subscale of the Autism Diagnostic Observation Schedule (ADOS) (Robertson, Tanguay, L'Ecuyer, Sims, & Waltrip, 1999). The PDD-NOS group demonstrated less severe social-communication deficits than did the autism group (Robertson et al., 1999). Similarly, in a factor-analysis of the Childhood Autism Rating Scale (CARS), the PDD-NOS group (n = 24) and the autism group (n = 66)demonstrated similar scores on the factors relating to social-communication deficits and odd sensory experiences (Stella, Mundy, & Tuchman, 1999). However, the PDD-NOS group was less impaired than the autism group on factors relating to emotional responsiveness and cognitive consistency (Stella et al., 1999). The results of both studies support a spectrum relationship between PDD-NOS and autism.

In an attempt to identify behavioural features that differentiate PDD-NOS from comparison groups, Mayes, Volkmar, Hooks, and Cicchetti (1993) used a clearly defined, moderately large PDD-NOS sample (n = 20), and matched (i.e., on chronological and mental ages) groups of children with autism (n = 20) and language disorder (n = 20). The three groups were compared on a set of behavioural items related to PDD. A subset of the

items that differentiated PDD-NOS was identified, and then compared across a second sample (PDD-NOS, autism, language disorder, n = 40 each). The PDD-NOS group consistently performed better than the autism group, especially in terms of social interaction skills. The PDD-NOS group demonstrated more deficits than the language group, particularly in the areas related to socialization and perseveration. In a crossgroups comparison, the PDD-NOS group shared the most behavioural features with the autism group. While differences between PDD-NOS and autism were identified in the Mayes et al. (1993) study, the nature of the differences appears to be a matter of degree of severity. Qualitatively, PDD-NOS shared many features with autism (Mayes et al., 1993).

Based on the current diagnostic conceptualization, the boundaries between PDD-NOS and autism are fuzzy. However, the results of these studies clearly suggest that the two conditions are closely related (Charman & Baird, 2002) and can be represented as two ends of a spectrum. Qualitatively, the two groups share a pattern of behaviours and impairments. Quantitatively, PDD-NOS is characterized by less severe impairment than autism. On a spectrum or continuum, PDD-NOS occupies a position that reflects fewer PDD characteristics and milder impairments relative to autism (Towbin, 1997).

There is limited information available on the nature of PDD-NOS. Understanding the relationship between PDD-NOS and autism ameliorates this limitation to a certain degree. Autism is well-researched, and for the most part, PDD-NOS tends to exhibit a similar pattern of impairments, but to a lesser degree. Speculations about the functional ability of PDD-NOS can be drawn from the autism literature. However, before the

association between functional ability and outcome can be explored for PDD-NOS, several key research limitations need to be addressed.

## Limitations to PDD-NOS Research

It is difficult to make statements about PDD-NOS that are reliable or can be generalized, because of the limited research base (Bryson & Smith, 1998; Buitelaar et al., 1999; Mays et al., 1993). Few studies focus specifically on PDD-NOS, and those that do are often compromised by issues such as small sample size. Further, the lack of explicit diagnostic criteria results in a heterogeneous group, and this further limits the applicability of PDD-NOS research.

PDD-NOS diagnostic criteria. PDD-NOS lacks explicit diagnostic criteria. Neither the DSM-IV nor the ICD-10 provides a clear diagnostic algorithm for the condition known as PDD-NOS (Buitelaar, & van der Gaag, 1998; Buitelaar et al., 1999). The DSM-IV criteria for PDD-NOS are vague and allow for the inclusion of a broad range of symptom presentations. The ICD-10 inclusion criteria are also broad, and describe two PDD-NOS-like groups: Atypical Autism (i.e., those who fail to meet full criteria for autism) and PDD Unspecified (i.e., those who demonstrate the key PDD symptoms, but do not meet specific criteria for any of the disorders due to limited information) (Luteijn, Luteijn, Jackson, Volkmar, & Minderaa, 2000). The boundaries for PDD-NOS provided by both major diagnostic classification systems are limited, and result in a loosely defined condition that is more readily identified as "not autism."

A seemingly minor editing error in the DSM-IV further contributes to the confusion over the boundaries of PDD-NOS. In the transition between the DSM-III-R and the DSM-IV, the inclusion criteria for PDD-NOS were broadened. The DSM-III-R criteria for PDD-NOS stated that an individual must demonstrate "impairment in social interaction *and* in verbal or nonverbal communication skills" (APA, 1987, p.39, italics added). These criteria were intended to be included in the DSM-IV (Volkmar, Shaffer, & First, 2000). However, the inclusion criteria for PDD-NOS in the DSM-IV stated that an individual must demonstrate "...impairment of reciprocal social interaction *or* verbal and nonverbal communication skills, *or* when stereotyped behavior, interests, and activities are present" (APA, 1994, p.77-78, italics added).

When the error was recognized, the data from the DSM-IV autism/PDD field trial were re-analyzed. It was determined that an already poorly defined condition was made even worse (i.e., the PDD-NOS criteria demonstrated good sensitivity, but poor specificity) (Volkmar et al., 2000). Re-wording the PDD-NOS criteria to make it more restrictive (i.e., impairments in "the social area *and* either communication *or* restricted interest"), improved the specificity considerably, and was proposed for future revisions of the DSM-IV (Volkmar et al., 2000, p. 74, italics added). While the proposed changes to the PDD-NOS criteria reduce the scope of the diagnosis to some degree, the criteria will still be broad and not explicit. The proposed changes were incorporated in the text revision of the DSM-IV (DSM-IV-TR).

There are several commonly used interpretations of the PDD-NOS criteria. First, PDD-NOS is often used as an interim or default diagnosis, with changes in symptom presentation expected as a result of developmental progression (Sicotte & Stemberger, 1999). Second, late onset PDD symptoms (i.e., after age 36 months) have also been identified as PDD-NOS (Filipek et al., 1999; Luteijn et al., 2000a). Third, PDD-NOS is frequently used by many to indicate sub-threshold autism. That is, a pattern of either mild

impairment in all three core PDD symptoms (i.e., the individual does not meet the 6/12 cutoff for autism), or impaired social skills but mild or no impairment in the other two core behaviours (i.e., communication impairments and stereotyped/repetitive behaviours) (Filipek et al., 1999; Lord & Risi, 1998; Luteijn et al., 2000b; Mayes et al., 1993; Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1998). This third view most closely resembles the revised criteria for PDD-NOS suggested by Volkmar et al. (2000), and emphasizes a pattern of impaired social interaction with either repetitive and restricted behaviours or delays in communication skills (Lord & Risi, 1998; Lord & Volkmar, 2002). The lack of explicit criteria for PDD-NOS limits both diagnostic reliability and the ability to research PDD-NOS (Buitelaar et al., 1999; Luteijn et al., 2000b).

Poorly defined inclusion criteria limit PDD-NOS research. The heterogeneity of a PDD-NOS diagnosis is well documented (Buitelaar, & van der Gaag, 1998; Buitelaar et al., 1999; Robertson et al., 1999). Both clinicians and researchers use the term PDD-NOS to describe a wide range of conditions, including variations in symptom patterns and symptom severity (Mayes et al., 1993). The lack of explicit diagnostic criteria for PDD-NOS has significant, negative implications for research in this area (Mayes et al., 1993). First, conducting research with a PDD-NOS sample is more difficult, and therefore, less likely to be undertaken. Second, the ability to generalize and replicate the results of PDD-NOS investigations is limited. The DSM-IV criteria for PDD-NOS are not rigorous enough for research purposes. As a result, investigators often establish individual sets of criteria that provide more specific boundaries for describing PDD-NOS samples. While this approach can improve the likelihood of study replication, a wide variation of such definitions exists across studies, limiting the ability to generalize (Buitelaar, & van der

Gaag, 1998; Buitelaar et al., 1999; Mahoney, et al., 1998). There is a clear need for a diagnostic algorithm for PDD-NOS in order to encourage further research into the nature of this condition.

Methodological issues. A number of significant methodological limitations are noted in PDD-NOS research. First, PDD-NOS samples are frequently small, such as the n = 7seen in both the Prior et al. (1998) and Sevin et al. (1995) studies. The obvious limitations associated with small samples, particularly those related to statistical analyses, apply to many PDD-NOS studies. In addition, small samples make it difficult to draw conclusions about PDD-NOS in general. Caution in interpreting results from small samples and the use of appropriate statistics can protect against over-interpretation.

Second, a broad range of ages and cognitive ability levels are noted in a number of PDD-NOS studies (e.g., Prior et al., 1998). The role of developmental progression in symptom expression cannot be accurately addressed in a sample that includes a range of age groups. Cognitive functioning is closely related to symptom presentation and functional ability in children with Pervasive Developmental Disorders (Stevens et al., 2000). A range of cognitive ability levels is seen across all PDD subtypes, particularly autism and PDD-NOS (Vig & Jedrysek, 1999). However, a majority of individuals with PDD (i.e., approximately 75 percent) experience some degree of mental retardation (Fombonne, 1997; Gray & Tonge, 2001; Joseph, Tager-Flusberg, & Lord, 2002; Lord & Volkmar, 2002; Wolf-Schein, 1996). PDD-NOS comparison groups frequently consist of individuals with relatively high cognitive skills (i.e., IQ above 70) (e.g., Prior et al., 1998), and as a result, do not represent individuals with PDD-NOS who have cognitive

impairments. The range of ages and cognitive ability levels in PDD-NOS samples limit the extent to which the results can be generalized.

Finally, very few studies focus solely on PDD-NOS, even though it is thought to be more common than autism (Mayes et al., 1993). PDD-NOS samples tend to be included as comparison groups for empirical investigations focused on autism, and have even been referred to as a "non-PDD" comparison group (Buitelaar et al., 1999; Prior et al., 1998; Robertson et al., 1999; Sevin et al., 1995). However, the current trend toward a spectrum conceptualization of the PDDs (i.e., Autism Spectrum Disorder) will likely address this. For example, PDD-NOS participants are being included in some studies as part of an "Autism Spectrum" group. While this is a step toward understanding the range of PDD impairments, it does not elucidate the specific strengths and weaknesses specific to PDD-NOS.

Because few studies focus on PDD-NOS, there is limited information about the nature of this condition. For example, little is known about the early developmental characteristics, symptom patterns, and stability of functional skills associated with PDD-NOS (Buitelaar et al., 1999; Prior et al., 1998; Robertson et al., 1999; Sevin et al., 1995; Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1998). Characteristics such as symptom patterns and functional ability change with developmental progression (Klin, Lang, Cicchetti, & Volkmar, 2000), and more information is needed about the developmental history of PDD-NOS. In order to provide useful information for treatment planning, it is important to understand the factors influencing a child's outcome (Szatmari et al., 2000). This emphasizes the need for empirical investigations of PDD-

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NOS. In order to understand PDD-NOS, explicit, replicable, and meaningful diagnostic criteria are needed (Lord & Risi, 1998).

# Inclusion Criteria for PDD-NOS

Given the heterogeneity of PDD-NOS samples in previous studies, there is a clear need to establish specific inclusion and exclusion criteria for the disorder (Buitelaar, & van der Gaag, 1998; Buitelaar et al., 1999). The DSM-IV criteria for PDD-NOS are too broad to effectively define research samples (Tanguay et al., 1999). Research criteria that set boundaries on the DSM-IV definition and can provide useful guidelines for identifying a PDD-NOS sample. However, these guidelines are often too encompassing and perpetuate the heterogeneity issue. For example, autism is often used as a benchmark for identifying PDD-NOS; PDD-NOS is diagnosed when subthreshold impairments are demonstrated in all three domains, relative to autism (Filipek et al., 1999; Mahoney, et al., 1998; Robertson et al., 1999; Tanguay et al., 1998). In other samples PDD-NOS is defined by the number of affected behavioural domains, demonstrating impairments in the social and communication domains, but not in the repetitive and stereotyped behaviours domain (Fitzgerald, 1999; Robertson et al., 1999; Tanguay, Robertson, & Derrick, 1998). Although these attempts to define PDD-NOS improve upon the DSM-IV criteria, these descriptive approaches are not specific enough. The inclusion criteria for PDD-NOS need to be explicit, meaningful, and easily replicated.

Proposed diagnostic algorithm for PDD-NOS. The descriptive approach to identifying PDD-NOS (i.e., using the number of domains affected by impairment or the severity of symptoms relative to autism) likely captures the nature of what is meant by "PDD-NOS." However, in order to draw conclusions that can be generalized and

replicated, more specific criteria are needed. With a goal of identifying a homogenous PDD-NOS research sample, Buitelaar and van der Gaag (1998) and Buitelaar et al. (1999) developed a diagnostic algorithm based on DSM-IV and ICD-10 criteria. Three diagnostic groups from the DSM-IV field trial for Autistic Disorder (i.e., autism, PDD-NOS, and non-PDD disorders) were compared on autism diagnostic criteria. The diagnostic algorithm for PDD-NOS consisted of diagnostic criteria that significantly differentiated between autism and PDD-NOS groups. The diagnostic algorithm was found to be more specific than either the DSM-IV or the ICD-10 criteria (Buitelaar & van der Gaag, 1998; Buitelaar et al., 1999). The proposed diagnostic criteria for PDD-NOS are summarized in Appendix B.

The diagnostic algorithm effectively differentiated between PDD-NOS and non-PDD disorders, as well as between PDD-NOS and autism (Buitelaar & van der Gaag, 1998; Buitelaar et al., 1999). However, all scoring criteria showed higher sensitivity for autism than for PDD-NOS (Buitelaar & van der Gaag, 1998; Buitelaar et al., 1999). While these results are promising, the diagnostic algorithm also generated a high number of false positive and false negative diagnoses. The authors suggest that there are symptoms and behaviours associated with PDD-NOS that are not addressed in the DSM-IV and ICD-10 criteria (e.g., disorganized thinking, anxiety, and emotional instability), and identifying and including these behaviours may improve the sensitivity and specificity of the PDD-NOS algorithm (Buitelaar & van der Gaag, 1998; Buitelaar et al., 1999). Until further investigations are conducted, the authors further recommend that the use of the diagnostic algorithm be limited to research samples (Buitelaar & van der Gaag, 1998; Buitelaar et al., 1999).

While the algorithm proposed by Buitelaar and van der Gaag (1998) and Buitelaar et al. (1999) present advantages over the available diagnostic criteria, there are also limitations. In addition to a high rate of false positive/false negative diagnoses, the effectiveness of the algorithm is also questionable for individuals with very low cognitive abilities. The proposed algorithm for PDD-NOS was developed on a sample representing a range of ages and intellectual levels, with all subjects demonstrating an IQ greater than 50. However, when the scoring criteria were applied to individuals with IQ scores less than 50, the results were less specific (Buitelaar & van der Gaag, 1998; Buitelaar et al., 1999). The high rate of mental retardation in PDD populations may limit the use of the algorithm to some degree.

The differences between the proposed algorithm and the standardized diagnostic criteria are extensive, which may limit the degree of comparison between samples that were defined with traditional criteria (i.e., DSM-IV) and with the new criteria. Further, the proposed algorithm has limited applicability for children who demonstrate profound to severe mental retardation. The proposed diagnostic algorithm for PDD-NOS represents an important initial step toward promoting PDD-NOS research. However, further replications and refinements of the proposed algorithm are needed. In the interim, a checklist for PDD-NOS based on DSM-IV criteria for autism may provide an effective alternative for defining the disorder.

*Checklist for PDD-NOS based on DSM-IV criteria.* Lutejin et al. (2000) noted the dearth of diagnostic measures designed specifically for PDD-NOS, as well as the importance of identifying characteristics specific to children with PDD-NOS. In order to accurately and reliably identify a PDD-NOS sample, they created a checklist for PDD-

NOS based on the DSM-IV diagnostic criteria for autism. Each item in the checklist reflects a symptom or behaviour from the DSM-IV text. The items are rated as present or absent and also rated on 4 point Likert scale to estimate severity.

The PDD-NOS checklist used by Luteijn et al. (2000) has several advantages and disadvantages. First, the checklist is based on criteria for autism, which presupposes a continuum relationship between PDD-NOS and autism. While the literature primarily supports such a relationship, the checklist will have limited applicability if genetic studies determine different etiologies for the two groups. Second, any changes between the DSM-IV and DSM-V criteria for autism will further reduce the usefulness of this checklist.

In terms of advantages, the items in the checklist are explicitly stated and easy to replicate between studies. In addition, the checklist makes it possible to set inclusion and exclusion criteria for PDD-NOS, as well as provide frequency counts for the number of impairments in each of the behavioural domains. Further, specific types of behavioural impairments can be described for PDD-NOS. Because the checklist items are based on the DSM-IV criteria, direct comparisons can be made between PDD-NOS and autism. In addition, because the DSM-IV criteria are widely used, the checklist will be readily understood, and results can be generalized. The approach used by Lutejin et al. (2000) effectively captures the common perception of PDD-NOS as a milder variant of autism and makes the DSM-IV criteria more explicit.

For the purposes of the present study, the PDD-NOS checklist will be used to identify and define the PDD-NOS sample. Given the current limitations in classifying and describing PDD-NOS, it is important to delineate the condition in a meaningful and

easily understood manner. The checklist criteria are based on the familiar DSM-IV criteria and present PDD-NOS in a way that is readily grasped by researchers and clinicians. The checklist is explicit and will allow for the identification of more homogeneous PDD-NOS samples.

#### Present Study

The goal of the present study was to investigate the characteristics associated with functional ability and subsequent outcome for an explicitly defined PDD-NOS sample. While some children diagnosed with PDD-NOS follow a stable developmental course, others experience a decrease in impairment (i.e., move off the PDD spectrum) or experience an increase in functional impairment (i.e., shifts from PDD-NOS to autism). The proportion of children following each of these trajectories is not clear from the extant literature. The present study focused on the outcome for the two clinically more fragile groups: those who retained the diagnosis of PDD-NOS and those whose symptoms increased in number or severity before the follow-up assessment.

Participants included children who received initial and follow-up diagnoses of either PDD-NOS or Autistic Disorder. Three groups were identified based on the outcome of the two diagnostic assessments: Stable PDD-NOS (i.e., those who retained the diagnosis of PDD-NOS), Stable Autism (i.e., those who retained the diagnosis of autism), and the Change group (i.e., those whose PDD-related deficits increased between the initial and follow-up assessments).

It was anticipated that the developmental course differs between those with a stable functional ability level and those who experience a relative decline in functional level. Research on autism indicates an association between functional ability, PDD symptom

presentation and outcome (Bryson & Smith, 1998; Nordin & Gillberg, 1998; Lord & Risi, 1998; Gillbert & Steffenburg, 1987). A greater degree of impairment is associated with a greater number of PDD symptoms at an early age. In addition, developmental progression of PDD symptoms is also associated with functional level (Adrien et al, 1993; Lord, 1995; Stone & Hogan, 1993). Communication impairments and repetitive and stereotyped behaviours often develop at later ages or stages of maturation. Delays in developmental progression can contribute to apparent increase in impairment (i.e., symptom severity) at later ages. Further, both adaptive and cognitive ability levels are associated with functional ability and outcome in PDD (Baron-Cohen et al., 1992; De Giacomo & Fombonne, 1998; Lord, 1995; Vostanis et al., 1994). Finally, characteristics of early development (i.e., prior to diagnosis) are also indicative of later functional level (Baron-Cohen, Allen, & Gillberg, 1992; Chakrabarti & Fombonne, 2001; Klin et al., 2000; Prior et al., 1998). For example, early recognition of behavioural concerns is suggestive of greater impairment and less functional ability at outcome.

There is limited empirical research on the nature of PDD-NOS, particularly on the features associated with functional ability and outcome. However, the relationship between PDD-NOS and autism is well established. Relative to autism, PDD-NOS represents a milder degree of impairment (Lord et al., 2000; Mahoney et al., 1998). Inferences about the relationships between outcome and functional ability (i.e., PDD symptom severity, adaptive and cognitive ability levels, developmental progression, and early history) for PDD-NOS can be derived from the autism and PDD literature.

Hypothesis 1: Group Differences in Severity and Stability of Functional Impairment.

(a) A pattern of relative functional impairment will exist between the three groups, with Autism demonstrating the greatest impairment, followed by the Change group, and finally PDD-NOS. This pattern of relative differences in functional ability will be apparent at both the first and second assessments.

(b) The functional ability of the two stable diagnostic groups (i.e., Stable PDD-NOS and Stable Autism) will remain constant between the first and second assessments. In contrast, the Change group (i.e., PDD-NOS at first assessment and autism at re-assessment) will experience an increase in impairment across all PDD related behaviours (i.e., those associated with social interaction and communication skills, as well as stereotyped and repetitive responses).

## Hypothesis 2: Symptom Patterns as a Predictor of Outcome

Different patterns will be apparent in the PDD symptom profiles (i.e., areas of impairment) of the three groups, and the patterns will be associated with different functional levels at follow-up. The Stable Autism group is expected to demonstrate a consistent symptom pattern, with impairment in each of the three PDD behavioural domains across both assessments. It is anticipated that the Stable PDD-NOS group will demonstrate a pattern of relatively mild impairment that is consistent over time. In comparison, the Change group will likely demonstrate an uneven symptom pattern in terms of severity, at the first assessment (i.e., impairments in the social and communication domains, or impairments in the social and stereotyped/repetitive behaviours tend to increase over time for children whose diagnoses shift from PDD-NOS to autism (Moore & Goodson, 2003; Eaves & Ho, 2003). At follow-up, the Change group will more closely

resemble the Stable Autism group in terms of symptom severity and symptom pattern (i.e., moderate to severe impairments in each of the three domains).

## Hypothesis 3: Differences in Adaptive Ability Associated with Outcome

Adaptive skill level reflects an individual's ability to function in daily life situations. It is anticipated that the deficits associated with a PDD will negatively impact the overall ability to manage day-to-day activities. According to recent literature, individuals with autism demonstrate specific patterns of adaptive deficits. More specifically, individuals with autism demonstrate a pattern of relative impairment within the adaptive skill domains (i.e., the most impairment in social skills, relatively less impairment in communication skills, and the least impairment in self-care and independence) (Kraijer, 2000). It is anticipated that the three groups in the present study will demonstrate (a) a similar pattern of relative impairment within the adaptive skill domains, with the greatest relative impairment in the Socialization domain, (b) different levels of adaptive ability, both at the first and second assessments (i.e., the Stable PDD-NOS group will be the least impaired overall, the Stable Autism group will be the most impaired overall, and the overall adaptive ability of the Change group will be between the other two groups and will decrease over time), and (c) differences in stability of adaptive skills, with the Stable Autism and Stable PDD-NOS experiencing consistent adaptive skill levels, and the Change group experiencing a relative decline in adaptive functioning.

Hypothesis 4: Early History Characteristics as Indicators of Functional Ability

(a) Relative differences in functional ability will be apparent early in development. Non-diagnostic characteristics, such as developmental progression, will reflect the differences in impairment between the three groups. It is anticipated that the developmental milestones of the Stable Autism group will demonstrate both significant, global delays and an atypical course. The Change group will also experience marked, global delays and an atypical developmental course in achieving behavioural milestones. In contrast, the Stable PDD-NOS group will demonstrate relatively mild, global delays.

(b) Prior to diagnosis (i.e., prior to age three), the three groups will have demonstrated different degrees of behavioural limitations. More specifically, the Stable Autism and Change groups will both demonstrate a greater number of parent-reported concerns in the areas of language development, social interaction, and sensory responses, than the Stable PDD-NOS group.

(c) It is expected that severity of impairment, as well as changes in degree of impairment, will be associated with the age at which parents sought professional intervention (i.e., diagnostic assessment) for their children. Therefore, it is anticipated that the Stable Autism group will be diagnosed earliest (i.e., at younger ages) followed by the Change group, with the Stable PDD-NOS group being diagnosed the latest (i.e., at older ages). Similarly, the length of time between assessments will also be influenced by changes in functional ability. The relative decrease in functional ability of the Change group. The length of time between initial and follow-up assessments for the Stable Autism group will be similar to that of the Change group.

## Hypothesis 5: Nature of Supports and Services in Relation to Outcome

The nature of specialized services and supports received by the child will be associated, in part, with severity of impairment. It is anticipated that the degree of assistance (e.g., behavioural support, speech therapy, and adult assistance in the

classroom or daycare) required for managing behavioural limitations, both at home and in educational settings, will differentiate the groups. The more severely impaired groups (i.e., Stable Autism and Change) will have received a greater number of supports and services than the Stable PDD-NOS group. The Change group will show the greatest increase in service use over time. The Stable PDD-NOS group will receive the least number of services, relative to the other two groups.

## CHAPTER II

#### METHOD

## **Participants**

The sample consisted of 59 children (48 boys, 11 girls), who participated in two PDD diagnostic assessments at a clinic affiliated with a regional hospital in an urban area of southwestern Ontario. The clinic provides assessment and treatment services for children in the surrounding county. The county has a population of approximately 375,000 people with an average income of \$36,000 per year (Statistics Canada, 2003). In terms of education, approximately 13 percent of the population did not complete high school, 47 percent achieved a high school diploma or the equivalent, and 40 percent completed a college diploma or university degree (Statistics Canada, 2003). Demographics specific to the present sample were not available.

Referrals to the clinic are made by professionals who work with children, such as medical doctors, psychologists, speech and language therapists, or teachers. In addition, parents can contact the clinic directly. An intake interview is conducted with the parents of prospective patients. On the basis of the intake interview, parents are referred to the appropriate clinic service. Children with a pervasive developmental disorder are referred to the Neurodevelopment Service, which provides assessment and treatment for children with developmental disabilities.

During clinic visits, the children in the present sample were seen by the Psychology Team, which included a registered psychologist, one of two team psychometrists, and a social worker. Each team member had extensive experience with pervasive developmental disorders, and had been working in the field for between 6 and 10 years.

Prior to each child's assessment, parents were interviewed by the team psychologist, to obtain a developmental history and to identify specific behavioural concerns. The child then participated in a cognitive assessment and a structured play session using the Childhood Autism Rating Scale (Schopler, Reichler, DeVellis, & Daly, 1980; Schopler, Reichler, & Renner, 1988), which was rated separately by both the psychologist and a psychometrist. The child's overall CARS score was an average of the two test scores. During the cognitive and behaviour assessment, the team social worker completed the Vineland Adaptive Behaviour Scale (Survey Form) with the parent.

The mean age at each assessment, age ranges, and the mean length of time between assessments for the total sample are summarized in Table 1. The participants were first diagnosed at approximately age 4 (M= 47.75 months, SD = 13.62) and were re-assessed at age 6 (M= 73.80, months, SD = 18.08). The mean length of time between assessments was approximately two years (M= 26.00 months, SD = 12.43). The participants were seen for a follow-up assessment on the recommendation of the psychologist, at the request of classroom teachers, or at the request of parents.

Children with autism demonstrate a range of cognitive ability levels; however, the majority (i.e., approximately 75 percent) demonstrate cognitive impairments (Vig & Jedrysek, 1999). The children in the present study demonstrated significant cognitive delays (Table 2), with the mean cognitive ability score falling between three and four standard deviations below average. A range of cognitive ability measures were used, and the procedure for rating cognitive ability level is summarized in the Measures section. Briefly, each child's cognitive ability level was determined by the number of

# Table 1

1 1

	Months			
N = 59	М	SD	Range	
CA at the Initial Assessment	47.75	13.62	34.13 - 61.37	
CA at the Follow-Up Assessment	73.80	18.08	55.72 - 91.88	
Length of Time between Assessments	26,00	12.43	13.57 - 38.43	

Total Sample (N): Chronological Age (CA) at the Initial and Follow-Up Assessments

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### Table 2

N = 59		Cognitive Ability Level <sup>1</sup>			
	М	SD	Range		
Initial Assessment	1.77	0.80	0.97 - 2.57		
Follow-Up Assessment	1.70	0.89	0.81 - 2.59		

Total Sample (N): Cognitive Ability Level at the Initial and Follow-Up Assessments

<sup>1</sup> Each child's cognitive ability level was assigned a value between 1 and 4, where 1 = scorebetween 3 and 4 standard deviations below average, 2 = a score between 2 and 3 standard deviations below average, 3 = a score between 1 and 2 standard deviations below average, and 4 = a score that is less than or equal to 1 standard deviation below average. standard deviations between the child's score and an average score on the cognitive ability measure that was used.

In addition to the communication deficits typically associated with PDD (e.g., echolalia and deficits in social aspects of language, such as imitation and eye contact), many children with autism also experience delays in acquiring language (Young et al., 2003). At the time of the first assessment (i.e., at 4 years), the present sample demonstrated a delay in the acquisition of single words, and many were not yet speaking in sentences. At the follow-up assessment (i.e., by age 6), the majority of the children were using single-words, although it was not clear whether the words were functional or the result of echolalia. Based on developmental milestones, the majority of the participants demonstrated at least a mild delay in language acquisition. The children with language delays were fairly evenly distributed across the three groups.

The participants were divided into three groups based on the outcome of the two diagnostic assessments: the Stable PDD-NOS group consisted of children who received a diagnosis of PDD- NOS at the first and second assessments (n = 24); the Stable Autism group consisted of the children who were diagnosed with autism at both assessments (n = 20); and the Change group consisted of children whose diagnosis shifted from PDD-NOS to autism (n = 15).

The sex ratio of this sample is representative of the broader PDD population, in which PDD diagnoses are approximately 4 times more common in boys than in girls (Buitelaar et al., 1999; Buitelaar & van der Gaag, 1998). The Stable PDD-NOS group consisted of 20 boys and 4 girls, the Change group consisted of 12 boys and 3 girls, and the Stable Autism group consisted of 16 boys and 4 girls. Descriptive characteristics of

each group are reported in the Results section, including chronological age at each assessment and cognitive ability level.

## Measures

*Childhood Autism Rating Scale* (Schopler et al., 1980; Schopler et al., 1988). The Childhood Autism Rating Scale (CARS) is a standardized measure designed to assess symptoms of pervasive developmental disorders in children (Sevin, Matson, Coe, Love, Matese, & Benavidez, 1995; Vig & Jedresyk, 1999). During a semi-structured behavioural observation session, the clinician rates the child on 15 symptom-related behaviours. Each of the behaviours is rated from 1 (normal) to 4 (severely impaired). The 15 behaviour scores are summed and the total score indicates PDD symptom severity. The cut-off score for autism spectrum is 30, with scores below 30 suggesting the child does not fall on the autism spectrum. Scores between 30 and 36.5 are associated with mild- to moderate impairment and scores from 37 to 60 indicate severe impairment.

The CARS is a commonly used assessment tool in the diagnosis of the Pervasive Developmental Disorders, and it consistently demonstrates satisfactory reliability (i.e., internal consistency alpha = .94; inter-rater reliability = .71; test-retest reliability = .88) and validity (i.e., criterion related validity, comparison of CARS total score and clinical rating r = .84) (Garfin, McCallon, & Cox, 1988; Schopler et al., 1980; Sevin et al., 1995; Sponheim, 1996). Both the CARS total score, as well as the subscale scores demonstrate good internal consistency, inter-rater reliability, and stability over time (Nordin & Gillberg, 1996; Sturmey, Matson, & Sevin, 1992). The CARS total score differentiates between autism and other developmental disorders, and children with physical and mental disabilities (Nordin & Gillberg, 1996). However, use of the CARS with very

young children (i.e., children under 2 years), and children with very low mental ages (i.e., less than 18 months) may result in false positives (Vig & Jedresyk, 1999).

Both the CARS total score and subscale scores were used in this study. Comparisons were made between and within groups on overall PDD severity (i.e., CARS total score), as well as selected PDD-related behaviours (i.e., the CARS sub-scales related to social and communication impairments).

*Criterion Checklist for PDD-NOS* (Luteijn et al., 2000). PDD-NOS is generally viewed as a mild variant of autism (Charman & Baird, 2002; Towbin, 1997) that does not have specific inclusion and exclusion criteria. To that end, the DSM-IV criteria for Autistic Disorder are often used as a means to operationally define PDD-NOS samples. The Criterion Checklist for PDD-NOS (or DSM-IV Checklist) consists of an itemized list of the DSM-IV diagnostic criteria for Autistic Disorder (Appendix E), which was used with the permission of the author (E. Luteijn, personal communication, 2001). It consists of 20 items, which are based on the text from the DSM-IV. Each item is coded on a 4point Likert scale ranging from absent "0" to severe "4." For the present study, the boundaries for a diagnosis of PDD-NOS were based on the DSM-IV description of PDD-NOS (i.e., significant impairment in social and communication domains, or in the social and repetitive/stereotyped behaviour domains, but an insufficient number of criteria for a diagnosis of Autistic Disorder).

The Checklist was chosen for the present study because it allowed the diagnostic criteria for PDD-NOS to be operationally defined, which enabled the comparison of specific PDD-related behaviours across groups. Because some of the earlier diagnoses in

the present study were based on the DSM-III-R, the use of the Checklist ensured that the same PDD criteria were met by all participants.

Cognitive Ability Measures. Cognitive measures were matched to each child's ability level at the time of the assessment, which resulted in a range of ability measures being used. The measures included the Bayley Scales of Infant Development (Bayley, 1969), Leiter International Performance Scale (Leiter, 1948), Psychoeducational Profile -Revised (Schopler, Reichler, Bashford, Lansing, & Marcus, 1990), Wechsler Preschool and Primary Scale of Intelligence-Revised (Wechsler, 1989), and Wechsler Intelligence Scale for Children-Third Edition (Wechsler, 1991). In addition, different types of scores were reported, including standard scores, scaled scores, and age equivalent scores. As a result, it was not possible to compare test scores directly. In order to describe and compare cognitive ability levels, individual test scores were assigned a value between 1 and 4, indicating the number standard deviations between the test result (age-equivalent, scaled, or standard score) and an average score. A score of 1 indicated that the child's cognitive ability level was between three and four standard deviations below average; a score of 2 indicated a cognitive ability level between 2 and 3 standard deviations below average; a score of 3 indicated a cognitive skill level between 1 and 2 standard deviations below average; and a score of 4 indicated that the child's cognitive ability level was less than one standard deviation below average.

Vineland Adaptive Behavior Scales - Survey Edition (Sparrow, Balla, & Cicchetti, 1984). The Vineland Adaptive Behavior Scales (VABS) assess "the ability to perform daily activities required for personal and social self-sufficiency" (Sattler, 2002, p. 191). The Survey Form of the Vineland consists of 297 items, and is administered in a 20 to 60
minute, semi-structured interview with parents. An overall standard score (Adaptive Behaviour Composite – ABC) and four domain standard scores (Socialization, Communication, Daily Living Skills and Motor Skills) are calculated. The ABC standard score indicates adaptive level: Low Adaptive Ability (69 and below), Moderately Low Adaptive Ability (70 to 84), Adequate Adaptive Ability (85 to 115), Moderately High Adaptive Ability (116 to 130), and High Adaptive Ability (131 and above).

The Vineland manual indicates strong psychometric properties (Anastasi, 1988; Sparrow et al., 1984). The test-retest reliability for the Survey Form ranges from .80 to .90 (Anastasi, 1988; Sattler, 2002). The split-half reliability is strong for the ABC and each of the domain scores: ABC (from .84 to .98); Communication (from .73 to .93); Daily Living Skills (from .83 to .92); Socialization (from .78 to .94); and Motor Skills (from .70 to .95) (Sattler, 1992). Overall, inter-rater reliability is adequate, with coefficients ranging from .62 to .75 (Sattler, 1992). The Vineland also demonstrates good construct and content validity (Anastasi, 1988; Sparrow et al., 1984). In terms of concurrent validity, the VABS demonstrates moderate correlations with other measures of intelligence and ability (e.g., r = .32 to .37 with K-ABC) (Anastasi, 1988; Sattler, 1992). Both the ABC and the four VABS domain scores were used in the present study. Comparisons were made between and within groups on adaptive skills. Changes in adaptive abilities over time were also calculated.

Parent Interview. During the initial and follow-up assessments parents participated in a non-standardized 30-minute interview developed by the team psychologist (Appendix B). Parents provided demographic information (e.g., sex, age of child), family and medical history, as well the child's treatment and intervention history. Current

concerns about the child's development and behaviour were recorded, as well as details about the child's early development (e.g., age of onset, developmental milestones). In addition, parents were asked whether their child demonstrated specific atypical behaviours prior to age 3. This part of the interview was based on a checklist developed at the Indiana Resource Center for Autism (Appendix C) entitled "Developmental History in the Diagnosis of Autism / PDD." According to the Indiana Resource Center for Autism, the checklist was used during the intake process, to guide the interview with parents. No technical data were available on the psychometric properties of the checklist. For the present sample, the checklist was incorporated into the initial parent interview. Parents were asked to report on the presence or absence of atypical behaviours in the areas of communication skills, sensory abilities, social skills, and play skills. Affirmative answers were scored as 1 and negative responses were scored as 0. The total number of affirmative answers from each of the behavioural domains was calculated, with higher scores (i.e., more affirmative responses) suggesting greater impairment. During the assessment, this part of the interview was used to indicate areas for further discussion with the parents.

There are two versions of the Developmental History questionnaire; a version for "high" functioning children and a version for "low" functioning children. At the time of the assessment the clinician chose which set of questions to ask, based on the child's perceived level of cognitive functioning. The majority of the participants in the present study received the "low" functioning version of the Developmental History questionnaire.

#### Procedure

The present study was reviewed by the Ethics Committee at the University of Windsor and received approval to proceed. Approval to conduct the study was also received from the Ethics Committee at the hospital affiliated with the assessment clinic. Eligible participants were identified through a review of the archival records at the clinic. The principal investigator reviewed the psychology files of 154 children, who were assessed between 1987 and 2001. The files included referral information completed by the parent and intake worker, the psychologist's notes from the parent interview (i.e., information about developmental and behavioural concerns, as well as school related experiences), the social worker's notes and test forms (i.e., CARS, cognitive measures, Vineland Adaptive Behavior Scales).

Wherever possible, steps were taken to ensure the investigator was blind to the diagnosis during the file review. Most files did not include evaluation reports, which helped ensure the investigator was blind to the child's diagnosis while recording file data. When evaluation reports were present, the diagnostic results were not reviewed. Instead, each child was assigned a participant number, which was used when the file data (excluding diagnosis) were recorded. A master list with the names and diagnoses of children was provided by the clinic, which made it possible to record diagnoses and file data separately. The first and second assessment results were typically filed together. Data from the second assessment were recorded separately from the first assessment results and coded under the same participant number. Sixty-seven potential participants were identified, based on the chart review. The remaining 87 files were either single-assessments (n = 79) or were incomplete (n = 8).

Following the chart review, each child's diagnosis was re-calculated using the DSM-IV Checklist for PDD. The principal examiner reviewed the file information available for each child and completed the DSM-IV Checklist. A trained research assistant also independently completed the DSM-IV Checklist for a subset of the participants (n = 30). Diagnostic outcome based on the DSM-IV Checklist was compared to the original diagnosis received through the assessment clinic. Diagnostic outcome based on the DSM-IV Checklist scores was also compared between the principal investigator and the research assistant. Cohen's kappa and percent agreement for the initial diagnosis, followup diagnosis, and diagnostic group membership (i.e., Stable PDD-NOS, Stable Autism, or Change) are reported in Table 3. The agreement between the original clinician and the principal investigator was at an acceptable level (i.e., greater than 80 %) for both of the assessment results, as well as for diagnostic group membership. Inter-rater reliability between the principal investigator and the research assistant was also in the acceptable range for both assessments and for group membership.

The 67 potential participants were grouped based on the stability of diagnosis (see Table 4). Six children demonstrated a relative improvement in functional ability, shifting from an initial diagnosis of autism to a follow-up diagnosis of PDD- NOS (n = 4) or from PDD-NOS to off the PDD spectrum (n = 2). Identifying early characteristics that predicted improvements in functional ability was beyond the scope of the present study, and these six children were excluded from further analyses. These children will be discussed further in the last chapter.

Sixty-one children were in the target groups that demonstrated either a stable or declining functional ability level (i.e., either stable diagnosis of PDD-NOS or autism, or a change from PDD-NOS to autism). However, two participants were excluded from further analyses, due to significant differences in age at the initial assessment. The initial

# Inter-rater Reliability for Diagnostic Outcome Using the DSM-IV Checklist

Comparisons	N	Percentage Agreement	Kappa (SE)
Initial Assessment			
Original Diagnosis and Checklist Diagnosis	67	84.0%	.66*** (.10)
Checklist Diagnosis: PI and RA <sup>1</sup>	30	88.2%	.67** (.21)
Follow-Up Assessment			
Original Diagnosis and Checklist Diagnosis	67	82.3%	.64*** (.10)
Checklist Diagnosis: PI and RA <sup>1</sup>	30	85.3%	.88*** (.12)
Stability of Diagnosis			
Original Diagnosis and Checklist Diagnosis	67	81.0%	.66*** (.08)
Checklist Diagnosis: PI and RA <sup>1</sup>	30	83.3%	.75*** (.10)

 $^{1}$  PI = Principal Investigator and RA = Research Assistant

\*\**p* < .01

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# Diagnosis at Initial and Follow-Up Assessments

Diag	nosis	
Initial Assessment	Follow-Up Assessment	N
PDD-NOS	PDD-NOS	26
PDD-NOS	Autism	15
Autism	Autism	20
Autism	PDD-NOS	4
PDD-NOS	Non- PDD	2

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assessments of these two participants occurred at school age (i.e., at age 9 years and 12 years), whereas the majority of the participants were first assessed at preschool age (i.e., age 4 years). The remaining 59 participants comprised the three comparison groups: the "Stable PDD-NOS" group, who received a diagnosis of PDD-NOS at both the first and follow-up assessments (n = 24). The "Stable Autism" group, who also received the same diagnosis at the initial and follow-up assessments (n = 20). Participants whose diagnosis changed from PDD-NOS to autism comprised the third group, or the "Change" group (n = 15).

#### CHAPTER III

#### RESULTS

Overview

Group differences in early history characteristics (i.e., characteristics that are apparent prior to diagnosis) are presented first, including developmental milestones, atypical behaviours, and the age at which parents first experienced concern about their children's development. Group differences in functional ability level at the initial assessment are summarized next, including chronological age, cognitive ability level, as well as the pattern of PDD symptoms, adaptive ability level, and parent concerns. Group differences in functional ability at the follow-up assessment are then presented. The stability of functional skill level is then summarized for each group; this section indicates which skill areas improved, declined, or remained stable. Finally, the results are summarized by hypothesis.

#### Early Development Characteristics

Parent recognition of problem. Parents of children with PDD typically report behaviour concerns or problems in their children's development within the first 18 months (Vostanis et al., 1998; Young, Brewer, & Pattison, 2003). The parents in this study recalled experiencing concern about their children's development within the first two years (M = 19.95 months, SD = 11.71). Parents of children in the Change and Stable Autism groups were first concerned about their children's development around the time of the first birthday (Stable Autism: M = 13.13 months, SD = 9.60; Change: M = 13.67months, SD = 13.24). In comparison, the parents of children in the Stable PDD-NOS group first experienced concern approximately 4 months later (Stable PDD-NOS: M =

17.18 months, SD = 13.48). An ANOVA indicated that the age difference between the three groups was not statistically significant (p = .26).

Atypical behaviours. Parents' initial concerns about their child's development often include atypical social interaction and delayed communication skills (Bernabei et al., 1998; Vostanis et al., 1994; Vostanis et al., 1998). The initial concerns of parents in this study are summarized by group in Table 5. The Developmental History questionnaire was used to identify parents' initial concerns. All participants in the Change and Stable Autism groups received the "low" functioning version of the questionnaire. However, a single participant from the Change group was missing data and was excluded from these analyses (Change n = 14). Fourteen participants in the Stable PDD-NOS group received the "low" functioning versions, the Stable PDD-NOS participants who received the "high" functioning versions, the Stable PDD-NOS participants who received the "high" functioning version were excluded from the analyses, resulting in a smaller Stable PDD-NOS sample for these analyses (Stable PDD-NOS n = 14).

Due to the relatively small samples, Kruskall-Wallis ANOVA tests were conducted for between-group comparisons. Relatively few parents endorsed early concerns about their child's developing play skills (e.g., intense interest in one object or activity, limited range of interests). The three groups did not differ significantly in this area of early development, H(2) = 3.79, p = .15. Parents of each of the three groups reported concerns about their children's language development (e.g., atypical progression of language skills, unusual speech mannerisms, pointing instead of speaking). However, the number of concerns reported by parents did not differ significantly between the groups, H(2) =0.90, p = .64.

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Initial	Concerns F	rior to A	lge 3 B	lased on	Parent-Report
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	Stable		Stable	
	PDD-NOS	Change	Autism	
	<i>n</i> = 14	<i>n</i> = 14	<i>n</i> = 20	
	М	М	М	
Atypical Behaviour <sup>1</sup>	(SD)	(SD)	(SD)	H (2)
Language	2.09 <sup>a</sup>	2.21 ª	1.95 <sup>a</sup>	0.90
	(0.83)	(0.70)	(0.83)	
Play	1.00 <sup>a</sup>	0.77 <sup>a</sup>	1.15 <sup>a</sup>	3.79
	(0.68)	(0.70)	(0.49)	
Social	1.45ª	1.79 <sup>b</sup>	1.17 °	12.64**
	(0.46)	(0.58)	(0.49)	
Sensory	2.07 <sup>a</sup>	1.69*	2.90 <sup>b</sup>	13.44***
	(0.83)	(0.99)	(0.97)	

<sup>1</sup> Language Total scores range from 0 to 3; Play Total scores range from 0 to 2; Social Total scores range

from 0 to 2; Sensory Total scores range from 0 to 4

<sup>a, b, c</sup> Means with the same superscript are not significantly different

\*\* *p* < .01

The Kruskall-Wallis test on atypical social behaviours (e.g., limited interest in peers, siblings, and group activities) yielded a significant between-group difference, H(2) = 12.64, p < .002. Post hoc comparisons indicated significant differences between all three groups: Stable PDD-NOS and Stable Autism (p = .03), Stable PDD-NOS and Change (p = .04), as well as Stable Autism and Change (p = .001), with the Change group showing the most difficulty, followed by the Stable PDD-NOS and the Stable Autism groups. A significant difference was also found between the three groups in sensory abnormalities (e.g., sensitivity to textures, sounds, visual stimuli, minor changes in their environment) that were apparent in early development, H(2) = 13.44, p = .001. Post hoc comparisons indicated that the Stable Autism group showed more sensory abnormalities than both the Stable PDD-NOS (p = .004) and Change (p = .001) groups. The Stable PDD-NOS and Change groups did not differ significantly in early sensory abnormalities (p = .25).

*Early developmental progression.* The age at which early motor and communication milestones were achieved was compared across the three groups. Means and standard deviations for the three motor milestones are reported in Table 6. In addition, group sizes for each milestone are reported in Table 6, as the number of participants missing data was variable.

Between-group comparisons (i.e., ANOVAs) yielded no significant differences between the groups on their motor milestones (Sitting: p = .92, Crawling: p = .51, Walking: p = .17). Between-group comparisons of communication milestones (i.e., first word and first phrase) are viewed as exploratory, due to the number of participants who were either not speaking at the time of the assessments, or who were missing data (Table 7). For example, approximately 25 percent of each group was missing data for the First

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	Stable	Change	Stable	
	  	  M	  M	
Milestone	(SD)	(SD)	(SD)	$F^1$
Sitting	n = 22	<i>n</i> = 10	n = 15	
	7.36	7.00	7.36	0.08
	(2.15)	(2.60)	(2.01)	
Crawling	<i>n</i> = 18	<i>n</i> = 10	<i>n</i> = 12	
	9.89	8.78	9.73	0.69
	(2.74)	(3.15)	(2.01)	
Walking	<i>n</i> = 23	<i>n</i> = 11	<i>n</i> = 16	
	14.69	12.22	12.82	0.86
	(3.58)	(4.12)	(1.94)	

# Chronological Age (in Months) at Which Motor Milestones Were Achieved

<sup>1</sup> Sitting: F(2, 44), Crawling: F(2, 37), Walking: F(2, 47). The analyses were non-significant.

1 1

	Stable PDD-NOS	Change	Stable Autism	
	M	М	М	
Milestone	(SD)	(SD)	(SD)	$H(2)^1$
First Word	<i>n</i> = 18	n = 10	n = 15	
	18.44	13.60	17.47	0.58
	(11.13)	(4.20)	(10.36)	
Phrase Speech	<i>n</i> = 15	<i>n</i> = 6	<i>n</i> = 6	
	36.33	27.67	32.17	-
	(14.31)	(7.34)	(16.81)	

Chronological Age (in Months) at Which Communication Milestones Were Achieved

<sup>1</sup> The Kruskall-Wallis test was non-significant.

Word milestone. All children in the Stable Autism and Stable PDD-NOS groups were using single words by the time of the first assessment. Of the 11 children in the Change group with data for the First Word variable, 10 were using single words. Due to the relatively small sample sizes, a non-parametric test was used to compare the three groups on the First Word variable. The Kruskall-Wallis analysis of variance indicated that the groups did not differ significantly on the age at which they started using single words, H(2) = 0.58, p = .78.

A considerable number of children from each group were not using phrase speech (i.e., combining words) at the time of the first assessment (Stable PDD-NOS: 5 of 24 or 21%; Change: 6 of 15 or 40%; Stable Autism: 9 of 20 or 45%). Further, data were missing for 20 percent of the Stable PDD-NOS group and more than 40 percent of the other two groups. Given that the majority of participants were either not yet speaking, or were missing data for the Phrase Speech milestone, the three groups were not compared on the age at which the milestone was achieved.

In addition to comparing the age at which developmental milestones were achieved, the three groups were also compared on the degree to which the milestones were delayed (i.e., Status Scores) (Table 8). A value indicating the degree of delay (1 = within normallimits, 2 = mild delay, and 3 = moderate/severe delay) was assigned to each participant's milestones. Individual milestones were rated and an overall estimate of developmental progression (i.e., the Global Development variable) was calculated based on the average rating of the five milestones.

The mean Global Development score for the total sample indicated a mild developmental delay (M = 1.73, SD = 0.55). A Kruskall-Wallis analysis of variance

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# Status Scores of the Five Developmental Milestones

	Stable PDD-NOS	Change	Stable Autism	
		8-		<b>-</b>
	М	М	М	
Milestone Status <sup>1</sup>	(SD)	(SD)	(SD)	$H(2)^2$
Sitting	<i>n</i> = 22	<i>n</i> = 10	<i>n</i> = 15	
	1.27	1.50	1.33	0.22
	(.46)	(.85)	(.62)	
Crawling	<i>n</i> = 18	<i>n</i> = 10	<i>n</i> = 12	
	1.22	1.20	1.08	0.51
	(.55)	(.63)	(.29)	
Walking	<i>n</i> = 23	<i>n</i> = 11	<i>n</i> = 16	
	1.22	1.18	1.06	0.54
	(.60)	(.60)	(.25)	
First Word	<i>n</i> = 21	<i>n</i> = 13	<i>n</i> = 16	
	1.81	1.69	1.75	0.50
	(.98)	(.95)	(1.00)	
Phrase Speech	<i>n</i> = 21	<i>n</i> = 13	<i>n</i> = 16	
	2.52	2.38	2.63	1.03
	(.75)	(.87)	(.81)	

<sup>1</sup> Status scored indicate degree of delay (1 = within normal limits, 2 = mild delay, and 3 = moderate/severedelay)

<sup>2</sup> The Kruskall-Wallis tests were non-significant.

yielded a non-significant result (p = .75) for the Global Development score, indicating that the three groups achieved similar levels of overall developmental progression. All three groups achieved their motor milestones within the expected age ranges (i.e., Status scores less than 1.50). Kruskall-Wallis analysis of variance tests indicated that there were no significant differences between the three groups in the developmental progression of motor milestones (Sitting: p = .89, Crawling: p = .78, Walking: p = .76).

The three groups all demonstrated mild delays in the age at which they starting speaking (i.e., First Word status score greater than 1.5 and less than 2.5). A Kruskall-Wallis analysis of variance indicated that there were no significant differences between the three groups, H(2) = 0.50, p = .78. All three groups also demonstrated mild to moderate delays in the age at which phrase speech emerged (i.e., Phrase Speech Status score greater than 2.0). A Kruskall-Wallis test yielded a non-significant result for the Phrase Speech variable, H(2) = 1.03, p = .60.

#### Functional Ability: Initial Assessment

Chronological age. Typically, children with ASD are first assessed and diagnosed at age 3 (Charman & Baird, 2002; Fombonne, 2002). The average age of this sample at the initial assessment was 3 years, 11 months (M = 47.75, SD = 13.62), and ranged from 2 years, 10 months to 5 years, 1 month. Means and standard deviations for age at initial assessment are summarized in Table 9, by group. Children with a stable diagnosis of PDD-NOS tended to be diagnosed later than children in the other two groups, at the upper end of the age range (i.e., M = 55.92 months, SD = 15.57). A one-way ANOVA, with post hoc Tukey's HSD tests yielded a significant difference between the three

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# Chronological Age (in Months) at the Initial Assessment

	Stable PDD-NOS	Change	Stable Autism	
	<i>n</i> = 24	n = 15	<i>n</i> = 20	F (2, 56)
Chronological Age M	55.92ª	42.53 <sup>b</sup>	41.85 <sup>b</sup>	9.40***
Chronological Age SD	15.57	9.11	8.34	
Chronological Age Range	40.35 - 71.49	33.42 - 57.64	33.51 - 41.85	

<sup>a, b</sup> Different superscripts indicate group differences

\*\*\*\* *p* < .001

groups on age at initial assessment, F(2, 56) = 9.40, p < .001. Post hoc comparisons demonstrated that the Stable PDD-NOS group was older than both the Change group (p = .004) and the Stable Autism group (p = .001). The Change and Stable Autism groups did not differ in age (p = .98).

Correlations were conducted between chronological age and the dependent variables, to determine whether chronological age should be included as a covariate for betweengroup comparisons. There were no significant correlations between the chronological age (first assessment) variable and the dependent variables. Therefore, one-way analyses of variance were conducted and age was not included as a covariate.

Cognitive ability. Approximately three-quarters of children with ASD experience significant cognitive deficits, with IQ scores more than 2 standard deviations below average (i.e., IQ scores < 70) (Lord & Volkmar, 2002; Wolf-Schein, 1996). The mean cognitive ability level for this sample was between 3 and 4 standard deviations below average (M = 1.77, SD = 0.80), which indicated moderate to severe cognitive deficits (refer to Table 10).

The type of measure used to estimate cognitive ability level was selected at the time of the assessment, based on the child's perceived level of functioning. For example, the PEP-R (Schopler et al., 1990) was used with lower functioning children, whereas the WPPSI-R and WISC-III (Wechsler, 1989; Wechsler, 1991) were used with higher functioning children. The cognitive measures were fairly evenly represented across the three groups, with each group including participants who used the Bayley Scales of Infant Development (Bayley, 1969), Leiter International Performance Scale (Leiter, 1948), Psychoeducational Profile - Revised (Schopler et al., 1990), Wechsler Preschool and

#### Cognitive Ability Level at the Initial Assessment

	Stable PDD-NOS	Change	Stable Autism	
	<i>n</i> = 24	<i>n</i> = 15	<i>n</i> = 20	H (2)
Cognitive Ability Level <sup>1</sup> M	2.17 <sup>a</sup>	1.36 <sup>b</sup>	1.60 <sup>b</sup>	9.49***
Cognitive Ability Level SD	0.89	0.50	0.68	
Cognitive Ability Level Range	1.28 - 3.06	0.86 - 1.86	0.92 - 2.28	

<sup>1</sup> Each child's cognitive ability level was assigned a value between 1 and 4, where 1 = cognitive ability more than 3 standard deviations below average, 2 = cognitive ability between 2 and 3 standard deviations below average, 3 = cognitive ability between 1 and 2 standard deviations below average, and 4 = cognitive ability less than or equal to 1 standard deviation below average.

<sup>a, b</sup> Different superscripts indicate group differences

\*\*\*\* *p* < .001

Primary Scale of Intelligence-Revised (Wechsler, 1989), and Wechsler Intelligence Scale for Children-Third Edition (Wechsler, 1991).

Cognitive ability level was coded as an ordinal variable, and therefore group comparisons were conducted with a Kruskall-Wallis ANOVA test. At the first assessment, the three groups differed significantly in degree of cognitive impairment, H(2) = 9.49, p<.009. Post hoc Kruskall-Wallis tests indicated that the Stable PDD-NOS group had higher cognitive ability estimates than both the Change group, H(1) = 7.86, p= .005, and the Stable Autism group, H(1) 4.77, p = .03. The cognitive ability levels of the Stable Autism and Change groups were not significantly different (p = .32). Correlations between the cognitive ability level variable and the dependent variables did not yield any significant associations. Therefore, cognitive functioning was not included as a covariate in any of the analyses for the initial assessment.

Parent concerns at the time of the first assessment. At the initial assessment, parents indicated whether they experienced concern about their child's development in each of the following areas: atypical behaviours, emotional responsiveness, language development, social interaction, academic skills, and future development. Each variable was dichotomous and endorsed as 1 = present and 2 = absent. Pearson Chi-Square analyses were conducted between groups for each area of concern.

The three groups differed significantly on parent concerns about atypical behaviour,  $X^2(2) = 12.70$ , p = .002. Parents of children with Stable PDD-NOS tended to identify atypical behaviours as a concern (71% present) at the initial assessment. Parents of children in the Change group tended to report that atypical behaviours were not a concern

at the first assessment (13% present). Atypical behaviours were identified by approximately half of the parents of children in the Stable Autism group (40% present).

There was a significant relationship between diagnostic group and whether parents endorsed concerns about their children's emotional responsiveness,  $X^2(2) = 10.35$ , p =.006. Parents of children in both the Stable PDD-NOS and Change groups tended to identify emotional responsiveness as an area of concern (Stable PDD-NOS: 63% present; Change: 67% present). In comparison, parents of children with Stable Autism tended to report that emotional responsiveness was not an area of concern (20% present).

The three groups did not differ on parent-reported concerns about social interaction skills  $X^2(2) = 0.02$ , p = .99. For all three groups, parents tended to identify social interaction as an area of concern (Stable PDD-NOS: present = 67%, Change: present = 67%, Stable Autism: present = 65%).

The chi-square scores for language development, academic skills, and future development were not interpreted, because cell sizes were less than five. The three groups showed similar patterns of responses for academic skills and future development, with the majority of parents indicating that these were not areas of concern at the time of the first assessment. The three groups showed similar patterns of parent concerns regarding language development, with the majority of parents indicating that the majority of parent concerns 73%, Stable Autism: present 80%).

PDD Symptoms. PDD symptom presentation was compared across the three groups using both the CARS Total score and the DSM-IV Checklist total severity score. CARS Total score means are presented in Table 11. At the time of the first assessment, all three

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#### Mean and Range of CARS Total Scores at the Initial Assessment

	Stable PDD-NOS Change		Stable Autism		
	<i>n</i> = 24	<i>n</i> = 15	<i>n</i> = 20	F (2, 56)	
CARS Total <sup>1</sup> M	30.62ª	31.12ª	37.08 <sup>b</sup>	30.97****	
CARS Total SD	3.18	1.97	3.11		
CARS Total Range	27.44 - 33.80	29.15 - 33.09	33.97 - 40.19		

<sup>1</sup>CARS Total cut-off score for a diagnosis of autism = 30; higher scores indicate greater impairment

<sup>a, b</sup>Different superscripts indicate group differences

\*\*\*\**p* < .0001

groups met or exceeded the CARS threshold for mild autism (i.e., CARS Total  $\geq$  30 points). The Stable PDD-NOS and Change groups demonstrated a mild degree of impairment, relative to the moderate degree of impairment experienced by the Stable Autism group. A one-way ANOVA yielded a significant difference between the three groups on the CARS Total score, F(2, 56) = 30.98, p < .0001. Post hoc tests (Tukey HSD) demonstrated that the Stable Autism group was significantly more impaired than either the Stable PDD-NOS group (p < .0001), or the Change group (p < .0001). The CARS Total scores of the Stable PDD-NOS and Change groups were not significantly different at the initial assessment (p = .86).

Selected CARS subscale scores were compared across groups, to determine whether the overall pattern of relative impairment (i.e., Stable Autism showing greater impairment than either the Stable PDD-NOS group or the Change group) was also apparent in specific skill areas. The subscale scores that reflected social impairment, communication impairments, as well as repetitive interests and stereotyped behaviours were examined using Kruskall-Wallis analyses (Table 12). The three groups demonstrated significant differences across each of the analyzed subscales. Post hoc comparisons were also conducted using Kruskall-Wallis analyses. Only the results with alpha levels of .01 or less were considered significant, due to the number of repeated analyses.

The Stable PDD-NOS and Change groups demonstrated similar levels of impairment in each of the examined repetitive/stereotyped behaviours, including Body Use (p = .24), Object Use (p = .24), and Taste/Smell/Touch (p = .37). The two groups also showed similar levels of impairment on the Visual Response (p = .06), Relating to People (p = .22), and Verbal (p = .19) subscales. The Change group was significantly less impaired

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	Stable PDD-NOS $n = 24$	Change $n = 15$	Stable Autism $n = 20$	
CARS Subscale	M (SD)	M (SD)	M (SD)	H (2)
Social Interaction Subsc	ales <sup>1</sup>		₩ 2.231, 9.3400, 0.111, 4.211, 5.977, 4.207, 4.207, 9.277, 4.207, 9.277, 4.207, 9.277, 4.207, 9.277, 4.207, 9.2	
Adaptation to Chang	ge 2.30 <sup>ª</sup> (.46)	1.81 <sup>b</sup> (.53)	2.78°(.51)	22.85****
Visual Response	1.98 <sup>a</sup> (.38)	2.06 <sup>a</sup> (.43)	2.41 <sup>b</sup> (.36)	15.39****
Emotional Response	e 2.16 <sup>a</sup> (.25)	1.97 <sup>b</sup> (.38)	2.32 <sup>a</sup> (.41)	14.49***
Relating to People	1.99 <sup> в, с</sup> (.36)	1.92 ° (.19)	2.48 <sup>b, c</sup> (.31)	27.37****
Communication Subscal	es <sup>1</sup>			
Verbal	2.68 <sup>a</sup> (.35)	2.78 <sup>a</sup> (.34)	3.05 <sup>b</sup> (.20)	20.43****
Non-Verbal	1.95 <sup>a</sup> (.36)	2.19 <sup>b</sup> (.28)	2.42 <sup>b</sup> (.27)	22.36****
Imitation	1.90 <sup>a</sup> (.66)	2.44 <sup>b</sup> (.48)	2.79 <sup>b</sup> (.60)	18.19****
Repetitive & Stereotyped	1 Subscales <sup>1</sup>			
Body Use	1.92 *(.32)	1.99 <sup>ª</sup> (.44)	2.32 <sup>b</sup> (.36)	16.34****
Object Use	2.25 <sup>a</sup> (.43)	2.16 <sup>a</sup> (.28)	2.75 <sup>b</sup> (.35)	20.32****
Taste/Smell/Touch	1.82 <sup>a</sup> (.41)	1.86 ª (.35)	2.03 <sup>a</sup> (.55)	7.13 <sup>*</sup>

Mean CARS Subscale Scores at the Initial Assessment:

<sup>1</sup>CARS Subscale scores range from 1 to 4, with higher scores indicating greater impairment.

 $^{\rm a,\,b,\,c}$  Means with the same superscript are not significantly different.

•*p* < .05

\*\*\**p* < .001

\*\*\*\**p* < .0001

than the Stable PDD-NOS group on two of the social interaction subscales (Adaptation to Change p = .005 and Emotional Response p = .001), and significantly more impaired than the Stable PDD-NOS group on two of the communication subscales (Imitation p = .008 and Non-Verbal p = .001).

The Change group was significantly less impaired than the Stable Autism group on the majority of the CARS subscales. The Change group showed less impairment on all four of the social interaction subscales: Adaptation to Change (p = .0001), Visual Response (p = .01), Emotional Response (p = .003), and Relating to People (p = .003). The Change group was less impaired than the Stable Autism group on the Body Use and Object Use subscales (p = .01 for both), as well as the Verbal subscale (p = .001). The two groups demonstrated similar levels of impairment on several of the subscales, including Imitation (p = .02), Non-Verbal (p = .03), and Taste/Smell/Touch (p = .05).

The Stable PDD-NOS group was significantly less impaired than the Stable Autism group on all but three of the selected CARS subscales (refer to Table 12). The two groups showed similar levels of impairment on the Emotional Response (p = .05), Relating to People (p = .05), and Taste/Smell/Touch (p = .02) subscales.

The mean severity scores based on the DSM-IV Checklist are presented in Table 13. The DSM-IV Checklist Total score, or degree of impairment, was compared between the three groups with a Kruskall-Wallis analysis of variance. The analysis yielded a significant difference between the three groups, H(2) = 39.03, p < .0001. Post hoc comparisons yielded significant differences between the Stable PDD-NOS and Stable Autism groups (p = .0001), as well as between the Change and Stable Autism groups (p = .0001). The Change and Stable PDD-NOS groups were not significantly different (p = .0001).

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Mean Severity Scores Based on the DSM-IV Checklist at the Initial Assessment

	Stable PDD-NOS $n = 24$	Change $n = 15$	Stable Autism $n = 20$	
DSM-IV Domains	M (SD)	M (SD)	M (SD)	H(2)
Total <sup>1, 2</sup>	1.10 <sup>a</sup> (0.22)	1.11 <sup>a</sup> (0.12)	1.84 <sup>b</sup> (0.16)	39.03***
Social Impairment <sup>1</sup>	1.01 <sup>a</sup> (0.20)	1.06 <sup>a</sup> (0.17)	1.79 <sup>b</sup> (0.12)	39.33****
Communication Impairment <sup>1</sup>	1.22 <sup>a</sup> (0.33)	1.29 <sup>a</sup> (0.23)	1.91 <sup>b</sup> (0.28)	32.17****
Repetitive/Stereotyped Behaviours	s <sup>i</sup> 0.80 <sup>a</sup> (0.37)	0.98 <sup>a</sup> (0.26)	1.82 <sup>b</sup> (0.32)	35.12****

<sup>1</sup> Scores range from 0 to 4, with low scores indicating mild PDD-related impairment and high scores indicating moderate to severe impairment.

<sup>2</sup> Total Score is the average of the three DSM-IV domain scores

<sup>a, b</sup> different superscripts indicate significant group differences

\*\*\*\*\**p* < .0001

.99). The pattern of impairment demonstrated by the DSM-IV Checklist is similar to that seen in the CARS Total scores. That is, the Stable Autism group demonstrated greater impairment on both the CARS Total and DSM-IV Checklist Total scores, than either the Change or the Stable PDD-NOS groups. The Change and Stable PDD-NOS groups showed relatively similar initial Total scores on both measures.

The DSM-IV Checklist domain scores (i.e., Social Impairment, Communication Impairment, and Stereotyped/Repetitive Behaviours) were compared across the three groups. Each of the three domain scores yielded the same pattern of relative impairment seen in the DSM-IV Checklist Total score (i.e., Stable PDD-NOS and Change groups were less impaired than the Stable Autism group). Significant differences existed between the three groups on Social Impairment, H(2) = 39.33, p<.0001, Communication Impairment H(2) = 32.17, p<.0001, and Repetitive/Stereotyped Behaviours, H(2) =35.12, p<.0001. Kruskall-Wallis post hoc comparisons yielded the same pattern in each of the three domains. Both the Stable PDD-NOS and Change groups exhibited significantly less impairment than the Stable Autism group (refer to Table 14), and the Stable PDD-NOS and Change groups were not significantly different (Social: p = .48, Communication: p = .55, Stereotyped/Repetitive: p = .21).

Adaptive skills. Adaptive ability scores were unavailable for three participants at the time of the first assessment: two from the Stable PDD-NOS group (n = 22 participants), and one from the Stable Autism group (n = 19). The Change group was not missing any adaptive ability scores (n = 15). The two participants with missing scores were excluded from the adaptive skills analyses. Mean standard scores and standard deviations for the

Adaptive Behavior Composite (ABC), Socialization domain, Communication domain, and Daily Living Skills domain (DLS) are presented in Table 14.

Each of the three groups exhibited an adaptive skill level in the impaired range (i.e., ABC < 69). However, the groups differed significantly in degree of overall impairment, F (2, 53) = 8.52, p < .001. Tukey HSD post hoc comparisons indicated that the Stable Autism group demonstrated a significantly lower adaptive ability score than the Change group (p = .0001), indicating a greater degree of impairment. The overall adaptive skill level of the Stable PDD-NOS group did not differ significantly from either the Change (p = .10) or the Stable Autism (p = .07) groups.

The three groups differed on the three adaptive domain scores. A one-way ANOVA yielded a significant group difference in Socialization skills, F(2, 52) = 9.20, p < .0001. Post hoc comparisons (Tukey HSD) indicated that children in the Stable PDD-NOS group had significantly higher social skills than both the Change group (p < .004) and the Stable Autism group (p < .001). The Change group and Stable Autism group demonstrated similar levels of impairment in the socialization domain (p = .97).

One-way ANOVAs also yielded significant group differences for the Communication domain, F(2, 53) = 3.76, p < .03) and the Daily Living Skills domain, F(2, 53) = 3.41, p < .04). For both the Communication and Daily Living Skills domains, the Change group demonstrated significantly higher scores than the Stable Autism group (p < .02 and p < .03, respectively). The Change group did not differ significantly from the Stable PDD-NOS group in either the Communication (p = .18) or the Daily Living Skills (p = .16) domains. The differences between the Stable PDD-NOS and Stable Autism groups were also non-significant for the Communication domain (p = .54) and the Daily

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	Stable		Stable	
	PDD-NOS	Change	Autism	
_	<i>n</i> = 22	<i>n</i> = 15	<i>n</i> = 19	
Adaptive	М	М	М	
Domains	(SD)	(SD)	(SD)	F (2, 53)
ABC <sup>1</sup>	54.73 <sup>ª, b</sup>	58.33 ª	51.05 <sup>b</sup>	8.52***
	(4.83)	(6.24)	(4.44)	
Socialization	58.86 *	55.00 <sup>b</sup>	54.89 <sup>b</sup>	9.20****
	(3.30)	(2.07)	(4.20)	
Communication	55.90 <sup>a, b</sup>	58.87ª	54.26 <sup>b</sup>	3.76*
	(4.09)	(5.04)	(5.73)	
Daily Living Skill	s 56.05 <sup>a, b</sup>	58.93 ª	54.79 <sup> b</sup>	3.41*
	(4.59)	(4.53)	(4.97)	

Adaptive Ability Scores (Vineland Adaptive Behavior Scale) at the Initial Assessment

<sup>1</sup> ABC = Adaptive Behavior Composite score

<sup>a, b</sup>Means with the same superscript are not significantly different

\**p* < .05

\*\*\* *p* < .001

\*\*\*\* *p* < .0001

Living Skills domain (p = .67).

Supports and services. Limited data were available on the nature of the supports and services received by the children in this study. File information indicated whether the children received the following services: behaviour interventions, one-to-one assistance at school, respite care, occupational or physical therapy, financial support, and speech therapy. However, details about the intensity of intervention, as well as the quality and goals of treatment were not available. In addition, the majority of participants were missing data for one or all of the Supports and Services variables at both the initial and follow-up assessments. As a result, the Supports and Services variables were not analyzed further.

#### Functional Ability: Follow-Up Assessment

*Chronological age.* Means and standard deviations for chronological age at followup and the length of time between assessments are presented in Table 15. The average length of time between the first and second assessments was 2 years, 2 months (M =26.00 months, SD = 12.43). A one-way ANOVA indicated that the three groups did not differ significantly in the length of time between assessments, F(2, 56) = 2.20, p =.12. The mean age at re-assessment was 6 years, 1 month (M = 73.80, SD = 18.08), with a range between 4 years, 7 months and 7 years, 8 months. A one-way ANOVA, with post hoc Tukey's HSD tests yielded a significant difference between the three groups, F(2, 56) = 5.02, p <.01. Post hoc tests demonstrated that the Stable PDD-NOS group was older than the Change group (p = .008), but not the Stable Autism group (p = .16) at follow-up. The Change and Stable Autism groups did not differ in age at follow-up (p = .37).

Because of the significant difference between groups, correlations were conducted

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Chronological Age (in months) at the Follow-Up Assessment and the Mean Length of Time Between Assessments

	Stable PDD-NOS	Change	Stable Autism	
	<i>n</i> = 24	<i>n</i> = 15	<i>n</i> = 20	F(2, 56)
Chronological Age M	81.42 <sup>a</sup>	64.07 <sup>b</sup>	71.95 <sup>a, b</sup>	5.02***
Chronological Age SD	18.91	16.05	14.95	
Chronological Age Range	62.51 - 100.33	<b>48.02 - 80</b> .12	57.00 - 86.90	
Months between Assessments $M$	25.42ª	21.47 <sup>ª</sup>	30.10 <sup>ª</sup>	2.20
Months between Assessments SD	12.05	9.90	13.78	
Months between Assessments Range	13.37 - 50.84	11.57 - 31.37	16.32 - 43.88	

<sup>a, b</sup> different superscript values indicate significant differences between groups

\*\*\*\* *p* < .001

\*\*\*\* *p* < .0001

between chronological age and the dependent variables to determine whether

chronological age should be included as a covariate for between-group comparisons. Significant correlations were found between chronological age and each of the following scores: CARS Total (r = -0.33, p < .01), Vineland Adaptive Behaviour Composite (r = -0.44, p < .01), and each of the three Vineland domain scores (Socialization: r = -0.36, p < .01, Communication: r = -0.45, p < .01, and Daily Living Skills: r = -0.36, p < .01). Therefore, chronological age was included as a covariate for each analysis.

*Cognitive ability.* Similar to the initial assessment results, the cognitive measures were fairly evenly represented across the three groups, with each group including participants who used the Bayley Scales of Infant Development (Bayley, 1969), Leiter International Performance Scale (Leiter, 1948), Psychoeducational Profile - Revised (Schopler et al., 1990), Wechsler Preschool and Primary Scale of Intelligence-Revised (Wechsler, 1989), and Wechsler Intelligence Scale for Children-Third Edition (Wechsler, 1991).

The sample continued to demonstrate cognitive impairments at follow-up, with a mean cognitive ability level 3 to 4 standard deviations below average (M=1.70, SD = 0.80). Means and standard deviations are presented in Table 16. A Kruskall-Wallis test yielded a significant difference between groups on cognitive level, H(2) = 20.26, p<.0001. Similar to the results at the first assessment, the Stable PDD-NOS group demonstrated a significantly higher cognitive ability level relative to both of the other two groups (Change: H(1) 12.92, p = .0001; Autism: H(1) 13.73, p = .001). The Stable Autism and Change groups did not differ significantly in their level of cognitive ability at follow-up (p = .76). Correlations between the cognitive ability level variable and the

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#### Cognitive Ability Level at the Follow-Up Assessment

	Stable PDD-NOS	Change	Stable Autism	
	<i>n</i> = 24	<i>n</i> = 15	<i>n</i> = 20	H (2)
Cognitive Ability Level <sup>1</sup> M	2.35 *	1.21 <sup>b</sup>	1.30 <sup>b</sup>	20.26****
Cognitive Ability Level SD	0.93	0.43	0.57	
Cognitive Ability Level Range	1.42 - 3.28	0.78 - 1.64	0.73 - 1.87	

<sup>1</sup> Each child's cognitive ability level was assigned a value between 1 and 4, where 1 = cognitive abilitymore than 3 standard deviations below average, 2 = cognitive ability between 2 and 3 standard deviations below average, 3 = cognitive ability between 1 and 2 standard deviations below average, and 4 = cognitiveability less than or equal to 1 standard deviation below average.

<sup>a, b</sup> different superscript values indicate significant differences between groups

\*\*\*\* *p* < .001

\*\*\*\*\* *p* < .0001

dependent variables yielded several significant associations. However, further examination of the cognitive functioning variable indicated that it violated the majority of the assumptions necessary to conduct an analysis of covariance. Therefore, the cognitive functioning variable was not included as a possible covariate. Implications for the results are reviewed in the Discussion section.

Parent concerns at the time of the assessment. Pearson chi-square analyses were conducted to compare parent-reported concerns across the three groups. Parents indicated whether they were concerned about the following areas of development: atypical behaviour, emotional responsiveness, language development, social interaction, academic skills, and future development.

The three groups did not differ significantly in any of the assessed areas of parent concern (p values > .09). The three groups did not differ on parent concerns about atypical behaviour,  $X^2(2) = 4.72$ , p = .10. The parents of children in both the Stable PDD-NOS and Stable Autism groups tended to report concerns about atypical behaviours (present > 58%, absent < 42%), whereas parents of the Change group were less likely to report concerns in this area (present 27%, absent 73%).

The three groups did not differ on concerns about emotional responsiveness,  $X^2(2) = 4.83$ , p = .09. Parents of the Stable PDD-NOS group tended to report concerns in this area more frequently than not (present = 63%), and the Change group parents were less likely to identify this as an area of concern (present = 27%). Parents of children in the Stable Autism group were fairly evenly divided (present = 45%).

Academic skills were infrequently identified as an area of concern for parents of all three groups, and there were no group differences,  $X^2(2) = 0.69$ , p = .71. Given that the majority of the participants were starting Kindergarten at the time of the assessment, it is not surprising that few parents endorsed academic performance as an area of concern.

The three groups did not differ in terms of parental concern about language development,  $X^2(2) = 3.46$ , p = .18. Early language skills were an area of concern for the majority of parents of the Stable PDD-NOS (present = 67%) and Change (present = 80%) groups. Half of the parents of the Stable Autism group reported concern about language development (present = 50%).

There were no group differences in concern regarding social interaction,  $X^2(2) = 0.74$ , p = .69. Social interaction was not a major concern for parents of both the Stable PDD-NOS (present = 38%) and Change groups (present = 40%). Half of the parents of the Stable Autism group reported concerns about social interaction (present = 50%).

A Chi-square was not conducted for the Future Development variable, because cell sizes were too small (< 5). However, the pattern of parent responses was similar across the three groups regarding their child's future development; for the most part, parents did not report concerns about their child's (present < 21%, absent > 60%) at the time of the follow-up assessment.

*PDD Symptoms.* Both the CARS Total score and the DSM-IV Checklist Total scores were compared across groups at follow-up. The means and standard deviations for the CARS Total score are presented in Table 17. At the second assessment, the CARS Total score for the Stable PDD-NOS group fell below the threshold for mild autism (i.e., CARS Total < 30), whereas both the Change and Stable Autism groups were at the upper end of the mild to moderate range for autism. Chronological age at the follow-up was significantly correlated with the CARS Total score at follow-up, and therefore it was

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	Stable PDD-NOS $n = 24$	Change $n = 15$	Stable Autism $n = 20$	F (2, 56)
CARS Total 1,2 M	27.91 <sup>ª</sup>	35.9 <b>8</b> <sup>b</sup>	36.11 <sup>b</sup>	38.30****
CARS Total 1,2 SD	2.55	2.59	4.12	
CARS Total Range	25.36 - 30.46	33.39 - 38.57	31.99 - 40.23	

Mean and Range of CARS Total Scores at the Follow-up Assessment

<sup>1</sup> CARS Total cut-off score for autism = 30, with higher scores indicating greater impairment

<sup>a, b</sup> Means with the same superscript were not significantly different.

\*\*\*\* *p* < .0001
included as a covariate and an ANCOVA was conducted.

A one-way analysis of covariance (ANCOVA) yielded a significant difference between the groups on CARS Total when the means were adjusted using chronological age as a covariate, F(2, 55) = 38.30, p < .0001. Chronological age did not have a significant impact on the CARS Total score, F(1, 58) = 0.58, p = .45, and the Eta Squared score indicated that a low 1.0 percent of the variance in the CARS Total score could be predicted from chronological age. Post hoc tests with Bonferroni correction were based on the adjusted means, and indicated that the Stable PDD-NOS group demonstrated a significantly lower CARS Total score than either the Stable Autism (p =.0001) or Change (p = .0001) groups. The Stable Autism and Change group CARS Total scores were not significantly different (p = 1.00).

Exploratory comparisons of selected CARS subscale scores were conducted with Kruskall-Wallis analyses. The three groups differed significantly in each of the selected subscales (refer to Table 18). Post hoc comparisons were also conducted using Kruskall-Wallis analyses. Only the results with alpha levels of .01 or less were considered significant, due to the number of repeated analyses. The Change group showed significantly greater impairment than the Stable PDD-NOS group in each of the social interaction (Adaptation to Change p = .0001, Visual Response p = .0001, Emotional Response p = .002, and Relating to People p = .0001) communication skills (Imitation p = .0001, Verbal p = .0001, and Non-Verbal p = .0001) subscales. The Change group also showed greater impairment than the Stable PDD-NOS group in two of the three repetitive/stereotyped behaviours subscales (Body Use p = .0001 and Object Use p = .0001). The two groups showed minimal differences on the Taste/Touch/Smell subscale

## Table 18

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5	Stable PDD-NOS	Change	Stable Autism	
	<i>n</i> = 24	<i>n</i> = 15	<i>n</i> =20	
CARS Subscale <sup>1</sup>	M (SD)	M (SD)	M (SD)	H (2)
Social Interaction Subsc	ales			
Adaptation to Chang	ge 1.85 <sup>*</sup> (.35)	2.59 <sup>b</sup> (.49)	2.49 <sup>b</sup> (.53)	24.33****
Visual Response	1.89 <sup>ª</sup> (.42)	2.54 <sup>b</sup> (.38)	2.51 <sup>b</sup> (.39)	22.94****
Emotional Response	1.88° (.39)	2.34 <sup>b</sup> (.49)	2.46 <sup>b</sup> (.45)	17.45****
Relating to People	1.83 * (.33)	2.36 <sup>b</sup> (.31)	2.37 <sup>b</sup> (.42)	24.18****
Communication Subscal	es			
Verbal	2.42 <sup>a</sup> (.47)	3.07 <sup>b</sup> (.28)	3.14 <sup>b</sup> (.35)	25.09****
Non-Verbal	1.65*(.31)	2.27 <sup>b</sup> (.36)	2.24 <sup>b</sup> (.31)	27.15****
Imitation	1.31*(.41)	2.36 <sup>b</sup> (.67)	2.57 <sup>b</sup> (.73)	29.92****
Repetitive & Stereotyped	I Subscales			
Body Use	1.90 <sup>a</sup> (.47)	2.77 <sup>b</sup> (.47)	2.40°(.49)	22.83****
Object Use	1.93 <sup>a</sup> (.43)	2.53 <sup>b</sup> (.31)	2.53 <sup>b</sup> (.57)	19.33****
Taste/Smell/Touch	1.61 <sup>a</sup> (.44)	1.87 <sup>a, b</sup> (.36)	1.92 <sup>b</sup> (.45)	7.93*

Mean CARS Subscale Scores at the Follow-Up Assessment

<sup>1</sup> CARS Subscale scores range from 1 to 4, with higher scores indicating greater impairment <sup>a, b, c</sup> Means with the same superscript were not significantly different.

\**p* < .05

\*\*\*\*\* *p* < .0001

(p = .03).

The Change and Stable Autism groups demonstrated a similar level of impairment on each of the social impairment (Adaptation to Change p = .47, Visual Response p = .84, Emotional Response p = .48, and Relating to People p = .62) and communication skill (Imitation p = .38, Verbal p = .20, and Non-Verbal p = .74) subscales, as well as two of the three stereotyped / repetitive behaviour subscales (Object Use p = .60 and Taste/Touch/Smell p = .96). On the third stereotyped/repetitive behaviour subscale (Body Use), the Change group was significantly more impaired than the Stable Autism group (p = .01).

The Stable Autism group was significantly more impaired than the Stable PDD-NOS group on all of the selected CARS subscale scores. The Stable Autism group demonstrated significantly higher scores on each of the social impairment subscales (Adaptation to Change p = .0001, Visual Response p = .0001, Emotional Response p = .0001, and Relating to People p = .0001), communication subscales (Imitation p = .0001, Verbal p = .0001, and Non-Verbal p = .0001), and repetitive/stereotyped behaviour subscales (Body Use p = .002, Object Use p = .0001 and Taste/Touch/Smell p = .01).

For the most part, the patterns of impairment seen in the CARS subscale scores are similar to the pattern seen in the CARS Total score (i.e., Change and Stable Autism groups more impaired than the Stable PDD-NOS group). In comparison to the first assessment results, the follow-up assessment results indicate an increase in impairment for the Change group, and relative stability for both the Stable PDD-NOS and Stable Autism groups. The mean severity scores based on the DSM-IV Checklist are presented in Table 19. The pattern of impairment demonstrated by the DSM-IV Checklist at follow-up is similar to that seen in the CARS Total scores at follow-up: the Stable PDD-NOS group demonstrated less impairment on both the CARS Total and DSM-IV Checklist Total scores, than either the Change or the Stable Autism groups. The Change and Stable Autism groups showed relatively similar initial Total scores on both measures. A Kruskall-Wallis analysis yielded a significant group difference on the DSM-IV Checklist total score, H(2) = 42.87, p < .0001. Post hoc comparisons yielded significant differences between the Stable PDD-NOS and Stable Autism groups (p = .0001), as well as the Stable PDD-NOS and Change groups (p = .0001). The Change and Stable Autism groups were not significantly different (p = .12).

The DSM-IV Checklist domain scores (i.e., Social Impairment, Communication Impairment, and Stereotyped/Repetitive Behaviours) were compared across the three groups using Kruskall-Wallis analyses. Significant differences existed between the three groups on each of the domain scores: Social Impairment, H(2) = 42.32, p < .0001, Communication Impairment, H(2) = 39.23, p < .0001, and Repetitive/Stereotyped Behaviours, H(2) = 40.87, p < .0001. Post hoc comparisons yielded the same pattern for the Social and Repetitive/Stereotyped domains; the Stable PDD-NOS group was significantly less impaired than either the Stable Autism or Change groups and the level of impairment seen in the Stable Autism and Change groups did not differ significantly (Social: p = .12, Repetitive/Stereotyped: p = .32). Post hoc comparisons of the Communication domain yielded significant differences between all three of the subgroups (refer to Table 19).

### Table 19

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Mean Severity Scores	Based on t	he DSM-IV	Checklist at the	he Foll	ow-Up A	Assessment
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	StablePDD-NOSChange $n = 24$ $n = 15$		Stable Autism n = 20	
-	М	М	М	
DSM-IV Domains	(SD)	(SD)	(SD)	H (2)
Total <sup>1, 2</sup>	1.02ª	1.74 <sup>b</sup>	1.84 <sup>b</sup>	42.87****
Domain Scores	(0.23)	(0.11)	(0.18)	
Social Impairment	0.99 ª	1.63 <sup>b</sup>	1.76 <sup>b</sup>	<b>4</b> 2.32 <sup>****</sup>
	(0.19)	(0.19)	(0.22)	
Communication Impairment	1.11 <sup>a</sup>	1.79 <sup>b</sup>	2.03°	39.23****
	(0.38)	(0.21)	(0.25)	
Repetitive/Stereotyped Behaviours	0.96 ª	1. <b>7</b> 9 <sup>b</sup>	1.74 <sup>b</sup>	40.87****
	(0.28)	(0.12)	(0.31)	

<sup>1</sup> Scores range from 0 to 4: Low scores indicate mild PDD-related impairment and high scores indicate

moderate to severe impairment

<sup>2</sup> Total = average of three DSM-IV domain scores

<sup>a, b, c</sup> Means with the same superscript are not significantly different.

\*\*\*\*\**p* < .0001

Adaptive skills. Two participants were missing data for the Vineland Communication domain score (1 from Stable PDD-NOS and 1 from Change). The Change group was also missing data for one participant for both the Socialization domain and the Daily Living Skills Domain. The participants with missing scores were excluded from the adaptive skills analyses. Chronological age at follow-up assessment was significantly correlated with the overall adaptive ability level (ABC) and with each of the three adaptive domain scores. ANCOVAs were conducted for between group comparisons, with chronological age as a covariate. Mean adjusted scores, and ANCOVA results for the Adaptive Behavior Composite (ABC), Socialization domain, Communication domain, and Daily Living Skills domain (DLS) are presented in Table 20 for each group.

The Adaptive Behaviour Composite (ABC) score was in the impaired range (i.e., ABC < 69) for each group. A one-way ANCOVA yielded a significant difference between the three groups when the ABC means were adjusted using chronological age as a covariate, F(2, 55) = 20.18, p < .0001. The covariate, chronological age, had a significant impact on the ABC score, F(1, 58) = 40.69, p < .0001, and the Eta Squared score indicated that 43 percent of the variance in the ABC total score could be predicted from chronological age. Post-hoc comparisons, with Bonferroni correction, were calculated using the adjusted means. The Stable PDD-NOS group demonstrated a significantly higher overall adaptive ability level relative to the Stable Autism (p = .0001) and Change (p = .0001) groups. The adaptive ability level did not differ significantly for the Stable Autism and Change groups (p = 1.00).

One participant from the Change group was missing data for the Socialization Domain score (n = 14). The three groups differed significantly on the Socialization

## Table 20

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Adaptive Ability Scores (Vineland Adaptive Behavior Scales) at the Follow-Up Assessment

	Stable PDD-NOS	Change	Stable Autism	
- Adaptive Domains	M (SD)	M (SD)	M (SD)	F
ABC <sup>1, 2</sup>	55.91ª	47.80 <sup>b</sup>	43.30 <sup>b</sup>	20.18****
Socialization <sup>3</sup>	(13.83) 60.46 <sup>a</sup>	(7.90) 54.14 <sup>b</sup>	(11.23) 49.90 <sup>b</sup>	26.92****
Communication <sup>4</sup>	(10.16) 62.43 <sup>a</sup>	(6.05) 50.17 <sup>b</sup>	(4.89) 49.85 <sup>b</sup>	13.53****
Daily Living Skills	(16.80) <sup>5</sup> 55.83 <sup>a</sup>	(8.61) 52.36 <sup>b</sup>	(17.09) 41.80 <sup>b</sup>	11.29****
	(13.80)	(10.56)	(16.09)	

<sup>1</sup>ABC = Adaptive Behavior Composite

 $^{2}F(2,55)$ 

 ${}^{3}F(2, 54)$ : missing data for 1 Change participant

<sup>4</sup> F (2, 53): missing data for 1 Stable PDD-NOS participant and 1 Change participant

 $^{5}F(2, 54)$ : missing data for 1 Change participant

<sup>a, b</sup> Means with the same superscript are not significantly different.

\*\*\*\* *p* = .0001

domain score, when means were adjusted for difference in chronological age, F (2, 54) = 26.92, p < .0001. Chronological age had a significant impact on the Socialization domain score, F (1, 57) = 36.06, p < .0001, and the Eta Squared score indicated that approximately 40 percent of the variance in the Socialization domain score could be predicted from chronological age. Post hoc comparisons with Bonferroni correction, using adjusted mean scores, indicated that the Stable PDD-NOS group scored significantly higher than either the Stable Autism (p < .0001) or the Change groups (p < .0001). The Stable Autism and Change groups did not differ significantly on Socialization score (p = .95).

Two participants were missing data for the Communication domain score, one from the Stable PDD-NOS group (n = 23) and one from the Change group (p = 14). The ANCOVA indicated that there was a significant difference between the groups on the Communication domain score, when the means were adjusted using chronological age as a covariate, F(2, 53) = 13.53, p < .0001. Chronological age had a significant impact on the Communication domain score, F(1, 56) = 33.34, p < .0001, and the Eta Squared score indicated that 40 percent of the variance in the Communication domain score could be predicted from chronological age. Post hoc comparisons, using Bonferroni correction, indicated that the Stable PDD-NOS group scored significantly higher on the Communication domain than either the Stable Autism (p < .0001) or the Change (p < .0001) groups, whereas the Stable Autism and Change group scores did not differ significantly (p = 1.00).

One participant from the Change group was missing data for the Daily Living Skills domain (n = 14). The ANCOVA yielded a significant difference between groups on the

Daily Living Skills domain, when the means were adjusted using chronological age as a covariate, F(2, 54) = 11.29, p < .0001. Chronological age had a significant impact on the Daily Living Skills domain score, F(1, 57) = 18.67, p < .0001, and the Eta Squared score indicated that approximately 25 percent of the variance in the domain score could be predicted from chronological age. Post hoc comparisons using Bonferroni correction yielded a significant difference between the Stable PDD-NOS and Stable Autism groups (p < .0001). The Daily Living Skills domain score of the Change group was not significantly different from either the Stable PDD-NOS (p = .07) or the Stable Autism (p = .21) groups.

#### Functional Skill Stability

*Cognitive ability.* The sample demonstrated a relatively stable level of cognitive functioning between the first (M =1.77, SD = 0.80) and second (M =1.70, SD = 0.80) assessments. The mean cognitive ability level was consistently 3 to 4 standard deviations below average. Wilcoxon Signed-Rank tests were conducted to determine the stability of cognitive functioning for each group. The cognitive ability level did not differ significantly between the initial and follow-up assessments for any of the three groups (Stable PDD-NOS: p = .10, Change: p = .16 Stable Autism: p = .06).

Parent concerns at the time of the assessments. Wilcoxon Signed-Rank tests were used to measure changes in the number of parent-reported concerns between the first and second assessments for each group. Parents of the Stable PDD-NOS group reported an increase in the number of concerns regarding their children's social skills, Wilcoxon z = -2.11, p < .04, with all other concerns remaining stable (p values > .10). The Change group parents reported an increase in concerns regarding their children's emotional

responsiveness, Wilcoxon z = -2.45, p < .01. Other areas of concern (i.e., behaviour, language skills, academic ability, future development, and social skills) remained stable (p values > .10). Parents of the Stable Autism group reported similar levels of concerns about their children's behaviour, emotional responsiveness, academic ability, future development, and social skills at both assessments (p values > .16). However, concerns about language development increased, Wilcoxon z = -2.12, p < .03.

PDD Symptoms. PDD symptom stability was examined for each group, by comparing CARS Total and subscale scores, as well as the DSM-IV Checklist Total and subscale scores from the first and second assessments. The CARS scores were compared using paired *t*-tests (Table 21) and the DSM-IV Checklist scores were compared with Wilcoxon Matched-Pairs Signed-Rank tests (refer to Table 22).

A paired *t*-test of the CARS Total score indicated a significant decrease in PDDrelated symptoms for the Stable PDD-NOS group, t(23) = 3.62, p < .001. The CARS Total score for the Stable PDD-NOS group was below the threshold for mild autism (i.e., < 30) at re-assessment. In comparison, the Change group demonstrated a significant increase in PDD-related impairments between the first (CARS Total M = 31.12, SD =1.97) and second (CARS Total M = 35.98, SD = 2.59) assessments, t(14) = -5.85, p <.0001. The Stable Autism group demonstrated minimal changes in symptom severity between the first (CARS Total M = 37.08, SD = 3.39) and second (CARS Total M =36.11, SD = 4.24) assessments (p = .42).

Selected CARS subscale scores were examined to identify behaviour and symptom areas that changed over time, for each group. An alpha level of .01 or less was required for significance, due to the number of comparisons. The Stable PDD-NOS group

## Table 21

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# Stability of CARS Total and Subscale Scores: Paired t-tests

	Stable PDDNOS	Change	Stable Autism
	<i>n</i> = 24	<i>n</i> = 15	<i>n</i> = 20
CARS Total Score	3.62***	-5.85****	1.01
CARS Social Subscales			
Adaptation to Chang	ge 3.34**	-5.12****	1.83
Visual Response	1.04	-4.06***	-0.99
Emotional Response	3.19**	-4.32***	-1.05
Relating to People	2.54	-4.83****	1.04
CARS Communication Subs	scales		
Verbal	3.03**	-2.97**	-1.07
Non-Verbal	3.63***	-0.57	2.44
Imitation	3.63***	0.26	1.55
CARS Repetitive/Stereotyped S	Subscales		
Body Use	0.29	-5.79****	-0.68
Object Use	3.09**	-3.69**	1.70
Taste/Smell/Touch	1.92	-0.05	0.75

\*\**p* < .01

\*\*\*\**p* < .001

\*\*\*\**p* < .0001

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## Table 22

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Stability of PDD Symptoms Based on the DSM-IV Checklist: Wilcoxon Signed-Ranks Tests

	Stable PDDNOS $n = 24$	Change $n = 15$	Stable Autism $n = 20$
		,, 10	
DSM-IV Checklist Total	-2.10	-3.41***	-0.24
DSM-IV Checklist Subscale	S		
Social	-0.21	-3.41***	-0.73
Communication	-1.86	-3.43***	-1.11
Repetitive/Stereotyp	ed -1.73	-3.42***	-1.09

\*\**p* < .01

\*\*\**p* < .001

\*\*\*\**p* < .0001

demonstrated consistent levels of impairment in two of the social interaction subscales (Visual Response p = .31 and Relating to People p = .02), as well as two of the repetitive/stereotyped subscales (Body Use p = .77 and Taste/Smell/Touch p = .07). The Stable PDD-NOS group demonstrated significant decreases in the remaining CARS subscales; including Adaptation to Change, Emotional Response, Verbal Communication, Non-Verbal Communication, Imitation, and Object Use (refer to Table 21). In comparison, the Change group demonstrated significant increases in the majority of the CARS subscale scores, including each of the four social interaction subscales, two of the communication skill scores and two of the repetitive/stereotyped subscales. The Change group showed relatively stable levels of impairment in the Non-Verbal (p = .58), Imitation (p = .80), and Taste/Smell/Touch (p = .96) subscales. The Stable Autism group demonstrated a consistent level of impairment between the assessments in all of the CARS subscales.

Both the Stable Autism and Stable PDD-NOS groups experienced minimal changes in the DSM-IV Checklist Total score and the domain scores over time. Wilcoxon Matched-Pairs Signed-Ranks tests for the Stable PDD-NOS group yielded nonsignificant results for both the Total score (p = .06) and domain scores (Social: p = .84, Communication: p = .06, and Repetitive/Stereotyped: p= .08). Likewise, the Stable Autism group demonstrated no significant differences for either the Total score (p = .81) or the domain scores (Social: p = .47, Communication: p = .27, and Repetitive/ Stereotyped: p = .28). In contrast, the Change group experienced a significant increase in the Total score (p = .001), as well as in each of the three domain scores ( $p^2 s = .001$ ). *Adaptive skills*. The stability of adaptive level was examined for each of the three

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groups, by comparing the adjusted adaptive behaviour composite score and the three domain scores from the first and second assessments (refer to Table 23).

The adaptive abilities of the Stable PDD-NOS group remained relatively constant. Paired *t*-tests yielded no significant changes in the ABC (p = .56), or any of the three domain scores (Socialization: p = .48, Communication: p = .11, Daily Living Skills: p =.88). Paired *t*- tests indicated a significant decrease in the Change group's ABC score, *t* (14) = 4.39, p < .001), as well as in the Communication, t (11) = 3.97, p < .002, and Daily Living Skills, t (13) = 2.37, p < .03) domains. The Change group did not demonstrate a significant difference in Socialization skill level between the first and second assessments (p = .64). The Stable Autism group also experienced a significant decrease in ABC score, t (18) = 3.34, p < .004), as well as in the Daily Living Skills, t (18) = 3.64, p < .002, and Socialization, t (18) = 4.32, p < .0001) domains. The Communication score did not change significantly between the two assessments for the Stable Autism group (p = .12). Summary of Results

Hypothesis 1: Group differences in severity and stability of functional impairment. All three groups demonstrated impairments in functional ability (i.e., each group showed symptoms of PDD, impairments in cognitive ability and adaptive skills, atypical behaviours in early history, and delayed developmental milestones). In terms of severity, the three groups represented a continuum of functional impairment, with the Stable PDD-NOS group demonstrating the least degree of impairment, and the Change and Stable Autism groups demonstrating relatively higher levels of functional impairment. The Stable PDD-NOS group demonstrated a significantly better outcome than the Stable Autism group. The performance of the Change group more closely resembled the Stable

# Table 23

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	Paired t-test			
	Stable PDDNOS $n = 21$	Change $n = 15$	Stable Autism $n = 19$	
Adaptive Behaviour Composite	-0.59	4.39***	3.34**	
Socialization	-0.73	0.48	4.32****	
Communication	-1.66	3.97**	1.63	
Daily Living Skills	-0.16	2.37*	3.64**	

Stability of Adaptive Skills (Vineland Adaptive Behavior Scales): Paired t-tests

\*p < .05

\*\**p* < .01

\*\*\**p* < .001

\*\*\*\*\**p* < .0001

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PDD-NOS group at the initial assessment and the Stable Autism group at the follow-up assessment.

In terms of stability, a consistent level of functional impairment was expected for both the Stable PDD-NOS and Stable Autism groups, whereas the functional impairment of the Change group was expected to increase. The Stable PDD-NOS group demonstrated a generally consistent level of functional ability between the two assessments, with improvement (i.e., a decrease) in some PDD-related symptoms. For the most part, the Stable Autism group also maintained a consistent level of functional ability, with a relative decrease in adaptive skills. As anticipated, the functional ability of the Change group decreased between the two assessments.

*Hypothesis 2: Symptom patterns as a predictor of outcome*. Rather than evaluating differences in overall symptom severity (the three groups were expected to differ based on their diagnostic outcome), the goal of the second hypothesis was to examine the pattern and stability of PDD symptoms within groups. It was anticipated that the initial presenting pattern of PDD symptoms and the stability of that pattern between the two assessments would be predictive of functional outcome. The Stable PDD-NOS group demonstrated relatively mild impairment in each of the three symptom domains at both the first and second assessments. The Stable Autism group also demonstrated the anticipated moderate to severe degree of impairment in each of the symptom domains at both assessments. However, the expected symptom pattern of the Change group was only partially demonstrated. At the first assessment, the Change group demonstrated mild, global impairment, much like the Stable PDD-NOS group. It had been anticipated that the Change group would demonstrate a limited symptom pattern at the first assessment

(i.e., impairment in two domains, including the social domain, with few symptoms in the third domain). The Change group demonstrated the anticipated moderate impairment in each of the three domains at follow-up.

Although the Change group did not demonstrate the expected pattern of PDD-related impairments at the initial assessment, it was possible to differentiate between the Change and Stable PDD-NOS groups using PDD symptom patterns. At the first assessment, the two groups demonstrated similar levels of impairment in the social domain, as well as similar numbers of repetitive/stereotyped behaviours. However, the Change group demonstrated significantly greater impairment in the communication domain, than did the Stable PDD-NOS group. At follow-up, the Change group demonstrated greater impairment in all three of the PDD-related domains than did the Stable PDD-NOS group. In comparison to the Stable Autism group, at the first assessment, the Change group demonstrated fewer social impairments and fewer repetitive/stereotyped behaviours, but a similar degrees of impairment in each of the three domains. As anticipated, the Stable PDD-NOS group demonstrated fewer PDD-related symptoms than the Stable Autism group in each of the three domains, at both the initial and follow-up assessments.

With regard to symptom stability, it was hypothesized that the two stable groups would demonstrate consistent levels of PDD symptoms, whereas the Change group would demonstrate an increase in PDD symptoms. As anticipated, the Stable Autism group demonstrated a consistent level of moderate to severe impairment overall, as well as in each of the three PDD symptom domains. The Change group also demonstrated the expected increase in overall impairment. In terms of PDD symptom domains, the Change

group demonstrated an increase in impairment in both the social and stereotyped/repetitive behaviours domains, and a relatively stable level of impairment in the communication domain. The Stable PDD-NOS group demonstrated mild PDD symptoms overall, at both the first and second assessments. However, this group also experienced a decrease in impairment in each of the three PDD symptom domains.

*Hypothesis 3: Differences in adaptive ability associated with outcome.* Three aspects of adaptive ability were compared between the groups: (a) pattern of relative impairment within the three adaptive domains, (b) overall level of adaptive ability, and (c) stability of adaptive skill level. It was anticipated that the adaptive skills of the three groups would show the same pattern of relative impairment (i.e., the greatest impairment in social skills, less impairment in communication skills, and the least impairment in self-care). All three groups demonstrated significant impairment in each of the three adaptive domains; however there was no apparent pattern of relative impairment. Even when cognitive ability level was controlled as a covariate (i.e., follow-up assessment results), the three groups demonstrated similar patterns of impairment across the adaptive domains.

In terms of overall adaptive skill level, the results from the first assessment did not follow the anticipated pattern of relative impairment; however, the results from the second assessment did. At the first assessment, it was anticipated that the Stable PDD-NOS group would demonstrate the highest overall adaptive skill level, followed by the Change group, then the Stable Autism group. However, the Stable PDD-NOS group demonstrated similar levels of overall adaptive ability to both the Stable Autism and Change groups. The Change group performed significantly better than the Stable Autism

group. The same pattern between the three groups was also seen in the Communication and Daily Living Skills domain scores. The Socialization domain score demonstrated the anticipated pattern of differences between the groups (i.e., Stable PDD-NOS demonstrated significantly stronger social skills than either the Change or Stable Autism groups, which demonstrated a similar level of impairment).

At the follow-up assessment, the Stable PDD-NOS group demonstrated significantly stronger overall adaptive skills than either the Stable Autism or Change groups. The Change and Stable Autism groups did not differ significantly in overall adaptive ability. The same pattern of relative impairment was seen for both the Socialization and Communication domains. The Stable PDD-NOS group demonstrated significantly higher self-care skills than the Stable Autism group, but not the Change group.

It was anticipated that functional outcome (i.e., group membership) would be associated with the stability of adaptive skills between the two assessments. The Stable PDD-NOS group demonstrated a consistent level of adaptive skills over time, both in the summary score and in each of the three domains. As expected, the Stable Autism and Change groups both demonstrated a relative decrease in overall adaptive skills between the two assessments. Within the adaptive skill domains, the Stable Autism group showed a decrease in social skills and self-care skills, but not in communication skills, which remained stable. The self-care and communication skills of the Change group decreased, and the social skills score remained relatively stable.

*Hypothesis 4: Early history characteristics as indicators of functional ability.* The fourth hypothesis focused on group differences in functional ability early in development (i.e., prior to diagnosis). It was anticipated that the atypical developmental progression of

the Change group would be apparent at early ages (i.e., prior to diagnosis), and would differentiate it from the Stable PDD-NOS group. It was expected that the Change group would resemble the Stable Autism group in early history characteristics.

It was anticipated that both the Stable Autism and Change groups would experience significant global developmental delays, primarily in the areas of speech and communication skills. In comparison, the Stable PDD-NOS group was expected to demonstrate relatively mild, global delays. All three groups demonstrated mild delays in overall early developmental progression, with mild delays in achieving both speech and physical milestones.

The three groups were expected to differ in terms of the presence of atypical behaviours early in development. More specifically, the Stable PDD-NOS group was expected to demonstrate fewer atypical behaviours than either the Stable Autism or Change groups, prior to diagnosis. In addition, fewer parent-reported concerns about atypical behaviours were expected for the Stable PDD-NOS group than for either the Stable Autism or Change groups at the time of the first and follow-up assessments. All three groups demonstrated similar levels of parent-reported concerns. However, the three groups demonstrated significantly different patterns of parent-reported concerns at the time of the first assessment. Atypical behaviours and emotional responsiveness were identified as concerns by the parents of the Stable PDD-NOS group, and emotional responsiveness was also a concern for parents of the Change group. Parents of all three groups endorsed social skill and language development as areas of concern. Relatively few parents in any of the groups identified academic skills and future development as

areas of concern. At the follow-up assessment, parents of all three groups were equally concerned about the different behaviours and areas of development.

Functional ability level at outcome was expected to be associated with the age at which parents first recognized and first reported atypical development, as well as the length of time between assessments. More specifically, it was anticipated that parents would identify concerns about their child's development and seek professional assessment at earlier ages for the Stable Autism and Change groups, than for the Stable PDD-NOS group. The parents of this sample first recognized delays or signs of atypical development in their children by age 19 months. However, there was no significant difference between the three groups in age at parent recognition. This result suggests that the degree of atypical behaviours was equally apparent (or not apparent) in each group prior to age 2 years.

On average, this sample was first seen for an assessment at age 47 months. Both the Stable Autism and Change groups were seen at significantly younger ages than the Stable PDD-NOS group (approximately two years earlier). The relative decrease in functional ability demonstrated by the Change group was expected to result in an earlier re-assessment than for the Stable PDD-NOS or Stable Autism groups. However, all three groups were seen approximately two years later for the follow-up assessment.

Hypothesis 5: Nature of supports and services in relation to outcome. It was anticipated that functional ability would be associated with the number of supports and services received by a child. More specifically, groups with greater overall impairment (Stable Autism and Change) were expected to receive a greater number of services than

the Stable PDD-NOS group. However, given the limited data available for these variables, the analyses were not conducted.

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### CHAPTER IV

### DISCUSSION

The goal of the present study was to predict functional outcome in children initially diagnosed with explicitly defined PDD-NOS. For the present study, functional ability was estimated based on a combination of skills and deficits, including PDD-related symptom severity, adaptive ability, cognitive level, and developmental progression. It was anticipated that the stability of these skills and deficits, as well as specific patterns of symptoms would predict differences in functional outcome for children initially diagnosed with PDD-NOS. The data generally support this expectation, as the children whose functional skills remained mildly impaired (i.e., Stable PDD-NOS) can be differentiated from those who showed a decrease in functional skills (i.e., Change group).

The results suggest that changes in functional ability for children initially diagnosed with PDD-NOS can be predicted by early history characteristics and patterns of PDD symptoms. Children with (a) an earlier first assessment, (b) a higher number of symptoms at their first assessment than the second, and (c) more parent-reported concerns in their early history have a greater likelihood of experiencing an increase in functional impairment over time, relative to other children initially diagnosed with PDD-NOS. In general, these results support the hypotheses about the role of early history variables in predicting outcome for children initially diagnosed with PDD-NOS, as well as the continuum relationship between PDD-NOS and autism. The role of each of these skills and deficits in predicting functional outcome for PDD-NOS is reviewed, followed by an examination of the implications, contributions and limitations of the present study.

*Symptom patterns*. The association between PDD symptom severity and functional ability is clear: as symptom severity increases, functional ability level decreases (refer to Lord & Risi, 1998). Therefore, the Stable PDD-NOS group was expected to demonstrate a higher level of functional ability than the Stable Autism group, and the Change group was expected to demonstrate a decrease in functional ability level. Further, the pattern of symptom severity (i.e., the degree of impairment in each of the three PDD-related domains) was expected to be associated with functional outcome. PDD-NOS represents a range of symptom patterns, with the two most common including relatively mild, global impairment (i.e., mild deficits in the three domains) or relatively mild impairment in one domain and moderate deficits in two others.

It was anticipated that the children with a mild, global pattern of PDD symptoms (i.e., Stable PDD-NOS) would demonstrate milder functional impairments. In comparison, children with a pattern of mixed mild to moderate pattern of symptoms (i.e., Change) would demonstrate poorer functional skills. Functional outcome was associated with both the severity of the overall level of PDD symptoms and the pattern of PDDrelated symptoms for the present sample. More specifically, two patterns of PDD symptoms were associated with poor functional outcome: first, moderate, global impairment in PDD symptoms (i.e., Stable Autism), and second, a combination of mild deficits in the social and repetitive/stereotyped behaviour domains and moderate deficits in the communication domain (i.e., Change). In comparison, a mild, global pattern of symptoms was associated with milder functional impairments at outcome (i.e., Stable PDD-NOS). These results are consistent with previous findings, in that the moderately impaired group (i.e., Autism) and the group with moderate deficits in the communication

domain (i.e., the Change group) demonstrated poorer outcomes than the group with mild impairments in all three domains (i.e., the Stable PDD-NOS group) (refer to Bryson & Smith, 1998; Nordin & Gillberg, 1998; Lord & Risi, 1998; or Gillbert & Steffenburg, 1987).

It was anticipated that children in the Change group would demonstrate an uneven symptom pattern, with primary deficits in social interaction and either communication skills or repetitive/stereotyped behaviours. Instead, communication skills were the primary deficit of the Change group at the first assessment, with relatively mild impairment in the other two domains. The uneven pattern of impairment was associated with an increase in symptom severity, as the social impairments and repetitive/stereotyped behaviours of the Change group increased at follow-up. The communication deficits of the Change group remained stable between the first and second assessments. An association between poor functional outcome and a primary deficit in the PDD domain of communication deficits was previously demonstrated by Eisenmajer et al. (1998), who found that a delay in communication skill development in children with PDD (i.e., autism, Asperger's, or PDD-NOS) was associated with poorer long-term functioning in general, as well as greater impairments in social aspects of communication, and a greater frequency of repetitive/stereotyped behaviours. The results of the present study, and those of Eisenmajer et al (1998) suggest that impairments in the communication domain, together with delays in language acquisition, may be among the initial presenting problems for children later diagnosed with autism. For these children, communication deficits may be more readily apparent than social deficits early in development. These results further suggest that follow-up assessments may be warranted

for children who initially present with PDD-NOS and demonstrate a primary deficit in the communication domain, relative to the other two domains.

In sum, PDD symptom severity was associated with degree of functional impairment for this sample, with greater symptom severity associated with poorer functional outcome. In addition, the pattern of symptom severity seen within the three PDD domains was also associated with functional outcome. More specifically, early PDD symptom patterns were associated with different levels of functional ability at outcome; a consistent level of severity across each of the three domains was associated with stable functional ability, whereas a pattern that included different levels of symptom severity was associated with a decrease in functional ability. Further, an uneven pattern of impairment, with the greatest degree of impairment in the communication domain, was associated with a decline in functional ability level.

Adaptive skills. Adaptive skill level (i.e., level of independence and self-care skills) is an indicator of functional ability level. Children with milder PDD symptoms (i.e., PDD-NOS) demonstrate higher adaptive summary scores and domain scores on the Vineland Adaptive Behavior Scales, than do children with moderate to severe PDD symptoms, or autism (see Gillham et al., 2000). In addition, functional ability level in children with PDD is also associated with the stability of adaptive skills. Children with PDD-NOS demonstrate fairly consistent adaptive scores over time; whereas children with autism tend to demonstrate a decrease in adaptive scores (see Eaves & Ho, 2003 and Gillham et al., 2000). The decrease in adaptive scores is associated with a failure to progress at the same rate as their same age peers, rather than a regression.

Consistent with previous PDD research (see Carter et al., 1998; Rodrigue et al., 1991; Schatz, & Hamdan-Allen, 1995), the current sample demonstrated adaptive summary scores and adaptive domain scores on the Vineland Adaptive Behavior Scales that were well below average. Previous studies consistently find that PDD-NOS groups demonstrate higher adaptive profiles than autism groups (refer to Gillham et al., 2000). The adaptive summary scores from the initial assessment did not differentiate between the three groups. However, the Stable PDD-NOS group demonstrated a significantly higher Socialization domain score, than the other two groups, indicating that the group with mild, global functional impairments was more socially adept than either the group with moderate, stable functional impairments (i.e., Stable Autism), or the group whose functional impairments increased (i.e., Change).

At follow-up, both the adaptive summary scores and adaptive domain scores were clearly associated with functional outcome. Those with stable, mild functional impairment demonstrated a higher adaptive profile than either of the other two groups. These results suggest that overall adaptive level may not be predictive of differences in functional outcome. However, differences in social ability, which is the hallmark of PDD, may predict functional ability level at outcome.

Functional impairment was associated with the stability of adaptive skills. More specifically, the adaptive skills of the group with mild functional impairment (i.e., Stable PDD-NOS) were consistent between the preschool and early school years. In comparison, the groups with moderate functional impairment (i.e., Stable Autism and Change) both demonstrated a significant decline in adaptive skills. These results are similar to those found in the PDD literature (see Eaves & Ho, 2003 and Gillham et al., 2000), which

indicate that adaptive scores of autism samples are more likely to decline than those of PDD-NOS samples. The decline in adaptive skills associated with autism is indicative of delayed or slower progression in skill development, rather than a skill loss (Fisch et al., 2002), which suggests that PDD groups with poorer functional outcome (i.e., autism and Change) continue to make gains in adaptive skills, but at a slower rate than that of their higher functioning peers with PDD. These results suggest that better functional outcomes are associated with stable adaptive skill profiles.

In sum, adaptive profiles can be used to predict functional impairment to a limited extent. Those with less functional impairment have stable adaptive skill profiles, whereas those with greater functional impairment tend to show a decline in adaptive skills. It is difficult to differentiate between PDD-NOS subgroups (i.e., those with stable versus decreasing functional impairment) on the basis of adaptive summary scores at preschool age. However, it is possible to differentiate between the two on the basis of early social skill acquisition, as the group with higher functional ability achieves a higher socialization domain score. In addition, groups with poorer functional outcome tend to acquire adaptive skills at a slower rate than their peers, and as a result, their adaptive profile scores appear to decline over time.

*Early history characteristics.* Impairments associated with PDD are apparent very early in development. Often, parents of children initially diagnosed with PDD-NOS or autism report noticing atypical behaviours well before their child's first diagnostic assessment. Retrospective interviews suggest that parents are able to identify early indicators of their child's decreased functional ability level, such as age at onset, as well as any areas of delayed or atypical development (e.g., presence of unusual behaviours or

the absence of typical behaviours). Degree of impairment can be associated with the nature of impairments seen early in development. It was anticipated that a child's functional skill level at outcome would be associated with significant early impairments (i.e., parent awareness of problems earlier in childhood, delayed milestones, etc.).

A child's age at the onset of PDD symptoms (i.e., the age at which impairment is first recognized by parents) and the age at which a child is diagnosed with PDD both provide useful information about functional ability. Children who demonstrate moderate to severe levels of impairment are recognized earlier by parents and diagnosed earlier by clinicians, in comparison to children who demonstrate relatively mild impairment (refer to Baron-Cohen et al., 1992; Buitelaar et al., 1999; Prior et al., 1998). Parents of children in the present sample first identified developmental concerns by the time their children were 19 months old, which is similar to the age typically reported in the PDD literature (i.e., between 12 and 24 months) (see Young et al., 2003). However, the age at which parents first recognized their child's atypical development was not associated with differences in functional impairment.

For the present sample, that age at which the children were first diagnosed was associated with functional outcome. Children who demonstrated moderate to severe functional impairment at outcome were diagnosed earlier than children with mild functional impairment at outcome. Both the Stable Autism and Change groups were assessed earlier than the Stable PDD-NOS group. This finding suggests that there was a difference in early symptom presentation or level of concern reported by parents and clinicians regarding both the Change and Stable PDD-NOS groups. However, because

parent recall and availability of resources influence age at onset and age at diagnosis, caution is needed in associating both with functional ability.

Parents often report concerns about atypical behaviours (e.g., the presence of unusual behaviours or the absence of expected behaviours) early in the course of their child's development. Initial concerns reported by parents usually emphasize social and communication impairments, including limited play skills, limited social interactions, as well as difficulty communicating (Bernabei et al., 1998; Charman & Baird, 2002; Vostanis et al., 1994; Vostanis, et al., 1998). All parents in the present sample indicated similar levels of concern regarding their children's early play and language skills (i.e., concerns first raised prior to the initial diagnosis). Atypical sensory behaviours were identified as an area of early concern by parents of the children with stable, moderate functional impairment (i.e., Stable Autism group). Social skill development was an area of significant concern for parents whose children's functional skills decreased over time (i.e., Change group). These results suggest that a greater number of parent-reported concerns regarding sensory responsiveness and social interaction early in development are associated with greater functional impairment at outcome. These results were interpreted with caution, as the data were from a non-standardized parent interview. Further, during the interview, parents only indicated whether they had concerns about a particular area of their child's development. Parent estimates about the severity of the problem would provide useful information regarding the severity of the child's overall functional impairment.

The progression of a child's developmental milestones (e.g., early motor, social, and language skill development) provides an early indicator of functional outcome. Children

with PDD typically experience mild to moderate delays in achieving developmental milestones (refer to Cox, 1993; Wilkinson, 1998), and greater delays are associated with an earlier diagnosis of PDD (refer to De Giacomo & Fombonne, 1998). The present sample demonstrated mild, global delays in achieving developmental milestones. This result is consistent, in part, with previous studies. However, because the three groups demonstrated similar levels of delay, there were no group differences in terms of achieving developmental milestones and functional outcome. These results were viewed as exploratory, as limited data were available for the analyses.

Further research with a larger sample may indicate an association between early development and long-term outcome, particularly in the areas of early communication and social deficits. Previous research indicates that early deficits in both communication and social skills are associated with poorer long term functioning in PDD (see Carpenter et al., 2002; Cox, 1993; Wilkinson, 1998). To a limited extent, children initially diagnosed with PDD-NOS in the present sample demonstrated differences in functional ability that were apparent early in development (i.e., prior to diagnosis). Those children with a poorer functional outcome demonstrated a greater degree of impairment in their early history, than did children with relatively mild functional impairments at outcome.

*Community support.* Limited data were available on the supports and services used by the participants in the present study. As a result, the supports and services variables were not analyzed. It is well documented that early intervention plays a pivotal role in the outcome of young children with PDD, especially behaviour intervention and speech therapy (Harris & Handleman, 2000; McGee, Morrier, & Daly, 1999). Differences in type and number of supports and services may have had an impact on functional ability

level, both between groups and within groups. The interpretation of the results is limited to a certain extent, because of potential differences in level of intervention between groups.

In sum, early predictors of change in functional impairment can be identified in an explicitly defined PDD-NOS sample. A group of those initially diagnosed with PDD-NOS maintained their overall profile of functional skills, and a subset of those initially diagnosed with PDD-NOS continued to develop PDD-related symptoms and demonstrate deficits in adaptive skills. Greater impairment at outcome is associated with an uneven pattern of PDD symptoms as well as a higher level of overall functional impairment early in development. Mild, global impairments are associated with a stable functional outcome, whereas a combination of mild and moderate deficits is associated with a decrease in functional skills.

*Contributions to the PDD literature.* There is a dearth of information about the characteristics and levels of functioning associated with a diagnosis of PDD-NOS. The present study contributes to the PDD literature by expanding the current understanding of PDD-NOS. The present study addressed several methodological issues that are frequently seen in the PDD literature. First, PDD-NOS is rarely the focus of empirical investigation, due to the heterogeneous nature of the group. Second, when PDD-NOS groups are included in research samples, they are frequently poorly defined. As a result, the findings are difficult to replicate and generalizations are limited in scope. The present study attempted to address these issues by identifying a relatively homogeneous sample, using explicit inclusion and exclusion criteria. Finally, PDD-NOS samples often represent a broad range of ages and cognitive ability levels. Both characteristics are associated with

developmental progression of PDD symptoms. The present study addressed this issue to a limited extent, with a relatively homogeneous sample in terms of chronological age, level of cognitive impairment, and language ability level. The Stable PDD-NOS group was at the upper end of the ranges for both age and cognitive functioning, and initial group differences in age and cognitive level may, in part, account for some of the group differences in functional outcome. However, from a clinical perspective, the Stable PDD-NOS group closely resembled the other two groups in both cognitive functioning and chronological age (i.e., all three groups demonstrated significant cognitive impairments and were initially diagnosed at preschool age).

*Theoretical and clinical implications.* The results of the present study have both theoretical and clinical implications for the PDD field. These results contribute to the conceptualization of PDD-NOS, and can also be applied to the classification of PDDs. Currently, the PDDs are classified as categorically distinct entities, and changes in symptom severity are difficult to explain. However, the shift to a continuum perspective is imminent. The three groups included in the present study can be readily incorporated into a continuum or spectrum model. As they are currently defined, the primary differences between PDD-NOS and autism consist of degree of PDD-related deficits and severity of overall functional impairment (Charman & Baird, 2002; Towbin, 1997). The Stable PDD-NOS and Stable Autism groups can be viewed as end-points on a continuum of PDD-related impairments. The Change group, who demonstrated an increase in PDD symptoms, initially resembled PDD-NOS and later resembled autism. A continuum model allows for changes in symptom presentation, such as the progression from mild to moderate PDD symptoms demonstrated by the Change group.

In terms of conceptualization, PDD-NOS currently represents a heterogeneous group of individuals who demonstrate features of autism to a varying degree. As the results of the present study suggest, PDD-NOS includes subsets of individuals who differ in their developmental trajectories. The Stable PDD-NOS group represents one subset that maintains a mild degree of impairment. Clinicians who use the label PDD-NOS to indicate very mild autism are likely identifying this group. Clinicians also use PDD-NOS as a provisional label for children whose symptoms are likely to change with maturation (i.e., those who shift further along the PDD spectrum or those who shift off the spectrum entirely). The Change group represents the subset of children whose PDD-related deficits become more apparent with time. The subset of children who shift off the PDD spectrum were not evaluated in detail in the present study. These children likely represent the subset for whom the PDD-NOS label is viewed as a "catch-all" classification, because their impairments are not clear at the time of assessment. More accurate identification of the subsets within the PDD-NOS category can help to improve the reliability and stability of the diagnosis.

PDD-NOS is a poorly understood condition. The subset of children who are initially diagnosed with PDD-NOS and who later shift to a diagnosis of autism is particularly baffling. Several possible explanations for the shift in diagnosis were evaluated in the present study, including selective skill regression, delayed developmental progression, and the limited sensitivity of current diagnostic measures. Although current diagnostic criteria and tests are somewhat limited in their applicability to very young or delayed children, research data indicate that clinical experience can ameliorate these limitations, and diagnoses can be made reliably by age 3 (Baranek, 1999; Klin et al., 2000; Klinger &

Renner, 2000; Lord, 1995). While the present sample experienced cognitive delays, they were first seen during the preschool years (i.e., between the ages 3 and 4), when symptom presentation is usually well established. In addition, the initial diagnoses were made by a clinician who was familiar with the developmental progression of PDD symptoms, as well as the complications of making a dual diagnosis of PDD and mental retardation.

Selective skill regression, particularly in communication skills, is seen in a subgroup of children with autism. Selective skill loss typically occurs prior to age 2 years (Charman & Baird, 2002). The present sample demonstrated a global pattern of functional impairment, rather than a selective skill loss. In addition, the decrease in functional impairment occurred in the period between preschool and early school years. Those with selective skill regression typically experience greater deficits in the social and communication domains compared to other children with autism. This was not the case for the present sample, which demonstrated impairments that were similar to those of the autism group. Finally, although the group demonstrated overall functional impairment, the pattern was not consistent with that seen in Childhood Disintegrative Disorder (i.e., typical early development followed by global regression and mental retardation by age 24 months). Parents of the Change group were aware of atypical behaviours very early in development, and the increase in functional impairment was not accompanied by a decline in cognitive ability level.

Delayed developmental progression appears to be a primary contributing factor to the decrease in functional impairment of the Change group. The influence of maturation on PDD symptom presentation is well documented (Bryson & Smith, 1998; Charman & Baird, 2002; Howlin & Goode, 1998; Klin et al., 2000; Waterhouse et al., 1996). PDD

symptoms are more recognizable, and often more severe in older children than in younger children (Adrien et al, 1993; Lord, 1995; Stone & Hogan, 1993). For example, although social impairments are apparent in children as young as 18 months, a broader range of social impairments is more apparent by the time children reach preschool and early school ages (Charman & Baird, 2002; Lord, 1995; Marcus & Stone, 1993). While nonverbal communication deficits are apparent early in development, verbal deficits are less recognizable in very young or preverbal children with autism (Gray & Tonge, 2001; Wilkinson, 1998). Motor mannerisms, repetitive behaviours, and unusual sensory responses are common in young children with autism (Klinger & Renner, 2000; Lord et al., 1993; Eaves & Ho, 1996; Marcus & Stone, 1993; Robins et al., 2001); however, the more complex repetitive and perseverative behaviours are often not seen until preschool and early school years (Charman & Baird, 2002; Gray & Tonge, 2001; Szatmari, 2000; Robins et al., 2001). Therefore, it seems reasonable to attribute the symptom pattern of the Change group in the present study (i.e., an increase in the social deficits and repetitive/stereotyped behaviours, and a stable level of communication impairment) to delayed developmental maturation.

Similarly, adaptive skill profiles of children with autism are also influenced by maturation; they tend to gain adaptive skills at a slower rate than their peers, which results in an apparent decrease in skill level (Fisch et al., 2002; Lord & Schopler, 1989a). However, the decrease in scores represents a delay in skill acquisition and not a skill loss (Fisch et al., 2002). The adaptive profile of the Change group in the present study showed a similar pattern, with a decrease in adaptive summary score and domain scores. Likewise, the Stable Autism group also demonstrated the same pattern. In contrast, the
adaptive profile of the Stable PDD-NOS group was stable, suggesting a rate of skill development that is consistent with maturation (Gillham et al., 2000).

Relative to other children initially diagnosed with PDD-NOS, children in the Change group appeared to have experienced delayed developmental progression, which resulted in a unique combination of deficits. As children in the Change group matured, their impairments became more apparent, both in daily functional skills as well as in PDDrelated behaviours.

The results of the present study also have clinical implications. These findings can help inform the decisions of clinicians making a PDD-NOS diagnosis. Clinicians often use PDD-NOS as a "catch-all" or provisional diagnosis for children who present with characteristics that resemble a mild variant of autism. As these results indicate, there are three potential outcomes for children initially diagnosed with PDD-NOS: a stable course of relatively mild impairment, a increase in impairment that becomes apparent with development, and a decrease in impairment. Clinicians may be able to more accurately identify the outcome for children initially diagnosed with PDD-NOS, based on the degree of impairment apparent very early in development, as well as the presenting pattern of PDD-deficits. Re-assessment will be warranted for the subset of children who initially present with significant impairments in their early history and a pattern of uneven impairment in the three PDD domains. As they mature, this subset of children who initially present with PDD-NOS will likely meet criteria for a diagnosis of autism.

*Limitations.* The ability to generalize from the present study to the PDD population is somewhat limited by the nature of the sample characteristics. The group sizes were fairly consistent with those seen in other clinically-based studies in the PDD field, which

tend to include groups of approximately 20 participants. However, the relatively small group sizes of the present study limited the extent to which in-depth comparisons were used. For example, identifying specific outcome predictors through multiple regression would have been possible with a larger sample. In addition, a larger sample would have greater potential for matching groups on chronological and mental ages. Developmental maturation influences PDD symptom presentation, therefore, chronological and mental ages need to be either matched or controlled as potential confounds. In the present study, the three groups were in the same clinical range for both age (i.e., preschool age) and cognitive ability level (i.e., mild to moderate impairment). However, statistically, the Stable PDD-NOS group was relatively older and performed at a higher cognitive skill level than the other two groups. Wherever necessary and feasible, chronological age was included as a covariate. Cognitive ability level was either not highly correlated with the dependent variable in each of the analyses, or it was not feasible to include cognitive ability level as a covariate due to variable characteristics. Therefore cognitive ability level was excluded as a potential covariate.

The results of the present study provide useful information, in that higher functional outcome appears to be associated with later diagnosis and less cognitive impairment in children initially diagnosed with PDD-NOS. However, the extent to which cognitive ability level influenced these results is difficult to determine. As a result, judicious use of statistical analyses and caution in interpreting the results is warranted. Further investigations of children initially diagnosed with PDD-NOS who are matched on chronological and mental ages will help to address this issue.

Three characteristics of the present sample restrict the extent to which the results can be generalized. First, the sample demonstrated significant cognitive impairment, whereas the broader spectrum of PDD includes a wide range of cognitive ability levels. The current results are primarily applicable to individuals with PDD and mental retardation, and not to those with mild cognitive impairments or average cognitive skills. Second, the sample was limited to children who received a follow-up diagnostic assessment, which may further differentiate them from the broader PDD population. Of the files reviewed for the present study, close to half of the children initially assessed at the clinic were seen for a follow-up assessment (43.5 percent). Reasons for re-assessment varied and were recommended by the diagnosing psychologist or medical practitioner, or were requested by parents or teachers.

Parents of the children initially diagnosed with PDD-NOS may have wanted to confirm what they perceived to be a provisional diagnosis. For the children who shifted between a diagnosis of PDD-NOS and autism, parents may have noticed a change in their children's functional abilities, and requested a re-assessment. Parents of children with a stable diagnosis of Autistic Disorder may have wanted an update of their children's functional skills. Given that most children were seen for re-assessment at age six, it is possible that the re-assessment was planned to facilitate the transition between preschool and Kindergarten, and to provide recommendations for curriculum planning. The reasons for re-assessment may differentiate the present sample from children seen for a single diagnostic assessment, and therefore limit the extent to which these results can be generalized.

In addition, circularity, or the use of diagnostic criteria to both identify and compare PDD groups, is a methodological problem frequently seen in the PDD literature. Circularity was an issue to a limited extent in the present study, as PDD diagnostic criteria were used to identify groups and groups were compared on the basis of symptom patterns. Ultimately, circularity can limit contributions to the PDD literature, by yielding expected group differences (i.e., differences are anticipated on the basis of diagnostic criteria). For example, it is inevitable that a PDD-NOS group will demonstrate fewer PDD-related behaviours in comparison to an autism group, given the differences in diagnostic criteria. However, for the purposes of this study it was appropriate to examine symptom patterns that would potentially differentiate between functional outcomes of the groups. In addition, group comparisons were not limited to diagnostic characteristics. A range of non-diagnostic features, such as adaptive ability, early history characteristics, and developmental progression, were also compared. By using a range of outcome measures, including those not directly associated with a PDD diagnosis, the problems associated with circularity were reduced.

Finally, the present sample did not include children who shifted off the PDD spectrum, after an initial diagnosis of PDD-NOS. There are three possible outcomes for children initially diagnosed with PDD-NOS: a stable level of functional skills, a decrease in functional skills, or an increase in functional skills. The first two groups were the focus of the present investigation because they required greater support and intervention. However, in order to make predictive statements about PDD-NOS based on early history characteristics and symptom patterns, it is necessary to consider the performance of those who improve.

The number of children in the present study who demonstrated an increase in PDDrelated symptoms (i.e., from PDD-NOS to autism) and the number of children who showed a decrease in PDD related symptoms (i.e., shifted from a diagnosis of autism to PDD-NOS) were comparable to the numbers seen in the literature. Of the 41 children initially diagnosed with PDD-NOS in the present study, 15 children (i.e., 37 percent) shifted to a diagnosis of autism at follow-up. This number is within the range demonstrated by other PDD-NOS samples, which varies widely from 25 to 67 percent (Eaves & Ho, 2003; Moore & Goodson, 2003; Stone et al., 1999). A relatively small number of children (i.e., 17 percent) in the present study showed an improvement in PDD symptoms, and shifted from an initial diagnosis of autism to a follow-up diagnosis of PDD-NOS. This finding was similar to the result found in the study by Eaves and Ho (2003), in which only 12 percent shifted from a diagnosis of autism to PDD-NOS.

Based on the file review for the present study, approximately five percent of the children initially diagnosed with PDD-NOS demonstrated an improvement in symptoms and shifted off the PDD spectrum (i.e., 2 of the 41 children initially diagnosed with PDD-NOS). However, a much higher rate of improvement was seen in two other studies, in which 20 percent and 30 percent of children initially diagnosed with PDD-NOS showed improvements (Stone et al., 1999 and Eaves & Ho, 2003, respectively). The present study had a significantly higher number of participants (i.e., n = 41) relative to the other two studies (i.e., n = 9 and 12), which may have contributed to the differences in outcome. It may be that relatively few children initially diagnosed with PDD-NOS who improved at outcome actually returned for a follow-up assessment.

There are no current studies that examine the characteristics of children who shift from a diagnosis of PDD-NOS to a diagnosis off the PDD spectrum. However, a limited number of studies have identified several features associated with a shift from autism to PDD-NOS (see Eaves & Ho, 2003; Gonzalez et al., 1991). More specifically, children who show an improvement in PDD-related symptoms but remain on the PDD spectrum tend to be higher functioning initially (i.e., in terms of cognitive skills), and show improvements in the social interaction domain (see Eaves & Ho, 2003; Gonzalez et al., 1991).

The present sample of four children who shifted from autism to PDD-NOS showed improvements in social interaction skills. In addition to demonstrating a mild decrease in CARS total scores (from a range of 31 to 39, to a range of 29 to 31), the group of four children also showed a decrease in the CARS subscale scores that related to social impairment. Further, while 75 percent of the parents expressed concern about social impairment at the first assessment, none of the parents reported concerns about social impairments at the follow-up. The group of four differed from the samples in the literature, in that they demonstrated significant cognitive impairments (i.e., cognitive ability scores between 3 and 4 standard deviations below average) at both the initial and follow-up assessments. The four children were seen for the first and second assessments at approximately the same ages as the other children in the sample (i.e., 4 years old at the initial assessment and 7 years old at the follow-up assessment).

The two children whose diagnosis shifted off the PDD spectrum from PDD-NOS were also seen at the same age as other children in the sample (i.e., 4 years old at the initial assessment and 6 years old at the follow-up assessment). Each child showed

significant cognitive impairments at the first assessment (i.e., one child scored between 3 and 4 standard deviations below average and the other child scored between 2 and 3 standard deviations below average). Both children showed an improvement of approximately one standard deviation in their cognitive ability level at the follow-up assessment. With regard to symptom presentation, the two children showed a significant improvement in overall symptom severity, and an improvement in each of the three PDDrelated domains. Both parents reported concerns about their child's emotional responsiveness at the first assessment, but not at the follow-up. Further, parent concerns about social skills, language ability, and atypical development were consistent between the two assessments.

The very small sample size limits the extent to which conclusions can be drawn about this group. Generally, the two children initially diagnosed with PDD-NOS who shifted off the PDD spectrum showed improvement in all PDD-related domains, as well as an improvement in cognitive ability level. Similarly, the children who shifted from autism to PDD-NOS resembled other children in the PDD literature, and showed an improvement in social interaction. Identifying the early characteristics that differentiate between those who improve and those who either decline or remain stable should be the next step towards predicting outcome for PDD-NOS.

*Future research.* The present study highlights the need for additional research on PDD-NOS. In addition to addressing the limitations of the present study, further investigation into the early history characteristics and patterns of PDD symptoms associated with an initial diagnosis of PDD-NOS is warranted. In particular, the pattern of PDD symptoms demonstrated by the Change group was somewhat unexpected. At the

first assessment the Change group demonstrated mild impairment in the social and repetitive/stereotyped behaviour domains, with moderate to severe impairment in the communication domain. It was anticipated that the social domain would be the primary area of impairment. However, it may be that communication deficits, such as echolalia, are more obvious than the more subtle social deficits associated with PDD in young children. In addition, communication skills provide the basis for developing social skills, which may explain why social impairments were not readily apparent at the first assessment for the Change group. Further examination of PDD symptom patterns in children initially diagnosed with PDD-NOS will help to address this issue.

The focus of the present study was on children who demonstrated a stable or decreasing level of functional impairment. However, in order to identify outcome predictors for children initially diagnosed with PDD-NOS, it is essential to also examine the symptom patterns and early characteristics of the children who show an improvement in functional ability level. Two potential groups warrant further investigation; those who shift from a diagnosis of PDD-NOS to off the PDD spectrum, and those who show improvements in functional skills but remain on the PDD spectrum (i.e., shift from a diagnosis of autism to PDD-NOS).

The present sample included children who were diagnosed over a 15 year period. Given the length of time between the first and last assessments, there are a number of variables that can provide additional information about the sample, as well as indicate whether changes occurred systematically over time. For example, the number of children with specific PDD diagnoses may have changed with the transition from the DSM-III-R to the DSM-IV. The number of children with different diagnoses (i.e., autism versus

PDD-NOS) can be compared between the beginning and end of the data collection period, or at intervals throughout data collection. In addition, comparing the characteristics, such as symptom patterns and functional skills, of children diagnosed at different intervals may help to identify other variables that are influenced by time.

Finally, the present study focused on children who received both an initial and follow-up diagnostic evaluation. A number of characteristics and factors likely differentiate between children who return for a re-assessment and those who are seen only once. A re-assessment may be due to factors associated with the child, such a complex pattern of behaviours presented initially, or a provisional initial diagnosis. Clinicians can recommend a re-assessment for numerous clinical reasons. Further, parents also have a role in determining whether their child is re-assessed (e.g., parental satisfaction with the initial assessment or their need for assistance in terms of school planning). Future PDD-NOS research should include a comparison of the functional ability levels and early history characteristics of children who received a follow-up evaluation and those who were seen for a single assessment only.

*Summary.* The current conceptualization of PDD-NOS includes children who are mildly affected by PDD symptoms, as well as children who will later meet full criteria for an autism diagnosis, and children who eventually shift off the PDD spectrum. For the group that moves further along the PDD spectrum, significant developmental delays appear to be related to an increase in symptom severity and a decrease in functional ability over time. This group demonstrates an increase in symptom severity in all three PDD domains, as well as a decrease in adaptive ability level. Very early in development (i.e., prior to age 3), this subset of children demonstrates greater impairment and greater

developmental delay than do other children with PDD-NOS. In comparison, the two participants who shifted off the PDD spectrum demonstrated slightly higher levels of functional skills initially, and showed improvements in both cognitive ability and symptom severity. These results suggest that early developmental delay and greater overall impairment are indicative of poor outcome for children who initially present with mild PDD symptoms.

From a clinical perspective, PDD-NOS is not well understood. It is generally viewed as a mild variant of autism, but little is known about its developmental course. The present study suggests that children initially diagnosed with PDD-NOS follow three different developmental pathways: one group maintains a mild, global pattern of impairment, one group demonstrates a shift from mild and moderate impairment to moderate and severe impairment, the third group shifts from mild impairment to off the PDD spectrum. The present study focused on the first two groups. Differences between the two groups are attributed to developmental progression; the group that demonstrates stable, mild impairment develops at a steady pace, whereas the group that demonstrates an increase in impairment appears to experience a lag or a plateau early in development. As a result, the second group demonstrates a full compliment of PDD symptoms later in development.

The results of the present study further suggest that the atypical developmental course of the second group can be identified during the preschool years. More specifically, children who shift from PDD-NOS to autism present with relatively mild PDD symptoms at preschool age, but their pattern of PDD symptoms indicates greater impairment in the communication domain. In addition, children who initially present with

PDD-NOS and later receive a diagnosis of autism also have a history of greater developmental delay than children with stable PDD-NOS.

It is difficult to make a reliable diagnosis of PDD-NOS based on current diagnostic criteria. However, as the results of the present study suggest, a clear understanding of the role of developmental progression in PDD symptom expression is essential in making an accurate diagnosis. Predicting functional ability at outcome assessment is also difficult. These results indicate that a subgroup of children with PDD-NOS experiences a decrease in functional ability over time, and a subgroup experiences an increase in functional ability over time. This finding emphasizes the need for close monitoring and follow-up assessments of young children initially diagnosed with PDD-NOS.

The results of the present study also have implications for the classification of PDDs. The current trend is away from a categorical approach and toward a re-classification of the PDDs as a spectrum. The transition from Pervasive Developmental Disorders to Autism Spectrum Disorder in the DSM-V will more accurately represent the continuum relationship between PDD-NOS and autism. It will also reflect conditions such as the Change group, which shift from mild to moderate impairment during the course of early development, as well as those that shift off the PDD spectrum.

Changing the description of PDDs from categorical to continuum will not alter the relationship between PDD-NOS and autism. PDD-NOS will continue to represent a mild variant of autism, and as such, it will likely occupy one end of the autism spectrum. As the present results suggest, there will be subgroups within the Autism Spectrum that demonstrate changes in functional ability over time. Changes in functional ability may suggest that subgroups follow different developmental pathways. Further examination of

groups that experience changes in functional ability, and the role of developmental progression in particular, will be helpful in understanding the complex nature of Autism Spectrum Disorder.

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## References

- Adrien, J.L., Faure, M., Perrot, A., Hameury, L., Garreau, B., Barthelemy, C., & Sauvage, D. (1991). Autism and family home movies: Preliminary findings. *Journal* of Autism and Developmental Disorders, 21, 43-49.
- Adrien, J.L., Lenoir, P., Martineau, J., Perrot, A., Hameury, L., Larmande, C., & Sauvage, D. (1993). Blind ratings of early symptoms of autism based upon family home movies. *Journal of the American Academy of Child and Adolescent Psychiatry*, 32, 617-626.
- American Psychiatric Association. (1987). Diagnostic and Statistical Manual of Mental Disorders (3<sup>rd</sup> ed., Rev.). Washington, DC: Author.
- American Psychiatric Association. (1994). Diagnostic and Statistical Manual of Mental Disorders (4<sup>th</sup> ed.). Washington, DC: Author.
- Bailey, A., Phillips, W., & Rutter, M. (1996). Autism: Towards an integration of clinical, genetic, neuropsychological and neurobiological perspectives. *Journal of Child Psychology and Psychiatry*, 37, 89-126.
- Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., Drew, A. (2000). A screening instrument for autism at 18 months of age: A 6-year follow-up study. *Journal of American Child and Adolescent Psychiatry*, 39, 694-702.
- Baranek, G.T. (1999). Autism during infancy: A retrospective video analysis of sensorymotor and social behaviours at 9-12 months of age. *Journal of Autism and Developmental Disorders*, 29, 213-224.
- Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can autism be detected at 18 months? The needle, the haystack, and the CHAT. *British Journal of Psychiatry*, 161, 839-842.
- Baron-Cohen, S., Tager-Flusberg, H., & Cohen, D. (1993). Understanding Other Minds. New York: Oxford University Press.
- Baron-Cohen, S., Cox, A., Baird, G., Swettenham, J., Nightingale, N., Morgan, K., et al. (1996). Psychological markers in the detection of autism in infancy in a large population. *British Journal of Psychiatry*, 168, 158-163.
- Bayley, N. (1969). Bayley Scales of Infant Development: Birth to TwoYears. San Antonio, TX: Psychological Corporation.
- Bernabei, P., Camaioni, L., & Levi, G. (1998). An evaluation of early development in children with autism and pervasive developmental disorders from home movies: preliminary findings. *Autism*, 2, 243-258.

- Bernabei, P. & Camaioni, L. (2001). Developmental profile and regression in a child with autism. Autism: The International Journal of Research and Practice, 5, 287-297.
- Bishop, D. V.M. & Norbury, C.F. (2002). Exploring the borderlands of autistic disorder and specific language impairment: A study using standard diagnostic instruments. *Journal of Child Psychology and Psychiatry*, 43, 917-929.
- Bodfish, J.W., Symons, F.J., Parker, D.E., & Lewis, M.H. (2000). Varieties of repetitive behavior in autism: Comparisons to mental retardation. *Journal of Autism and Developmental Disabilities*, 30, 237-243.
- Boelte, S. & Poustka, F. (2000). Diagnosis of autism: The connection between current and historical information. *Autism*, 4, 382-390.
- Bryson, S.E. & Smith, I.M. (1998). Epidemiology of autism: Prevalence, associated characteristics, and implications for research and service delivery. *Mental Retardation and Developmental Disabilities Research Reviews*, 4, 97-103.
- Buitelaar, J.K., & van der Gaag, R. (1998). Diagnostic rules for children with PDD-NOS and Multiple Complex Developmental disorder. *Journal of Child Psychology and Psychiatry*, 39, 911-919.
- Buitelaar, J.K., van der Gaag, R., Klin, A., & Volkmar, F. (1999). Exploring the boundaries of Pervasive Developmental Disorder Not Otherwise Specified: Analyses of data from DSM-IV Autistic disorder field trial. Journal of Autism and Developmental Disorders, 29, 33-43.
- Burack, J.A. & Volkmar, F.R. (1992). Development of low- and high-functioning autistic children. *Journal of Child Psychology and Psychiatry*, 33, 607-616.
- Carpenter, M., Pennington, B.F., & Rogers, S.J. (2002). Interrelations among socialcognitive skills in young children with autism. *Journal of Autism and Developmental Disorders*, 32, 91-106.
- Carpentieri, S., & Morgan, S.B. (1994). Brief report: A comparison of patterns of cognitive functioning of autistic and nonautistic retarded children on the Stanford-Binet-Fourth Edition. Journal of Autism and Developmental Disorders, 24, 215-223.
- Carpentieri, S., & Morgan, S.B. (1996). Adaptive and intellectual functioning in autistic and nonautistic retarded children. Journal of Autism and Developmental Disorders, 26, 611-620.
- Carter, A.S., Volkmar, F.R., Sparrow, S.S., Wang, J., Lord, C., Dawson, G., Fombonne, E., et al. (1998). The Vineland Adaptive Behavior Scales: Supplementary norms for

individuals with autism. Journal of Autism and Developmental Disorders, 28, 287-302.

- Chakrabarti, S. & Fombonne, E. (2001). Pervasive developmental disorders in preschool children. Journal of the American Medical Association, 285, 3093-3099.
- Charman, T. (1999). Autism and the pervasive developmental disorders. Current Opinions in Neurology, 12, 155-159.
- Charman, T. & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. Journal of Child and Adolescent Psychology and Psychiatry, 43, 289-305.
- Coplan, J. (2000). Counseling parents regarding prognosis in autistic spectrum disorder. *Pediatrics*, 105, 65-67.
- Cox, A., Klein, K., Charman, T., Baird, G., Baron-Cohen, S., Swettenham, J., et al. (1999). Autism spectrum disorders at 20 and 42 months of age: Stability of clinical and ADI-R diagnosis. *Journal of Child Psychology and Psychiatry*, 40, 719-732.
- Cox, R.D. (1993). Normal childhood development from birth to five years. In E. Schopler, M.E. Van Bourgondien, & M.M. Bristol (Eds.), *Preschool Issues in Autism* (pp.39-57). New York: Plenum Press.
- Dahlgren, S.O. & Gillberg, C. (1989). Symptoms in the first two years of life. European Achieves of Psychiatry and Neurology Science, 238, 169-174.
- Davidovitch, M., Glick, L., Holtzman, G., Tirosh, E., & Safir, M.P. (2000). Developmental regression in autism: Maternal perception. Journal of Autism and Developmental Disabilities, 30, 113-119.
- De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child and Adolescent Psychiatry*, 7, 131-136.
- Eaves, L. C., & Ho, H.H. (1996). Brief report: Stability and change in cognitive and behavioural characteristics of autism through childhood. *Journal of Autism and Developmental Disorders*, 26, 557-569.
- Eaves, L. C., & Ho, H.H. (2003). The very early identification of autism: Outcome to age 4 ½ to 5. Manuscript submitted for publication.
- Eisenmajer, R., Prior, M., Leekam, S., Wing, L., Ong, B., Gould, J., & Welham, M. (1998). Delayed language onset as a predictor of clinical symptoms in pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 28, 527-533.

- Fein, D., Stevens, M., Dunn, M., et al. (1999). Subtypes of pervasive developmental disorder: Clinical characteristics. *Child Neuropsychology*, 5, 1-23.
- Filipek, P.A., Accardo, P.J., Barank, G.T., Cook, E.H., Dawson, G., Gordon, B., et al. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 29, 439-484.
- Fisch, G.S., Simensen, R.J., & Schroer, R.J. (2002). Longitudinal changes in cognitive and adaptive behavior scores in children and adolescents with the Fragile X Mutation or autism. *Journal of Autism and Developmental Disorders*, 32, 107-115.
- Fitzgerald, M. (1999). PDD-NOS [Letter to the editor]. Journal of the American Academy of Child and Adolescent Psychiatry, 38, p. 229.
- Fombonne, E. (1998). Epidemiology of autism and related conditions. In F.R. Volkmar (Ed.), Autism and Pervasive Developmental Disorders (pp.32-63). Cambridge: Cambridge University Press.
- Fombonne, E. (1999). The epidemiology of autism: A review. *Psychological Medicine*, 29, 769-786.
- Freeman, B.J., Ritvo, E.R., Needleman, R., & Yokota, A. (1985). The stability of cognitive and linguistic parameters in autism: A five-year prospective study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 24, 459-464.
- Gillberg, C., Ehlers, S., Schaumann, H., Jakobsson, G., Dahlgren, S., Lindblom, R., et al. (1990). Autism under age 3 years: A clinical study of 28 cases referred for autistic symptoms in infancy. *Journal of Child Psychology and Psychiatry*, 31, 921-931.
- Gillberg, C., Nordin, V., & Ehlers, S. (1996). Early detection of autism. Diagnostic instruments for clinicians. *European Child and Adolescent Psychiatry*, 5, 67-74.
- Gillberg, C. & Steffenburg, S. (1987). Outcome and prognostic factors in Infantile Autism and similar conditions: A population-based study of 46 cases followed through puberty. *Journal of Autism and Developmental Disorders*, 17, 273-287.
- Gillberg, C. & Wing, L. (1999). Autism: Not an extremely rare disorder. Acta *Psychiatrica Scandinavica*, 99, 399-406.
- Gillham, J.E., Carter, A.S., Volkmar, F.R., & Sparrow, S.S. (2000). Toward a developmental operational definition of autism. *Journal of Autism and Developmental Disorders*, 30, 269-278.
- Gonzalez, N.M., Alpert, M., Shay, J., Campbell, M., & Small, A.M. (1993). Autistic children on follow-up: Change of diagnosis. *Psychopharmacology Bulletin*, 29, 353-358.

- Gray, K.M. & Tonge, B.J. (2001). Review article: Are there early features of autism in infants and preschool children? *Journal of Pediatric Child Health*, 37, 221-226.
- Harris, S., & Handleman, J. (2000). Age and IQ at intake as predictors of placement for young children with autism: A four-to six-year follow-up. *Journal of Autism and Developmental Disorders*, 30, 137-142.
- Howlin, P. & Goode, S. (1998). Outcome in adult life for people with autism and Asperger's Syndrome. In F.R. Volkmar (Ed.), Autism and Pervasive Developmental Disorders (pp. 209-241). Cambridge: Cambridge University Press.
- Howlin, P. & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients. Autism, 1, 135-162.

Indiana Resource Center for Autism (1991). Autism Assessment Sourcebook.

- Joseph, R.M., Tager-Flusberg, H., & Lord, C. (2002). Cognitive profiles and socialcommunicative functioning in children with autism spectrum disorder. *Journal of Child Psychology and Psychiatry*, 43, 807-821.
- Klin, A., Lang, J., Cicchetti, D.V., & Volkmar, F.R. (2000). Brief report: Inter-rater reliability of clinical diagnosis and DSM-IV criteria for Autistic Disorder: Results of the DSM-IV autism field trial. *Journal of Autism and Developmental Disorders*, 30, 163-167.
- Klin, A., Mayes, L.C., Volkmar, F.R., & Cohen, D.J. (1995). Multiplex developmental disorder. *Developmental and Behavioral Pediatrics, 16*, S7-S11.
- Klinger, L.G. & Renner, P. (2000). Performance-based measures in autism: Implications for diagnosis, early detection, and identification of cognitive profiles. *Journal of Clinical Child Psychology*, 29, 479-492.
- Kurita, H. (2001). Current status of autism studies. Seishin Shinkeigaku Zasshi Psychiatria et Neurologia Japonica, 103, 64-75.
- Leiter, R.G. (1948). Leiter International Performance Scale. Chicago: Stoelting Company.
- Liss, M., Harel, B., Fein, D., Allen, D., Dunn, M., Feinstein, C., et al. (2001). Predictors and correlates of adaptive functioning in children with developmental disorders. *Journal of Autism and Developmental Disorders*, 31, 219-230.
- Lord, C. (1995). Follow-up of two-year-olds referred for possible autism. Journal of Child Psychology and Psychiatry, 36, 1365-1382.

Lord, C. (2000a). Preface. Journal of Autism and Developmental Disabilities, 30, 181-182.

- Lord, C. (2000b). Ask the Editor [Editor's response]. Journal of Autism and Developmental Disabilities, 30, 265.
- Lord, C. & Risi, S. (1998). Frameworks and methods in diagnosing autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 4, 90-96.
- Lord, C., Risi, S., Lambrecht, L., Cook, E.H., Leventhal, B.L., DiLavore, P.C., et al. (2000). The Autism Diagnostic Observation Schedule-Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal* of Autism and Developmental Disorders, 30, 205-223.
- Lord, C. & Schopler, E. (1989a). The role of age at assessment, developmental level, and test in the stability of intelligence scores in young autistic children. *Journal of Autism and Developmental Disorders*, 19, 483-489.
- Lord, C. & Schopler, E. (1989b). Stability of assessment results of autistic and nonautistic language-impaired children from preschool years to early school age. *Journal of Child Psychology and Psychiatry*, 30, 575-590.
- Lord, C. & Volkmar, F. (2002). Genetics of childhood disorders: XLII. Autism, Part 1: Diagnosis and assessment of autistic spectrum disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41, 1134-1136.
- Loveland, K.A., & Kelley, M.L. (1988). Development of adaptive behavior in adolescents and young adults with autism and Down syndrome. *American Journal* on Mental Retardation, 93, 84-92.
- Luteijn, E.F., Luteijn, F., Jackson, S., Volkmar, & Minderaa, R. (2000a). The Children's Social Behavior Questionnaire for Milder Variants of PDD Problems: Evaluation of the psychometric characteristics. *Journal of Autism and Developmental Disorders*, 30, 317-330.
- Luteijn, E.F., Serra, M., Jackson, S., Steenhuis, M.P., Althaus, M., Volkmar, F., & Minderra, R. (2000b). How unspecified are disorders of children with a pervasive developmental disorder not otherwise specified? A study of social problems in children with PDD-NOS and ADHD. European Child and Adolescent Psychiatry, 9, 168-179.
- Mahoney, W.J., Szatmari, P., MacLean, J.E., Bryson, S.E., Bartolucci, G., Walter, S.D., et al.(1998). Reliability and accuracy of differentiating pervasive developmental disorder subtypes. *Journal of American Academy of Child and Adolescent Psychiatry*, 37, 278-285.

- Marcus, L.M. & Stone, W.L. (1993). Assessment of the young autistic child. In E. Schopler, M.E. Van Bourgondien, & M.M. Bristol (Eds.), *Preschool Issues in Autism* (pp. 149-173). New York: Plenum Press.
- Mayes, S.D. & Calhoun, S.L. (1999). Symptoms of autism in young children and correspondence with the DSM. *Infants and Young Children*, 12, 90-97.
- Mayes, S.D. & Calhoun, S.L. (2003). Ability profiles in children with autism. Autism: International Journal of Research and Practice, 7, 65-80.
- Mayes, L., Volkmar, F., Hooks, M., & Cicchetti, D. (1993). Differentiating Pervasive Developmental Disorder Not Otherwise Specified from autism and language disorders. *Journal of Autism and Developmental Disorders*, 23, 79-90.
- McGee, G., Morrier, M., & Daly, T. (1999). An incidental teaching approach to early intervention for toddlers with autism. *Journal of the Association for Persons with Severe Handicaps*, 24, 133-146.
- Moore, V. & Goodson, S. (2003). How well does early diagnosis of autism stand the test of time? Autism: International Journal of Research and Practice, 7, 47-63.
- Myhr, G. (1998). Autism and other Pervasive Developmental Disorders: Exploring the dimensional view. Canadian Journal of Psychiatry, 43, 589-595.
- Nordin, V. & Gillberg, C. (1998). The long-term course of autistic disorders: Update on follow-up studies. Acta Psychiatrica Scandinavica, 97, 99-108.
- Ohta, M., Nagai, Y., Hara, H., & Sasaki, M. (1987). Parental perception of behavioural symptoms in Japanese Autistic children. *Journal of Autism and Developmental Disorders*, 17, 549-563.
- Osonoff, S., South, M., & Miller, J.N. (2000). DSM-IV-defined Asperger syndrome: Cognitive, behavioral and early history differentiation from high-functioning autism. *Autism: The International Journal of Research and Practice*, 4, 29-46.
- Osterling, J. & Dawson, G. (1994). Early recognition of children with autism: A study of first birthday home videotapes. *Journal of Autism and Developmental Disorders*, 24, 247-257.
- Oswald, D.P., & Volkmar, F.R. (1991). Brief report: Signal detection analysis of items from the Autism Behavior Checklist. Journal of Autism and Developmental Disorders, 21 (4), 543-549.
- Prior, M., Leekam, S., Ong, B., Eisenmajer, R., Wing, L., Gould, J., & Dowe, D. (1998). Are there subgroups within the autism spectrum? A cluster analysis of a group of

children with autistic spectrum disorders. Journal of Child Psychology and Psychiatry, 39, 893-902.

- Robertson, J.M., Tanguay, P.E., L'Ecuyer, S., Sims, A., & Waltrip, C. (1999). Domains of social communication handicap in autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38, 738-745.
- Robins, D.L., Fein, D., Barton, M.L., & Green, J.A. (2001). The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and Pervasive Developmental Disorders. *Journal of Autism and Developmental Disorders*, 31, 131-144.
- Rodrigue, J.R., Morgan, S.B, & Geffken, G.R. (1991). A comparative evaluation of adaptive behavior in children and adolescents with autism, Down syndrome, and normal development. *Journal of Autism and Developmental Disorders, 21*, 187-196.
- Rogers, S.J. (2001). Diagnosis of autism before the age of 3. International Review of Mental Retardation, 23, 1-31.
- Rogers, J.S. & Di Lalla, D. (1990). Age of symptom onset in young children with pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, 863-872.
- Rutter, M. & Schopler, E. (1992). Classification of pervasive developmental disorders. Journal of Autism and Developmental Disorders, 22, 459-481.
- Sattler, J.M. (2002). Assessment of Children: Behavioral and Clinical Applications (4th ed.), San Diego: Jerome M. Sattler, Publisher, Inc.
- Scambler, D., Rogers, S.J., & Wehner, E.A. (2001). Can the Checklist for Autism in Toddlers differentiate young children with autism from those with developmental delays? Journal of the American Academy of Child and Adolescent Psychiatry, 40, 1457-1463.
- Schatz, J., & Hamdan-Allen, G. (1995). Effects of age and IQ on adaptive behavior domains for children with autism. Journal of Autism and Developmental Disorders, 25, 51-60.
- Schopler, E., Reichler, R.J., Bashford, A., Lansing, M.D., & Marcus, L.M. (1990). The *Psychoeducational Profile Revised (PEP-R)*, Austin: Pro-Ed.
- Schopler, E., Reichler, R.L., DeVellis, R.F., & Daly, K. (1980). Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). Journal of Autism and Developmental Disorders, 10, 91-103.

- Schopler, E., Reichler, R.L., & Renner, B.R. (1988). *The Childhood Autism Rating Scale*. Los Angeles: Western Psychological Services.
- Sevin, J.A., Matson, J.L., Coe, D., Love, S.R., Matese, M.J., & Benavidez, D.A. (1995). Empirically derived subtypes of pervasive developmental disorders: A cluster analytic study. *Journal of Autism and Developmental Disorders*, 25, 561-578.
- Short, A.B. & Schopler, E. (1988). Factors relating to age of onset in autism. Journal of Autism and Developmental Disorders, 18, 207-216.
- Sicotte, C. & Stemberger, R.M.T. (1999). Do children with PDDNOS have a Theory of Mind? Journal of Autism and Developmental Disorders, 29, 225-233.
- Siegel, B., Pliner, C., Eschler, J., & Elliott, G.R. (1988). How children with autism are diagnosed: Difficulties in identification of children with multiple developmental delays. *Developmental and Behavioral Pediatrics*, 9, 199-204.
- Singer, G.H.S., Irvin, L.K., Irvine, B., Hawkins, N.E., Hegreness, J., & Jackson, R. (1993). Helping families adapt positively to disability: Overcoming demoralization through community supports. In G.H.S. Singer & L.E. Powers (Eds.). Families, Disability, and Empowerment: Active Coping Skills and Strategies for Family Interventions (pp. 67-83), Baltimore, MD: Paul H. Brooks Publishing Company.
- Smith, B., Chung, M.C., Vostanis, P. (1994). The path to care in autism: Is it better now? Journal of Autism and Developmental Disorders, 24, 551-563.
- Sparrow, S.A., Rescorla, L.A., Provence, S., Condon, S.O., Goudreau, D., & Cicchetti, D.V. (1986). Follow-up of "atypical" children - a brief report. Journal of the American Academy of Child and Adolescent Psychiatry, 25, 181-185.
- Sponheim, E. (1996). Changing criteria of autistic disorders: A comparison of the ICD-10 research criteria and DSM-IV with DSM-III-R, CARS and ABC. Journal of Autism and Developmental Disorders, 26, 513-525.
- Statistics Canada. (2003, September). Community Highlights for Essex County. Retrieved March 9, 2004, from Statistics Canada website: http://www.statcan.ca/start.html.
- Stella, J., Mundy, P., & Tuchman, R. (1999). Social and non-social factors in the Childhood Autism Rating Scale. Journal of Autism and Developmental Disorders, 29, 307-317.
- Stevens, M.C., Fein, D.A., Dunn, M., Allen, D., Waterhouse, L.H., Feinstein, C., & Rapin, I. (2000). Subgroups of children with autism by cluster analysis: A longitudinal examination. Journal of the American Academy of Child and Adolescent Psychiatry, 39, 346-352.

Stone, W.L., Hoffman, E.L., Lewis, S.E., & Ousley, O.Y. (1994). Early recognition of autism: Parental reports versus clinical observation. Archives of Pediatric and Adolescent Medicine, 148, 174-179.

÷

- Stone, W.L., & Hogan, K.L. (1993). A structured parent interview for identifying young children with autism. Journal of Autism and Developmental Disorders, 23, 639-652.
- Stone, W.L., Lee, E.B., Ashford, L., Brissie, J., Hepburn, S.L., Coonrod, E.E., & Weiss, B.H. (1999). Can autism be diagnosed accurately in children under 3 years? *Journal* of Child Psychology and Psychiatry, 40 (2), 219-226.
- Stone, W.L. & Lemanek, K.L. (1990). Parental report of social behaviors in autistic preschoolers. Journal of Autism and Developmental Disorders, 20, 513-522.
- Stone, W.L. & Lemanek, K.L., Fishel, P.T., Fernandex, M.C., & Altemeier, W.A. (1990). Play and imitation skills in the diagnosis of autism in young children. *Pediatrics*, 86, 267-272.
- Stone, W.L., Ousley, O.Y., Hepburn, S.L., Hogan, K.L., & Brown, C.S. (1999). Patterns of adaptive behavior in very young children with autism. *American Journal on Mental Retardation*, 104, 187-199.
- Stone, W.L., Ousley, O.Y., Yoder, P.J., Hogan, K.L., & Hepburn, S.L. (1997). Nonverbal communication in two- and three-year-old children with autism. Journal of Autism and Developmental Disorders, Special Issue: Preschool Issues in Autism, 27, 677-696.
- Stone, W.L. & Yoder, P.J. (2001). Predicting spoken language level in children with autism spectrum disorders. *Autism*, 5, 341-361.
- Sturmey, P., Matson, J.L., & Sevin, J.A. (1992). Brief report: Analysis of the internal consistency of three autism scales. *Journal of Autism and Developmental Disorders*, 22, 321-328.
- Szatmari, P. (1992). The validity of autistic spectrum disorders: A literature review. Journal of Autism and Developmental Disorders, 22, 583-599.
- Szatmari, P. (2000). The classification of autism, Asperger's syndrome, and pervasive developmental disorder. *Canadian Journal of Psychiatry*, 45, 731-738.
- Szatmari, P., Bryson, S.E., Streiner, D.L., Wilson, F., Archer, L., & Ryerse, C. (2000). Two-year outcome of preschool children with autism or Asperger's syndrome. *American Journal of Psychiatry*, 157, 1980-1987.

- Tager-Flusberg, H., Joseph, R., & Folstein, S. (2001). Current directions in research on autism. Mental Retardation and Developmental Disabilities Research Reviews, 7, 21-29.
- Tanguay, P.E. (2000). Pervasive developmental disorders: A 10-year review. Journal of the American Academy of Child and Adolescent Psychiatry, 39, 1079-1095.
- Tanguay, P.E., Robertson, J.M., & Derrick, A.M. (1998). A dimensional classification of autism spectrum disorder by social communication domains. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37, 271-277.
- Tanguay, P.E., Robertson, J.M., & Derrick, A.M. (1999). PDD-NOS [Letter to the editor]. Journal of the American Academy of Child and Adolescent Psychiatry, 38, p.229.
- Tolbert, L., Brown, R., Fowler, P., & Parsons, D. (2001). Brief report: Lack of correlation between age of symptom onset and contemporaneous presentation. *Journal of Autism and Developmental Disorders*, 31, 241-245.
- Towbin, K.E. (1997). Pervasive developmental disorder not otherwise specified. In D.J. Cohen & F.R. Volkmar (Eds.), *Handbook of Autism and Pervasive Developmental Disorders* (pp.123-147). New York: Wiley.
- Van Bourgondien, M.E., Marcus, L.M., & Schopler, E. (1992). Comparison of DSM-III-R and Childhood Autism Rating Scale for diagnoses of autism. *Journal of Autism* and Developmental Disorders, 22, 493-506.
- Van der Gaag, R.J., Buitelaar, J., Van den Ban, E., Bezemer, M., Njio, L., Van Engeland, H. (1995). A controlled multivariate chart review of multiple complex developmental disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34, 1096-1106.
- Vig, S. & Jedrysek, E. (1999). Autistic features in young children with significant cognitive impairment: Autism or mental retardation? *Journal of Autism and Developmental Disorders*, 29, 235-248.
- Volkmar, F.R., Cicchetti, D.V., Dykens, E., Sparrow, S.S., Leckman, J.F., & Cohen, D.J. (1988). An evaluation of the Autism Behavior Checklist. Journal of Autism and Developmental Disorders, 18, 81-97.
- Volkmar, F.R., Cook, E., Pomeroy, J., Realmuto, G., & Tanguay, P. (1999). Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38, 32S-54S.

- Volkmar, F.R., Klin, A., Siegel, B., Szatmari, P., Lord, C., Campbell, M., et al. (1994). Field trial for autistic disorder: Results of the DSM-IV Autism Field Trial. Journal of American Psychiatry, 151, 1361-1367.
- Volkmar, F.R., Klin, A., & Cohen, D.J. (1997). Diagnosis and classification of autism and related conditions. In D.J. Cohen & F.R. Volkmar (Eds.). Handbook of Autism and Pervasive Developmental Disorders. New York: Wiley.
- Volkmar, F.R., Shaffer, D., & First, M. (2000). PDDNOS in DSM-IV [Letter to the editor]. Journal of Autism and Developmental Disorders, 30, p.74-75.
- Volkmar, F.R., Sparrow, S.S., Goudreau, D., Cicchetti, D.V., Paul, R., & Cohen, D. (1987). Social deficits in autism: An operational approach using the Vineland Adaptive Behavior Scales. *Journal of the American Academy of Child and Adolescent Psychiatry*, 26, 156-161.
- Vostanis, P., Smith, B., Chung, M.C., & Corbett, J. (1994). Early detection of childhood autism: A review of screening instruments and rating scales. *Child: Care, Health, and Development, 20*, 165-177.
- Vostanis, P., Smith, B., Corbett, J., Sungum-Paliwal, R., Edwards, E., Gingell, K., et al. (1998). Parental concerns of early development in children with autism and related disorders. *Autism*, 2, 229-242.
- Wadden, N.P.K., Bryson, S.E., & Rodger, R.S. (1991). A closer look at the Autism Behavior Checklist: Discriminant validity and factor structure. *Journal of Autism* and Developmental Disorders, 21, 529-541.
- Waterhouse, L., Morris, R., Allen, D., Dunn, M., Fein, D., Feinstein, C., et al. (1996) Diagnosis and classification in autism. *Journal of Autism and Developmental Disorders*, 26, 59-86.
- Wechsler, D. (1989). Manual for the Wechsler Preschool and Primary Scale of Intelligence, Revised (WPPSI-R). San Antonio, TX: Psychological Corporation.
- Wechsler, D. (1991). Manual for the Wechsler Intelligence Scale for Children, Third Edition (WISC-III). San Antonio, TX: Psychological Corporation.
- Werner, E., Dawson, G., Osterling, J., & Dinno, N. (2000). Brief report: Recognition of autism spectrum disorder before one year of age: A retrospective study based on home videotapes. *Journal of Autism and Developmental Disorders*, 30, 157-162.
- Wilkinson, K.M. (1998). Profiles of language and communication skills in autism. Mental Retardation and Developmental Disabilities Research Reviews, 4, 73-79.

Wolf-Schein, E. (1996). The autistic spectrum disorder: A current review. Developmental Disabilities Bulletin, 24, 33-55.

Young, R.L., Brewer, N., & Pattison, C. (2003). Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism: The International Journal of Research and Practice*, 7, 125-143.

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## Appendix A

## DSM-IV Diagnostic Criteria for Autistic Disorder

The following criteria were adapted from the *Diagnostic and Statistical Manual of* Mental Disorders, 4<sup>th</sup> Edition (p. 70):

A. 6 or more items from the following, with at least two from (1), and one each from (2) and (3):

(1) Qualitative impairment in social interaction (minimum 2 items)

- a) marked impairment in eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- b) failure to develop peer relationships appropriate to developmental level
- c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
- d) lack of social or emotional reciprocity
- (2) Qualitative impairments in communication (minimum 1 item)
  - a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
  - b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
  - c) stereotyped and repetitive use of language or idiosyncratic language
  - d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

- (3) Restricted repetitive and stereotyped patterns of behavior, interests and activities (minimum 1 item)
  - a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - b) apparently inflexible adherence to specific, nonfunctional routines or rituals
  - c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - d) persistent preoccupation with parts of objects

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B. Delays prior to age 3 in one of the following areas: social interaction, language as used in social communication, or symbolic or imaginative play

C. Rett's Disorder or Childhood Disintegrative Disorder were ruled out

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### Appendix B

## Proposed Diagnostic Algorithm for PDD-NOS

The following algorithm was adapted from Buitelaar and Van der Gaag (1998, p. 919) and Buitelaar et al. (1999, p. 42-43).

Diagnostic Algorithm:

A. A total of three (or more) items from (1), (2), and (3), with at least one item from (1)

- (1) Qualitative impairment in social interaction:
  - a) marked impairment in the use of multiple non-verbal behaviours such as eyeto-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - b) failure to develop peer relationships appropriate to developmental level
  - c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
  - d) lack of social or emotional reciprocity
- (2) Qualitative impairments in communication:
  - a) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
  - b) stereotyped and repetitive use of language or idiosyncratic language

(3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities:

a) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

B. Does not meet criteria for Autistic Disorder or for another pervasive developmental disorder

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## Appendix C

#### Criterion Checklist for PDD-NOS (Luteijn et al., 2000).

Rate each item on the following scale:

- 1. Not present
- 2. Few, if any symptoms. Minimal or no impairment in school and social functioning
- 3. A moderate number of symptoms are present. Interference with functioning ranges between mild and severe.
- 4. Many symptoms are present. A significant, pervasive, or widespread impairment is apparent in functioning at home, at school, and with peers.

Social Interaction:

- 1. Impairment in the use of eye to eye gaze to regulate social interaction
- 2. Impairment in the use of facial expression to regulate social interaction
- 3. Impairment in the use of body postures or gestures to regulate social interaction
- 4. Failure to develop peer relationships appropriate to developmental level
- 5. A lack of spontaneous seeking to share enjoyment with others
- 6. A lack of spontaneous seeking to share interests or achievements with others (e.g. by a lack of showing, bringing, or pointing out objects of interest).
- 7. Impairment or deviant response to other people's emotions.
- 8. A lack of modulation of behaviour according to social context.

Communication Impairments:

- 9. Delay in the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
- 10. Impairment in the ability to initiate a conversation with others.

11. Impairment in the ability to sustain a conversation with others.

- 12. Stereotyped and repetitive use of language.
- 13. Idiosyncratic language.

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14. Lack of varied, spontaneous make-believe play appropriate to developmental level.

15. Lack of varied, spontaneous social imitative play appropriate to developmental level. Repetitive and Stereotyped Behaviours:

- 16. Preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in intensity.
- 17. Preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in focus.
- 18. Apparently inflexible adherence to specific, non-functional routines or rituals.
- 19. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).

20. Preoccupation with parts of objects (e.g., their odour, feel of their surface, or noise).

Indicate yes or no to the following three questions:

- Delays or abnormal functioning in social interaction, with onset prior to age 3 years.
- Delays or abnormal functioning in language as used in social communication, with onset prior to age 3 years.
- Delays or abnormal functioning in symbolic or imaginative play, with onset prior to age 3 years.

## Appendix D

#### Outline of Parent Interview

Early History Information:

- 1. Describe any difficulties with the pregnancy or birth of the child
- 2. Describe any problems in the first year with eating, sleeping, health, or other
- 3. Indicate the age at which the child met developmental milestones (i.e., sat, crawled, walked, spoke first word, put 2 to 3 words together)
- 4. Describe any major illnesses or accidents that resulted in hospitalization of the child
- 5. Detail any learning, behavioural, emotional or medical problems in siblings, parents, or other relatives

Parents' Understanding of Child's Behaviours:

- What are the parents' primary concerns regarding child's behavior at the time of the assessment
- 2. Describe parents' explanations for child's behavior
- How old was the child when the parents were first concerned about the child's behaviour and development
- 4. What are the parents' goals for the assessment

Treatment, Interventions and Education:

- Child's current grade, and whether child failed any grades. Also daycare experiences.
- 2. Detail special assistance child receives at home (e.g., respite care, in-home worker, behavioural interventions, financial support, OT, PT, Speech Therapy) or

while at school / daycare (i.e., classroom assistance, one-to-one aide, resource teacher, behavioural interventions, OT, PT, Speech Therapy)

- 3. Describe type of classroom (i.e., integrated, segregated)
- 4. Outline child's academic strengths and weaknesses

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## Appendix E

# Developmental History in the Diagnosis of Autism/PDD

Discuss each behavior from the time when the child was 3 to 4 years old, or younger. Language Domain:

- 1. When the child was young they wondered if he or she might be deaf
- Growing up, the child rarely pointed to things as a means of requesting an item or to draw attention to an object or person unless prompted by someone
- 3. The child's language development was unusual in that he or she had unusual first words (e.g., "grapefruit") or unusual pragmatics or speech may have developed initially but then ceased to develop further

Sensory Domain:

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- Child was fascinated with spinning objects and watched or spun objects for long periods
- Child was a picky eater (i.e., ate only certain foods sometimes related to colour, texture, or temperature). May have had trouble moving from baby foods to junior foods
- 3. Child either had an extreme reaction to loud sounds or extreme visual stimuli or may show no reaction. Child may be inconsistent in the level of reaction to similar stimuli
- Minor changes in the child's life such as changes in daily schedules, room arrangements, or in the usual car route caused extreme upset for the child Social Domain:
- 1. The child was not interested in playing with other children his or her own age.

More responsive to play involving an adult. Did not do well in group games.

2. The child also ignored siblings or played very little with them

Play Domain:

- The child had and continued to have certain fascinations (i.e., intense interest in mechanical things or continually repeats commercials or sings songs heard on TV or radio)
- 2. The child insisted on holding a favourite object and became extremely upset if this object was taken away

# VITA AUCTORIS

Lena Janine Freeman was born in 1973 in Vancouver, British Columbia. She graduated in 1991 from Steveston Senior Secondary School and went on to complete a B.A. in Psychology at the University of British Columbia in 1995. Lena completed her M.A. in Child Clinical Psychology at the University of Windsor in 1998. She is currently completing her PhD at the University of Windsor.