PROSPECTIVE IDENTIFICATION OF AUTISM SPECTRUM DISORDERS IN INFANCY AND TODDLERHOOD:

The Social Attention and Communication Study (SACS)

Submitted by

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JOURNAL PUBLICATIONS RELATED TO THIS THESIS

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2006

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2008

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2009

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2008

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Autism diagnosis crucial. By Melinda Marshall. 22nd July, 2008

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Timing vital for detecting autism. By Kamahl Cogdon. 15th September, 2008

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Autism breakthrough. By Kamahl Cogdon. 26th September, 2008

Progress Leader

A first for autism. By Cassie Maher. 30th September, 2008

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Promising program. News Section. 21st October, 2008

Television Program

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Autism diagnosis. 6th November, 2008

2009

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Early diagnosis set to help children with autism. 10th February, 2009

Preston Leader
Fast alert program on autism. 16th February, 2009

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ABC Radio National, All in the Mind
Autism: Genetics, early detection and the ethics of screening newborns. With Natasha Mitchell. 16th – 18th May, 2009

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Autism rates much higher than previously thought. With Sophie Scott. 23rd July, 2009

Television Program

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Australasian Science Magazine.
Early autism diagnosis offers hope. By Steven Luntz. May 2010

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ABBREVIATIONS

AD – Autistic Disorder

ADI-R – Autism Diagnostic Interview-Revised

ADOS – Autism Diagnostic Observation Schedule

ASD – Autism Spectrum Disorder

ASD-sibs – Siblings of Children with Autism Spectrum Disorder ("high-risk" siblings)

AspD – Asperger's Disorder

CHAT – Checklist for Autism in Toddlers

CDC – Centers for Disease Control and Prevention

CDU – Child Development Unit

DD/LD – Developmental and/or Language Delays

DSM-IV-TR – Diagnostic and Statistic Manual of Mental Disorders, Fourth Edition, Text Revision

DQ – Developmental Quotient

ESAT – Early Screening of Autistic Traits Questionnaire

ITC – Infant-Toddler Checklist

LGA – Local Government Area

MCH – Maternal and Child Health

M-CHAT – Modified Checklist for Autism in Toddlers

MSEL – Mullen Scales of Early Learning

PDD-NOS – Pervasive Developmental Disorder-Not Otherwise Specified

PPV – Positive Predictive Value

SACS – Social Attention and Communication Study

TD – Typically Developing

THESIS SUMMARY

Despite behavioural markers of Autism Spectrum Disorders (ASDs) being evident within the first year of life, there remains little research on the prospective identification of children with ASDs in a community-based setting, prior to 18-months of age. The aim in the Social Attention and Communication Study (SACS) was to identify infants and toddlers 'at risk' of an ASD during their first 2 years of life. A total of 241 Maternal and Child Health (MCH) nurses were trained on the early signs of ASDs at 8-, 12-, 18-, and 24-months of age. Utilising a developmental surveillance approach with a community-based sample, a cohort of 22,168 children was monitored on early social attention and communication behaviours. Infants and toddlers identified as 'at risk' for an ASD by their MCH nurse were referred to the SACS team from 12-months of age. Developmental assessments were conducted at 6-monthly intervals until 2 years of age, when a diagnostic assessment was completed. A total of 216 children were referred to the SACS team, with 110 being formally assessed. Of these, 89 children were classified with an ASD at 24-months and 20 children had developmental and/or language delays (DD/LD), resulting in a Positive Predictive Value of 81%. The estimated rate of ASDs in the SACS cohort ranged from 1:119 to 1:233 children. Estimated sensitivity ranged from 69% to 83.8%, and estimated specificity ranged from 99.8% to 99.9%. The key markers of ASDs from 12- to 24-months of age were impaired *Eye Contact* and *Pointing*; from 18-months of age, *Social Communication* ('showing' behaviours) became important in discriminating between children with ASDs and children with DD/LD. Investigation of children's developmental profiles revealed that children with ASDs displayed an uneven cognitive profile, with *Receptive Language* being the most impaired ability from early in life. It was concluded that developmental surveillance of social attention and communication behaviours, which differ according to the age at which the child is monitored, results in the accurate identification of children with ASDs between 12- to 24-months of age. Education on early signs of ASDs is recommended for all primary health care professionals to facilitate earlier identification and diagnosis, so that intervention can begin at the earliest possible opportunity.

STATEMENT OF AUTHORSHIP

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma. No other person's work has been used without due acknowledgement in the main text of the thesis. The thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

This thesis contains several journal articles. As such, a number of people have made contributions to the studies and material presented in this thesis. Associate Professor Cheryl Dissanayake made a number of contributions, including providing the initial idea for the project, assisting with the research design and analysis of these studies, and in the drafting of the manuscripts. Lael Ridgway assisted in the development and dissemination of the training workshops to Maternal and Child Health nurses as part of the study outlined in this thesis. Melissa Coulson and Irene Giaprakis assisted with the assessment of the children and the administration work involved in the study outlined. Carmela Germano and Ben Ong assisted with the data analysis. Predominantly, however, I conducted the empirical research presented here, produced all of the written material, analysed the data, and provided the conceptual and theoretical framework for the thesis.

All research procedures reported in this thesis were approved by the La Trobe University Human Ethics Committee (HEC approval number 06-94) and the Victorian Department of Human Services Human Research Ethics Committee (DHS HREC approval number 77/06).

Josephine Barbaro

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FORMAT AND STRUCTURE OF THESIS

The Higher Degrees Committee of La Trobe University permits Doctor of Philosophy candidates to submit a series of manuscripts (published, in-press, in-submission) as an alternative to the traditional thesis style. The guidelines for this format are supplied in 'THESIS – Appendix A' (p. 282). This alternative format was adopted for two reasons: to invite ongoing international peer review and critique, and to facilitate thought and discussion in research communities as a result of any publications. The articles presented here represent a series of studies that follow a logical sequence. The introductory and general discussion chapters are more economical than those of a traditional thesis, and serve to integrate and highlight the main conclusions of each article.

This thesis is comprised of seven sections. The first section provides a general introduction to Autism Spectrum Disorders (ASDs) and a rationale for the proceeding chapters. The first published paper contains a review of the literature on the early signs, early identification tools, and early diagnosis of ASDs, and in its conclusions, sets up the empirical studies that follow. The empirical work is presented in a series of four papers. Each paper corresponds to one manuscript, which has been published or submitted for publication. The seventh section provides a general discussion that summarises each paper, and highlights and integrates the main findings and issues raised by each paper. Limitations and future research directions are also addressed.

This thesis has been formatted in accordance with the guidelines of the American Psychological Association (APA, 2010), regardless of the format and style requirements of the international peer-reviewed journal to which manuscripts were submitted. The only exception is that figures and tables for each study are presented in the body of the manuscript, rather than being attached at the end.

Reference

American Psychological Association. (2010). *Publication manual of the American Psychological Association.* (6th ed.). Washington, DC: American Psychological Association.

THESIS OUTLINE

A brief outline of the thesis is provided here to assist the reader, as it comprises a series of published papers and unpublished papers submitted for publication.

General Introduction

The general introduction provides an overview of Autism Spectrum Disorders (ASDs), current prevalence rates, a brief overview of the early markers of autism, as well as an introduction to the topic of this thesis, including the research objectives.

Paper 1 (Literature Review)

Paper one (Barbaro & Dissanayake, 2009) provides a review of the current literature on the early signs of ASDs, the early identification tools available for use with infants and toddlers, and the diagnostic tools capable of diagnosing ASDs in toddlers. This paper also highlights problems with the screening tools currently available, and makes recommendations for future research, which are addressed in this thesis.

Paper 2

Paper two (Barbaro, Dissanayake, & Ridgway, 2010) is a didactic paper written for Paediatric Nurses and related primary health care practitioners. Its purpose was to outline the successful implementation of the Social Attention and Communication Study (SACS), and details the approach utilised for early identification of ASDs within the Maternal and Child Health (MCH) system. The paper provides a detailed description of the early markers used to identify ‘at risk’ infants and toddlers, and includes the results of the evaluation of the SACS undertaken by the MCH nurses who implemented the study.

Paper 3

Paper three (Barbaro & Dissanayake, 2010) describes the first empirical study from this thesis. It details the results from the developmental surveillance of infants and toddlers undertaken at MCH centres from 8- to 24-months for the purpose of identifying children ‘at risk’ of ASDs. The Positive Predictive Value, as well as the estimated specificity, sensitivity, and prevalence rates in the SACS cohort are each described in this paper. A number of recommendations are made for the future surveillance of children with an ASD.

Paper 4

Paper 4 (submitted for publication) examines which behaviours used in the SACS, to identify and refer 'at risk' children, were the most important markers of an ASD. The presence/absence of each behaviour monitored at 12-, 18-, and 24-months was analysed to determine its efficacy in distinguishing between children with Autistic Disorder, broader Autism Spectrum Disorder, and developmental and/or language delay. It was advocated that the most discriminatory and predictive makers of ASDs be used during Level 2 surveillance.

Paper 5

Paper 5 (submitted for publication) examines the developmental profiles of the infants and toddlers who were assessed within the SACS. Its purpose was to investigate group differences between children with ASDs and children with developmental and/or language delays on the Mullen Scales of Early Learning (MSEL; Mullen, 1995) from as early as 12-months. Within group differences on the individual subscales of the MSEL, as well as change across time from 12- to 24-months, were also explored. On the basis of the findings, implications for early intervention are discussed.

General Discussion

The general discussion provides a summary of each of the papers presented in this thesis. The main findings, which contribute to our understanding of ASDs in early life and its early detection, are discussed. The methodological limitations of the research are outlined, and directions for future research are explored prior to the final conclusions being drawn.

Reference

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GENERAL INTRODUCTION

OVERVIEW OF AUTISM SPECTRUM DISORDERS

Autism Spectrum Disorders (ASDs) are lifelong neurobiological disorders, and are among the most prevalent, severe, and debilitating developmental disorders affecting children. These conditions are characterised by a triad of impairments, including qualitative impairments in social interaction, verbal and non-verbal communication, and a restricted repertoire of activities and interests combined with repetitive and/or stereotyped behaviours (Diagnostic and Statistical Manual of Mental Disorders-IV-TR; DSM-IV-TR; American Psychiatric Association, APA; 2000; International Classification of Diseases-10, ICD-10; World Health Organization, WHO, 1993). The diagnostic criteria for ASDs are virtually identical in the DSM-IV-TR (APA, 2000) and ICD-10 (WHO, 1993); the DSM-IV-TR is the diagnostic manual used in Australia.

Although Leo Kanner (1943) was the first to detail autism, namely social aloofness, complex rituals, and insistence on sameness, it was Lorna Wing (1969) who identified the *triad of impairments*, which were less restrictive than the criteria originally outlined by Kanner. Autism Spectrum Disorder is a general term used for individuals who display the triad of impairments as detailed by Wing, but some of these individuals may not meet Kanner's more restrictive criteria.

The term 'Autism Spectrum Disorder' is inclusive of three of the five Pervasive Developmental Disorders outlined in the DSM-IV-TR (APA, 2000), and comprises Autistic Disorder (AD; 'classic autism'), Asperger's disorder (AspD), and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Autistic Disorder involves profound deficits in all three areas of the triad, and is associated with a wide range of cognitive functioning. Approximately three-quarters of individuals with AD have an associated intellectual disability (i.e., IQ < 70, APA, 2000), and are thus referred to as 'low-functioning'. However, recent data indicate that only 41% to 44% of individuals on the *entire spectrum* (all ASDs)

have a co-morbid intellectual disability (Centers for Disease Control and Prevention; CDC, 2009). The remaining individuals who do not have associated intellectual disability are classified as having 'high-functioning autism' (HFA; Tager-Flusberg, Joseph, & Folstein, 2001). Although individuals with HFA do not possess associated intellectual impairments, they share the same triad of impairments as individuals with 'low-functioning' AD. Thus, the term 'high-functioning' can be misleading. Furthermore, it must be noted that the term 'high-functioning autism' is not listed in the DSM-IV-TR (APA, 2000) as a separate PDD; rather, it is a term adopted by researchers, professionals and parents alike to differentiate those individuals with AD with and without intellectual impairment.

Individuals with AspD closely resemble those with HFA (i.e., social-emotional and communicative impairments, and a restricted range of activities and interests, without accompanying intellectual impairments), but they do not show evidence of the delays in language development that characterise AD (APA, 2000; Sigman & Capps, 1997). Thus language onset is the main criterion differentiating AspD and HFA. However, despite their absence of language delays, individuals with AspD do have problems in communication, as they do not use or understand language in the typical way. In particular, their pragmatic language skills are impaired, such that their understanding and interpretation of language is often concrete and inflexible. Consequently, these individuals experience difficulties with the comprehension of language that is figurative or sarcastic (Adams, Green, Gilchrist, & Cox, 2002; Bishop, 1989; Eisenmajer et al., 1996; Wing, 1981).

The expressive language of individuals with AspD is often also atypical, and can be characterised by preoccupations with obsessive interests; it is also rarely used to elaborate on another's conversational topic (Adams et al., 2002; Bishop, 1989; Eisenmajer et al., 1996; Wing, 1981). Furthermore, whereas young typically developing (TD) children use their

language to both obtain their needs and to 'share' their world with others by expressing interest in people, places, and objects, young children with AspD (and HFA) typically use their language to fulfil their needs (Gillberg, 2002).

As individuals with HFA and AspD present with very similar behavioural profiles, there has been much discussion as to whether these groups should be considered together as part of the same spectrum of disorder, rather than being conceptualised as distinct diagnostic entities (Barbaro & Dissanayake, 2007; Frith, 1991; Leekam, 2007; Macintosh & Dissanayake, 2004; Mayes, Calhoun, & Crites, 2001). In a review of the empirical evidence of the similarities and differences between HFA and AspD, Macintosh and Dissanayake (2004) concluded that although there are some quantitative differences between the groups, there are few qualitative differences on most of the main symptoms and associated features of the disorders. It is therefore argued that these two groups should be seen as part of an autism *spectrum*, which is currently being recognised in the drafting of the DSM-V (see Appendix A).

Pervasive Developmental Disorder-Not Otherwise Specified is the category adopted for those individuals who do not fulfil all the DSM-IV-TR (APA, 2000) criteria for a diagnosis of AD or AspD. These individuals may have a late age of onset, atypical or sub-threshold symtomatology, or they may display all of these (APA, 2000). Although the least known of all the ASDs, PDD-NOS accounts for over a third of individuals with an ASD, and is considered a 'milder variant' of ASD (Chakrabarti & Fombonne, 2001; Gernsbacher, Dawson, & Goldsmith, 2005).

Males are at an increased risk of having an ASD, with the ratio of males to females at approximately 3-4:1 (CDC; 2009; Yearing-Allsopp et al., 2003). The gender ratio for those individuals with ASD without an intellectual disability (i.e., HFA and AspD) is even higher

at 9:1 (Baron-Cohen & Hammer, 1997; Wing, 1981). Females with an ASD who do not have an intellectual disability are less likely to be diagnosed than males with the same profile, as it has been suggested that they may be more socially competent than affected males (Filipek et al., 1999; McLennan, Lord, & Schopler, 1993; Volkmar, Szatmari, & Sparrow, 1993). Thus, the ratio between males and females with milder variants of ASD may not be a high as suggested in the literature.

Although the underlying neuropathology of ASDs remains unknown, there is much evidence to suggest that these conditions have a strong genetic component. First degree relatives of individuals with an ASD have a 50- to 100-fold increased risk of having an ASD (Rutter, Bailey, Simonoff, & Pickles, 1997). They also have higher rates of social, emotional and cognitive difficulties, and affective disorders such as anxiety and depression (Bailey, Palferman, Heavey, & Le Couteur, 1998; DeLong, 1994; Hughes, Leboyer, & Bouvard, 1997; Piven et al., 1991, 1992). Furthermore, twin studies indicate that there is a 60% concordance rate for AD, a 71% concordance rate for ASD, and a 91% concordance rate for social and communication deficits amongst monozygotic twins (Bailey et al., 1995). The recurrence rate of ASD in siblings of affected individuals is reported to be between 2% to 8% (Muhle, Trentacoste, & Rapin, 2004). It is for this reason that many studies of early markers of ASDs focus on the infant siblings of children with an ASD (Rogers, 2009; Zwaigenbaum et al., 2009).

Prevalence Rates

As the conceptualisation of ASD has changed from Kanner's (1943) original descriptions, so too have the prevalence rates (Bryson, Rogers, & Fombonne, 2003; Wing, 1969; Wing & Attwood, 1987; Wing & Gould, 1979; Wing & Potter, 2002). The first epidemiological study by Lotter (1966), undertaken in the United Kingdom, reported the

prevalence of autism at 4 per 10,000 individuals. However, the most recent epidemiological surveys have found that the best estimate prevalence rates for the combined ASDs is currently around 100 per 10,000 individuals, or 1% of the population (Baird et al., 2006; CDC, 2009; Kogan et al., 2009).

The only epidemiological study carried out in Australia (commissioned by the Australian Advisory Board on Autism Spectrum Disorders) is based on service records, and reported a prevalence rate of 1 in 160 individuals (Williams, MacDermott, Ridley, Glasson, & Wray, 2008). Indeed, the Australian Bureau of Statistics (ABS) figures indicate more than a two-fold increase in new diagnoses of ASD from 13,000 cases in 1998, to 30,000 in 2003 (Australian Bureau of Statistics, 2004).

Early Markers of ASDs

As indicated in *Paper 1* of this thesis, there are several early markers for the identification of ASDs in infancy and toddlerhood. Abnormalities in social attention and communication are the most frequently reported behaviours in infants who go on to receive a diagnosis of an ASD, and are the most predictive of an ASD diagnosis (Barbaro & Dissanayake, 2009). Currently, Level 1 screening instruments, using social attention and communication behaviours as key markers, have been able to prospectively identify previously unidentified cases of ASDs in community-based samples. However, the results from these few studies have reported poor sensitivity on their measures, or have had high false positive rates, such that no instrument to date can be recommended for universal screening (Barbaro & Dissanayake, 2009).

A highly predictive, but brief, observational tool containing a checklist of the behaviours that are absent in infants with ASDs would prove invaluable for the detection of these infants. As a result, children who would previously go unrecognised until 3 years of age

could potentially be identified though routine and repeated developmental surveillance, and reliably diagnosed by at least 2 years of age. The repeated monitoring of behaviours throughout the infancy period, rather than screening at only one age, may prove more useful in detecting ASD in infancy.

The Current Study – The Social Attention and Communication Study (SACS)

In Victoria, Australia, infant development is monitored by trained Maternal and Child Health (MCH) nurses at regular intervals from birth to 3.5 years. As 96% of Victorian babies access the MCH service soon after birth, and attendance remains relatively high within the first two years of life, this universal service has enormous potential to identify infants at risk of a host of developmental disorders, including ASDs. Of particular relevance here is the fact that some of the behaviours noted as impaired in children with ASDs aged 24-months and younger are routinely monitored and recorded at key MCH consultations. In addition to these behaviours, the standard developmental assessments undertaken by MCH nurses include a range of social, communication and language behaviours that are absent in young children with ASDs, and as such, are also relevant to the identification of these children.

There were four main objectives in undertaking the research described in this thesis: 1) to conduct a longitudinal study within the universal MCH service in metropolitan Melbourne, to determine whether routine and repeated monitoring of social attention and communication behaviours can be used to prospectively identify infants and toddlers who will receive a diagnosis of an ASD at 24-months; 2) to highlight the role that primary health care professionals can play in the early identification of ASDs; 3) to identify which specific social attention and communication behaviours used to identify children ‘at risk’ are the most discriminating and predictive markers of ASDs from 12- to 24-months, and 4) to investigate

the developmental profiles of the children identified, as few studies to date have investigated the cognitive development of very young children with ASDs.

The objectives in this study were achieved by monitoring infants' and toddlers' development in key areas during four of the routine consultations undertaken at MCH centres at 8-, 12-, 18-, and 24-months. The study was necessarily longitudinal, with infants who showed an absence of key behaviours at these consultations being followed up over the first two years of life. This repeated sampling design has advantages over the administration of a screening tool at a single age, as the chances of identifying these children in infancy and toddlerhood is greatly increased. Once children 'at risk' of ASDs were identified, the early behavioural markers of ASDs, and their developmental profiles across the second year of life, were investigated.

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Appendix A

DSM-V 299.00 Autistic Disorder Proposed Revision

Autism Spectrum Disorder

Must meet criteria 1, 2, and 3:

1. Clinically significant, persistent deficits in social communication and interactions, as manifest by all of the following:
    a. Marked deficits in nonverbal and verbal communication used for social interaction;
    b. Lack of social reciprocity;
    c. Failure to develop and maintain peer relationships appropriate to developmental level.
2. Restricted, repetitive patterns of behavior, interests, and activities, as manifested by at least TWO of the following:
    a. Stereotyped motor or verbal behaviors, or unusual sensory behaviors;
    b. Excessive adherence to routines and ritualized patterns of behaviour;
    c. Restricted, fixated interests.
3. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).

PAPER 1

LITERATURE REVIEW OF ASDs IN INFANCY AND TODDLERHOOD

Paper 1

Autism Spectrum Disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification tools, and early diagnosis

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Abstract

To date, the biological basis of Autism Spectrum Disorders (ASDs) remains unknown. Thus, identification and diagnosis is reliant on behavioural presentation and developmental history. There have been significant advances in our knowledge of the early signs of ASDs through the use of retrospective videotape analysis, parental report, screening studies, and more recently, studies of high-risk infant siblings. Despite behavioural markers being identified within the first year of life, the current average age of diagnosis for ASDs remains at around 3 years of age or older. Consequently, these children are not receiving intervention in their early years, which is increasingly recognised as an important time to begin intervention. There remains little research on the prospective identification of these children in a community-based sample prior to 18-months of age. It is recommended that future prospective studies monitor behaviour repeatedly over time, thereby increasing the opportunity to identify early manifestations of ASDs, and facilitating the charting of subtle behavioural changes that occur in the development of infants and toddlers with an ASD.

Key words: autism spectrum disorder; autistic disorder; infancy; early identification; early diagnosis; screening tools

Autism Spectrum Disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification tools, and early diagnosis

The last decade has seen significant advances in our knowledge of the very early manifestations of Autism Spectrum Disorders (ASDs), beginning with the use of retrospective home videotapes for the purpose of examining behavioural features in infants who later received a diagnosis of an ASD[1]. This increasing knowledge of the early ASD phenotype has led to attempts to prospectively identify ASDs in infancy and toddlerhood. Importantly, prospective studies allow the researcher to elicit behaviours at a specific age, rather than relying on spontaneous presentation on videotape, or retrospective parental report. More recently, prospective studies of infant siblings of children with an ASD have also contributed to increased knowledge of the early phenotype.

Despite the unquestioned neurobiological basis of ASDs, limited knowledge regarding the underlying neuropathology for these related conditions has meant that diagnosis is reliant on behavioural presentation and developmental history. Although there now is increasing empirical information on the very early developmental histories and behavioural presentation of children with ASDs, scientific knowledge about the early signs vastly precedes standard practice, with the average age of diagnosis still at around 3 years of age. Thus, the purpose in this paper is to bring together recent advances in the field, including recent research involving 'high-risk' infants, to inform practitioners about the very early signs of ASDs, as well as the instruments used to identify these signs, consequently informing their current practice.

[1] Unless otherwise stated, ASD will be used throughout the review to refer to Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified.

Together, this body of work will be reviewed with the ultimate aim of reducing the age at which ASDs are diagnosed. Early identification and diagnosis provides the best opportunity for early intervention, which can prevent ASDs from becoming fully manifest in the developing child, thereby serving to maximise developmental outcomes (Dawson, 2008; Helt et al., 2008).

Age of Onset / Recognition of Symptoms

Although the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (DSM-IV-TR; American Psychiatric Association, APA, 2000) and the International Classification of Diseases-10 (ICD-10; World Health Organization, WHO, 1993) state that the onset of impairment in Autistic Disorder (AD) must be prior to 36-months, a large proportion of children manifest developmental problems between 12- and 24-months (De Giacomo & Fombonne, 1998; Rogers & Di Lalla, 1990; Short & Schopler, 1988), with some showing abnormalities prior to 12-months of age (Adrien et al., 1991, 1992, 1993; Baranek, 1999; Osterling & Dawson, 1994, 1999; Stone, Hoffman, Lewis, & Ousley, 1994; Werner, Dawson, Osterling, & Dinno, 2000).

Neither the DSM-IV-TR (APA, 2000) nor the ICD-10 (WHO, 1993) specify an age of onset criterion for Asperger's Disorder (AspD). However, onset in AspD is usually reported to be later than in AD, as these children develop language at an appropriate age and display less severe symptoms. As there are fewer symptoms to alert parents and professionals that development is impaired, AspD is typically not identified prior to children becoming part of a preschool or school setting (i.e., usually after 4 years of age; Brereton & Tonge, 2002; Fitzgerald & Corvin, 2001). Nonetheless, it *is* possible to identify some (albeit a very small percentage) children with AspD prior to 36-months (McConachie, Le Couteur, & Honey, 2005; Scott, 2005). Thus, it is the *recognition* of impairments in AspD, and not onset, which occurs later than 36-months.

Individuals with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), by definition, do not need to have an onset of impairment prior to 36-months (APA, 2000; WHO, 1993). However, this is not typical of most individuals with PDD-NOS (Buitelaar, Van der Gaag, Klin, & Volkmar, 1999).

Infant Signs of ASDs: Review of the Retrospective Literature

Retrospective Videotape Analyses

Adrien and colleagues were the first researchers to utilise home videotapes to assess the behaviours of children with and without an ASD before and after their first birthday (Adrien et al., 1991, 1992, 1993). Using the Infant Behavioural Summarized Evaluation Scale, the key behaviours that differentiated the groups were in the areas of socialisation (ignores people; prefers aloneness; poor social interaction; no eye contact) and communication (lack of vocal communication; lack of appropriate facial expressions; no social smile; lack of gestures; no or poor imitation of others).

In their study of first birthday videotapes, Osterling and Dawson (1994) found that four behaviours correctly differentiated 90% of their sample of children later diagnosed with an ASD from those without an ASD. These were a low frequency of looking at others (including eye contact) and orienting to name call, an absence of showing objects, and a lack of pointing. These findings were later replicated (Mars, Mauk, & Dowrick, 1998; Osterling & Dawson, 1999). A deficit in orientating to name call has consistently been found to differentiate children with and without an ASD as early as 8-months of age, in both retrospective and prospective studies (Baranek, 1999; Nadig et al., 2007; Werner et al., 2000). Interestingly, Osterling, Dawson, and Munson (2002) found that while 12-month-olds with an ASD *and* associated intellectual disability oriented to their names and looked at others less frequently than infants with *only* an

intellectual disability, both groups engaged in repetitive motor actions more frequently when compared to typically developing (TD) infants. Thus, repetitive and stereotyped behaviours may not be specific to ASDs, but associated with intellectual disability; the findings suggest that social attention and communication behaviours are better early indicators of ASDs (Werner & Dawson, 2005).

Observations of home videotapes by Clifford and Dissanayake (2008) revealed that infants later diagnosed with an ASD showed deficits in social smiling and eye contact as early as 6-months of age compared to infants without an ASD. In toddlerhood, affected children showed deficits in initiating and responding to joint attention behaviours. They found that requesting behaviours were less problematic, indicating that it is the *sharing* quality of joint attention behaviours that is deficient in these children, and not *the act* of requesting attention. Clifford et al. (2007) also found a lack of protodeclarative showing in children with AD compared to TD and developmentally delayed (DD) infants.

Although the use of retrospective home videotapes is an effective means of charting the very early development of children with an ASD, there are limitations to this methodology. Firstly, the behaviours observed are constrained to selective and less naturalistic representations of the child's behaviour, as the videotapes are usually of the child's birthday party or a family event, and not of undesirable or unpredictable situations. Furthermore, it is not possible to elicit a desired behaviour, such as response to a social smile, thus limiting observations to behaviours spontaneously demonstrated in the situation (Baranek, 1999).

Retrospective Parental Reports

Retrospective parental reports have long been used as a source of information about the development of ASDs in infancy. Vostanis et al. (1998) requested the parents of children with an ASD, learning disabilities, and language disorders to complete a questionnaire about their child's development between 12- and 18-months. The children with an ASD were rated significantly lower on items involving social attention and communication, including imitation, pointing at objects, playing peek-a-boo, seeking and enjoying cuddles, checking for their parents, interest in other children, and waving bye-bye without being asked.

Young, Brewer, and Pattison (2003) asked 153 parents of children with an ASD to complete a questionnaire concerning their child's very early development, and the age of onset of problematic behaviours. Parents were primarily concerned about their child's difficulties in social awareness and understanding, a lack of shared enjoyment in interaction, and poor eye contact. Little interest in other children, and a lack of social referencing (joint attention behaviours) were also reported, with 95% of parents indicating that these behaviours occurred before the age of 2 years.

The Early Development Interview (EDI) was recently developed to chart the development of children with an ASD from birth to 2 years (Werner & Dawson, 2005, 2006). The parents of young children with an ASD, DD, and TD children were interviewed with the EDI regarding various behaviours including social attention and communication behaviours. The children with an ASD were reported to have more social deficits than TD children from as early as 3- to 6-months of age, and more deficits than children with DD at 13- to 15-months of age. Consistent with the retrospective videotape studies, these deficits included poor eye contact, failure to orient to their name, deficits in the use of joint attention, and little engagement in social

interaction. Werner and Dawson (2005) concluded that social behaviours were the best indicators of diagnostic differences between children with an ASD and TD children, as well as between children with an ASD and DD, albeit at a later age.

Baranek and colleagues (Baranek, Watson, Crais, & Reznick, 2003; Reznick, Baranek, Reavis, Watson, & Crais, 2007; Watson et al., 2007) developed a parental questionnaire that focuses on the behaviour of children at risk for ASDs prior to 12-months, called The First Year Inventory (FYI). In order to examine the construct validity of the FYI, Watson et al. (2007) developed a retrospective version, and gave this to parents of preschoolers with an ASD, developmental disability, and TD children. The items that were most useful in distinguishing between ASDs and developmental disability were orienting to name call, following a point, social orienting, interest in children his/her age, social smiling, facial expression, playing peek-a-boo, and demanding attention of the caregiver. Items on imitation, expressive communication, sensory processing, regulatory patterns, reactivity, and repetitive behaviours generally differentiated children with an ASD and developmental disability from TD children, but were not good at distinguishing the former groups. Thus, once again, the items that best distinguish children with and without an ASD are located in the realm of social attention and communication.

A limitation of parental report studies is that parents' responses are vulnerable to incorrect memory recall, recall biases, and distortion of events (Zwaigenbaum et al., 2005). Furthermore, various factors, including parental alertness in recognising behaviour, socio-economic status, personality, intelligence, and parental mental health can influence their responses, reducing reliability of the data (Gillberg, 1989). However, it is worth noting that the

findings from the parent report studies do largely concur with the findings from the videotape studies (Clifford & Dissanayake, 2008).

In addition to the behavioural signs identified by retrospective studies, more recently, biological markers, namely enlarged head circumference, have been investigated as possible signs of ASDs. Although head circumference size is normal or near normal at birth, subsequent accelerated head growth over the first 2 years of life leads to approximately 20% of children with an ASD having a head circumference above the 97th percentile (Dissanayake, Bui, Huggins, & Loesch, 2006; Fukumoto et al., 2008; Zwaigenbaum et al., 2008). Used together with social attention and communication behaviours, head circumference data may be a useful accompaniment when determining the diagnostic status of a child. However, this information must be used with caution as no prospective data have yet been collected to show whether atypical head growth in very early infancy can predict a diagnosis of an ASD (Zwaigenbaum et al., 2008).

Age of Diagnosis

Despite the accumulating evidence that signs of ASDs are present in early infancy, the interval between many parents' first concerns and a definitive diagnosis is around 3 to 4 years (Mandell, Novak, & Zubritsky, 2005). This interval increases to as high as 9 years for those diagnosed with AspD (Baron-Cohen, Allen, & Gillberg, 1992; Chung, Smith, & Vostanis, 1995; Howlin & Asgharian, 1999; Howlin & Moore, 1997; Young et al., 2003). Recent developments in the early identification field have facilitated lowering the average age of diagnosis for the ASDs, with the average age of diagnosis in the USA being 3.1 years for AD, 3.9 years for PDD-NOS, and 7.2 years for AspD (Mandell et al., 2005). However, given that the literature is showing that signs of ASDs are present in the first year of life, the mean ages for diagnosis are

still very high, especially for ASDs other than AD. There are a number of reasons for the late diagnosis of ASDs despite their early behavioural manifestations, which are outlined below.

Current Diagnostic Criteria

A significant limitation to an early diagnosis is the fact that many of the characteristic behaviours currently used in diagnosis of ASDs, based on the DSM-IV-TR (APA, 2000) and the ICD-10 (WHO, 1993) criteria, are not apparent before 36-months. These criteria are based on symptoms that are rarely seen in infants and toddlers with ASDs, but are common in older children and adults (Gray & Tonge, 2001; Stone et al., 1999). For example, difficulties socialising with peers and deficits in language skills are symptoms that develop later in childhood, and are thus not easily observed in infancy (Stone et al., 1994). Some of the behaviours may also be secondary, developing to compensate for the primary 'core' deficits of ASDs, which are those that are seen early in the development of the disorder (Rogers & Pennington, 1991; Young & Brewer, 2002).

In addition, the DSM-IV-TR (APA, 2000) and ICD-10 (WHO, 1993) require a presence of repetitive behaviours, interests, stereotypies, or rituals to diagnose an ASD. This is problematic when attempting to diagnose very young children, as these behaviours present in only a minority of children prior to 18-months and tend to develop, or become more apparent, at around 3 to 4 years of age (Gray & Tonge, 2001; Mooney, Gray, & Tonge, 2006; Turner, 1999; Young & Brewer, 2002). Therefore, the absence of these behaviours in infants and toddlers with social and communication impairments does not *exclude* the possibility of an ASD (Gray & Tonge, 2001). However, more recently, data suggests that repetitive and stereotyped movements can distinguish between children with an ASD and those with delayed or typical development late in the second year of life (Morgan, Wetherby, & Barber, 2008). The focus on behaviours

evident later in development inevitably means that the diagnosis of infants and toddlers is delayed. In order to promote early diagnosis, the criteria in current diagnostic manuals require modification to reflect those behaviours that are present in the infancy period (Lord, 1995).

Late Onset / Regression

Although most children with an ASD show problems before 12-months of age, there is a cohort of children who appear to develop typically in the first 15- to 21-months of life. These infants reach appropriate language and social skill milestones, but then progressively 'lose' these skills, with the majority losing skills between the ages of 13- to 18-months (Goldberg et al., 2003; Interactive Autism Network, 2008; Kurita, 1985; Volkmar, Cohen, Hoshino, Rende, & Paul, 1988; Volkmar, Stier, & Cohen, 1985; Werner & Dawson, 2005). This 'regression' occurs in approximately 20% of children with an ASD, although this figure has been reported to be as high as 49% (Davidovitch, Glick, Holtzman, Tirosh, & Safir, 2000; Filipek et al., 1999; Hoshino et al., 1987; Kurita, 1985; Siperstein & Volkmar, 2004). The differing percentages may be an outcome of the diagnostic status of the child, with a recent report (Interactive Autism Network, 2008) charting the incidence of regression to be highest in those with a diagnosis of AD (as opposed to AspD and PDD-NOS).

The most frequently reported skill loss is language, followed by social skills (Davidovitch et al., 2000; Goldberg et al., 2003; Siperstein & Volkmar, 2004). However, it should be noted that most cases of regression do not involve *completely* normal development prior to regression (Lord, Shulman, & DiLavore, 2004; Richler et al., 2006; Werner & Dawson, 2005), with some children having lower language abilities than their TD peers prior to regression (Brown & Prelock, 1995; Siperstein & Volkmar, 2004). Nonetheless, the existence of regression in a subset of children with ASDs means that professionals must remain cognizant of this group

of children. If this period of regression remains unrecognised, diagnoses may be unnecessarily delayed.

Language Development

It is usually the absence of typically developing language, which becomes evident at about 2 years, that leads to children being referred and diagnosed with an ASD (Rice, Warren, & Betz, 2005). Delay in language development is one of the first and most frequently expressed concerns of parents of children later diagnosed with an ASD (De Giacomo & Fombonne, 1998; Howlin & Asgharian, 1999; Young et al., 2003). It is thus not surprising that delays in referral are seen when a child is verbal, and are exacerbated when the child does not have associated intellectual disability. These children usually receive a diagnosis of AspD, which, as previously mentioned, is diagnosed much later than AD (Brereton & Tonge, 2002; Fitzgerald & Corvin, 2001). Indeed, Mandell et al. (2005) found that children with severe language deficits received a diagnosis of an ASD 1.2 years earlier than children with less severe language deficits.

Knowledge of Infant Symptoms

Most general practitioners and paediatricians do not have specialised skills or training regarding ASDs in infancy (Baron-Cohen et al., 1992). Consequently, they do not possess sufficient clinical expertise to identify the subtle symptoms of ASDs in infancy, and often attribute any abnormalities to general developmental problems (De Giacomo & Fombonne, 1998). Too often, parents are reassured by their physician and told “not to worry”, and that “they’ll grow out of it”. Howlin and Asgharian (1999), studying over 770 families in the UK, found that over *a quarter* of parents of children with AD and *a third* of parents of children with AspD were reassured that their child was developing normally. The average age of the children with AD when parents first sought help was 2 years, and with AspD, 3.5 years; yet, on average, a

diagnosis was given at 5.5 years of age for the children with AD, and 11 years of age for the children with AspD.

What is most concerning is the lack of familiarity amongst practitioners with the tools to identify ASDs. Wiggins, Baio, and Rice (2006) found that 70% of practitioners do not use a diagnostic instrument when assessing for an ASD. Furthermore, Dosreis, Weiner, and Newschaffer (2006) found that 82% of the paediatricians sampled screened for general developmental delays, but only 8% screened for ASDs. The main reason cited was lack of familiarity with specific tools for ASDs (62% of respondents).

Even in toddlerhood, many physicians are not recognising the signs of ASDs, and are unnecessarily delaying diagnosis. As a consequence, children with an ASD are not receiving intervention in their critical early years (Chung et al., 1995; Dawson, 2008; Prizant & Wetherby, 1988; Rogers, 1996, 2001; Rutter, 1983).

Importance of Early Detection and Diagnosis

Early identification of the signs of ASDs is the first step to facilitating early referral and diagnosis. Early diagnosis provides the best opportunity for early intervention, which serves to maximise developmental outcomes for affected children and their families. It is widely recognised that the earlier intervention begins in a child's development, the better the opportunities to move the young child toward a more typical developmental trajectory, due to the plasticity of the young brain (Dawson, 2008; Shonkoff & Phillips, 2000). However, few studies have investigated the efficacy of intervention prior to 2 years of age, and there continues to be a need for more Randomised Controlled Trial (RCT) studies in this area (Dawson, 2008; McConachie & Diggle, 2007; Rogers & Vismara, 2008). Despite this, the results from these few studies, including those that use case reports and single-subject designs, are promising (Dawson,

2008; Green, Brennan, & Fein, 2002; Harris & Handelman, 2000; Mahoney, Boyce, Fewell, Spiker, & Wheeden, 1998; Mahoney & Perales, 2005; McGee, Morrier, & Daly, 1999; Rogers & Vismara, 2008; Vismara & Rogers, 2008; Vismara, Rogers, & Colombi, 2009).

Importantly, the onset of secondary (compensatory) behaviours may be prevented, or at least minimised, with early intervention (Young & Brewer, 2002; Young et al., 2003). Furthermore, if a child is referred before a 'drop off' in language and social skills, the impact of early intervention is even greater, as it may prevent some of these losses (Dawson, 2008). Mundy and Crowson (1997) proposed a 'cybernetic model' of ASDs, whereby an Initial Pathological Process (IPP; i.e., a decrease in attending to and processing social stimuli) feeds back upon itself over the first 2 years of life, resulting in a Secondary Neurological Disturbance (SND; i.e., resulting in secondary deficits of ASDs). They argue that without early intervention, the effects of SND push the child with an ASD further away from the path of typical development, as the IPP and SND continue to feedback on the child's developing nervous system. Thus, early detection leading to early intervention reduces the cumulative effects of SND, consequently keeping the child closer to the path of typical development, in comparison to those who do not receive such intervention (see Figure 1).

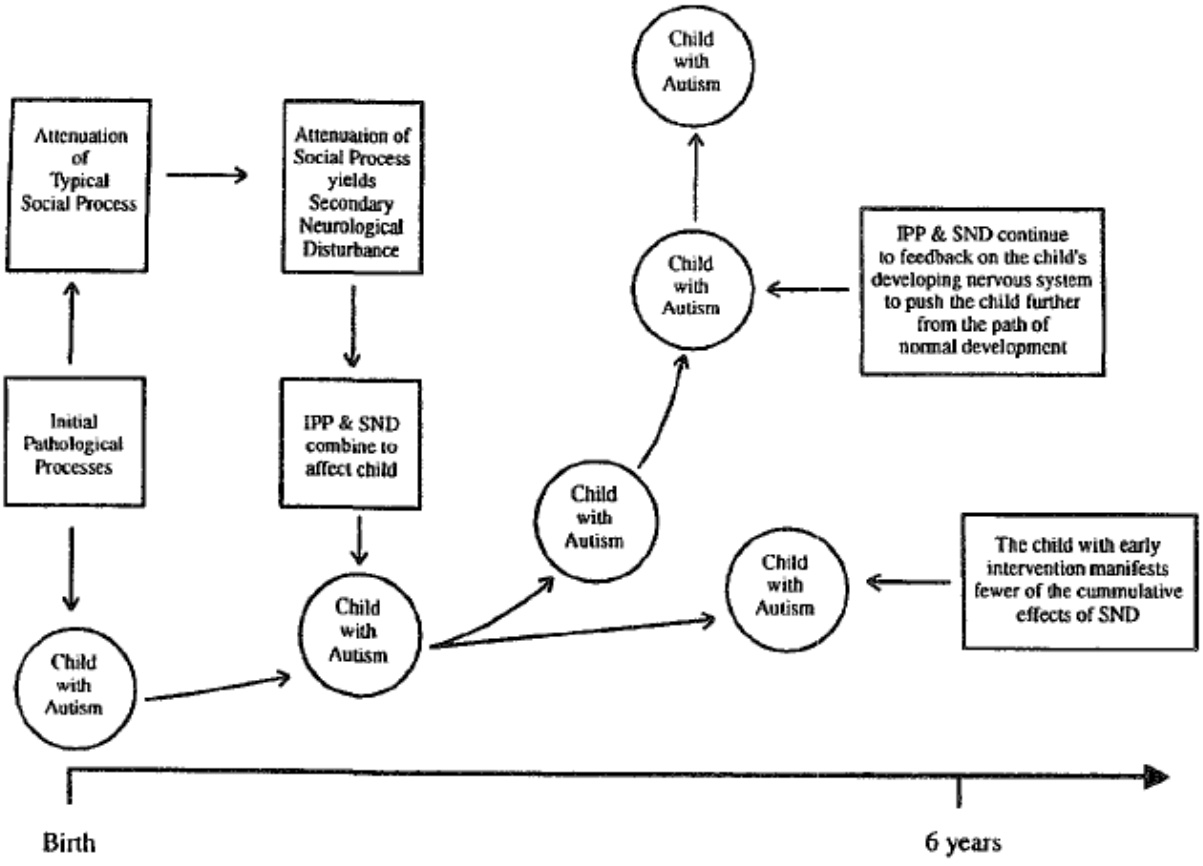

Figure 1. Mundy and Crowson's (1997) cybernetic model of ASDs.

Early detection and diagnosis also means that the delays and the resulting distress that families often face when trying to obtain a diagnosis for their child are avoided or minimised (Siperstein & Volkmar, 2004). Indeed, the main factor associated with parental satisfaction in the diagnostic process is early diagnosis (Howlin & Moore, 1997). Thus, it is no surprise that parents want to be told at the earliest possible opportunity if there is any concern about their child's development or well-being (Quine & Pahl, 1987).

Screening Studies

The increasing knowledge of the early signs of ASDs coupled with the benefits of early intervention has led researchers to develop screening tools to identify ASDs in infancy and toddlerhood. While the majority of these studies are based on Level 2 screening (i.e., screening for ASDs in populations with developmental anomalies), some studies have attempted to identify children with an ASD who have not previously been identified with developmental problems. Prospective screening studies conducted in the general population are known as Level 1 screening studies (Pinto-Martin & Levy, 2004; Volkmar, Chawarska, & Klin, 2005). Prospective studies have also been conducted with siblings of children with an ASD (ASD-sibs), as they are at increased (genetic) risk of developing an ASD (Bailey et al., 1995; Grice & Buxbaum, 2006; Szatmari, Jones, Zwaignbaum, & MacClean, 1998).

Delayed Population (Level 2) Screening Studies

Level 2 screens focus specifically on differentiating children at risk for an ASD from other developmental difficulties, such as general developmental or language delays, and are more detailed than Level 1 (or general population based) screens. They are usually administered in specialised settings, take more time to administer (Pinto-Martin & Levy, 2004; Volkmar et al., 2005), and have thus provided substantial information about ASDs in infancy and toddlerhood.

The Screening Tool for Autism in Two-Years-Olds (STAT; Stone & Ousley, 1997) was designed to differentiate 2-year-old children at risk of AD from those at risk of other developmental disabilities. It is an interaction-based measure of 12 items assessing play, motor imitation, communication, and joint attention skills. In order to *develop* a scoring algorithm that would maximise identification of AD, and also to examine the *validity* of the STAT, Stone, Coonrod, and Ousley (2000) used this tool with 19 children with AD and 54 children with non-AD developmental disorders. The *development* analyses resulted in a sensitivity of 1.00, and a specificity of .91, and the *validity* analyses resulted in a sensitivity of .83 and a specificity of .86.

In order to develop cut-off scores for the STAT, Stone et al. (2004) used signal detection procedures with developmentally matched groups of 26 children with AD and 26 children with non-ASD disorders. The specificity, sensitivity, positive and negative predictive values were all very high, and the inter-rater agreements and test-retest reliability were also high. However, despite the excellent psychometric properties of the STAT, it is designed for use with children aged 2 to 3 years, and is only aimed at differentiating AD (rather than all ASDs) from other developmental disorders (Coonrod & Stone, 2005).

To determine the utility of the STAT with children below 24-months of age, and its ability to distinguish between the milder forms of ASDs and other developmental problems, Stone, McMahon, and Henderson (2008) administered it to 71 high-risk children (59 ASD-sibs and 12 referred due to developmental concerns) aged 12- to 23-months. Using an increased cut off score to reflect less developed social and communication skills in younger children, the screening properties for identifying children with an ASD at 14-months and older were good (sensitivity: .93; specificity: .83; Positive Predictive Value (PPV): .68; Negative Predictive Value (NPV): .97), but inadequate for 12- to 13-month olds. As the sample size of the children who

went on to receive a diagnosis of an ASD was small (n = 19), these results should be interpreted with caution until they are replicated in larger samples.

A new tool, the Autism Detection in Early Childhood (ADEC; Young, 2007), has recently been developed in Australia. Previously known as the Flinders Observational Schedule of Pre-Verbal Autistic Characteristics (FOSPAC; Young, Brewer, & Pattison, 2001), it is a semi-structured observational scale for identifying the primary core deficits seen in pre-verbal infants with AD. It has been developed as a screening tool for non-clinicians as well as professionals, and can be used with children as young as 12-months. The behaviours targeted are early social and communication behaviours.

The psychometric properties of the ADEC were assessed in a sample of 149 children with AD, 60 TD children, and 60 children with language or other developmental disorders [Young et al., 2003, as cited in Young et al., (2007)]. It was shown to have good internal consistency (Cronbach's α = .85), good test-retest reliability (r = .82), and very high inter-rater reliability (r = .97). The specificity of the ADEC was .80, and the sensitivity was .70, with these figures increasing to .90 and .88, respectively, when only children less than 30-months of age were considered. However, despite the promising psychometric properties of the ADEC, these data are preliminary, and are yet to be published in a peer reviewed journal. Furthermore, these data are based on children with AD, many of whom were older than the targeted age. Thus, the properties of the ADEC for use with young children with all forms of ASD are yet to be established. Moreover, the study needs to be replicated with a younger, community-based sample.

Prospective Studies

Prospective studies of ASDs, conducted in community-based samples, are highly desirable for a number of reasons. First, the researcher can attempt to elicit the behaviours of interest at a particular age and under standardised conditions, allowing comparison between different groups and at different time points in the child's life. Furthermore, behaviours can be studied longitudinally, so that the relationship between early deficits and later behavioural manifestations can be examined. In addition, prospective studies have the added benefit of not only informing us of the signs of ASDs in infancy (as do Level 2 screens), but also of being able to identify previously unrecognised cases of ASDs. Prospective studies have been conducted on both high-risk populations (ASD-sibs), and in the general population.

Sibling studies. Twin studies indicate that there is a 60-92% concordance rate for ASDs in monozygotic twins and a 0-10% concordance rate in dizygotic (DZ) twins and siblings of affected individuals (Bailey et al., 1995; Grice & Buxbaum, 2006; Szatmari et al., 1998). Consequently, studies of ASD-sibs have been an invaluable source of information on the very early development of ASDs. The Autism Observation Scale for Infants (AOSI; Bryson, Zwaigenbaum, McDermott, Rombough, & Brian, 2008) was developed to investigate the behavioural manifestations of ASDs between 6- to 18-months in a sample of ASD-sibs. It includes 18 specific risk markers for ASDs, and uses a standardised procedure for detecting each of these markers through a semi-structured, play based assessment. Using the AOSI, Zwaigenbaum et al. (2005) conducted a longitudinal study of 150 ASD-sibs ('high-risk' for ASDs) and 75 'low-risk' infants matched on gender, birth-order, and age. Observations at 6-months of age did not predict classification of an ASD at 24-months. However, by 12-months, the presence of seven risk markers prospectively identified six of the seven children diagnosed

with an ASD at 24-months, compared to two of the 58 non-ASD siblings, and none of the 23 low-risk controls. Thus, the sensitivity and specificity of the AOSI were .84 and .98 respectively.

The individual markers on the AOSI that predicted a diagnosis of an ASD at 24-months were: abnormal eye contact, visual tracking, disengagement of visual attention, orienting to name, imitation, social smiling, reactivity, social interest, and sensory-orienting behaviours (all $p < .003$, adjusting for multiple comparisons). These preliminary data now need to be replicated in the full sample. Unfortunately, as there was no non-ASD developmentally delayed comparison group, we cannot be sure if these behavioural markers are specific to ASDs or whether they share these markers with other developmentally disabled groups of infants (Zwaigenbaum et al., 2005).

Bryson et al. (2007) prospectively followed nine of the ASD-sibs from the Zwaigenbaum et al. (2005) study who received an ASD diagnosis (at 24-months) at 6-monthly intervals until 24-months of age, and then again at 36-months. All of these children showed, in varying degrees, a combination of impaired social-communicative development. Furthermore, there was evidence for the emergence of two subgroups, with the first subgroup defined by a major drop in cognitive development from 12- to 24-months; the second subgroup maintained their cognitive profile of average or near average IQ. The cognitive profiles of these two groups were indistinguishable at 12-months (eight of the nine infants had average or close to average IQs), yet six of these children had severe cognitive impairments by 24- and/or 36-months of age.

Landa and Garrett-Mayer (2006) compared a group of ASD-sibs ($n = 60$) and TD infants ($n = 27$) at 6-, 14-, and 24-months, on their performance on each of the subscales of the Mullen Scales of Early Learning (MSEL; Fine and Gross Motor, Visual Reception, and Receptive and Expressive Language; Mullen, 1995). As with Zwaigenbaum et al. (2005) and Bryson et al.

(2007), there were no statistical differences in the behavioural presentations of ASD and non-ASD groups at age 6-months, and there was 'developmental worsening' between 14- and 24-months for the ASD group. This period of slowed development between 14- and 24-months emphasises the importance of early intervention, as this increase in developmental delay may be minimised if intervention begins *before* this stage.

Sullivan et al. (2007) conducted a prospective study on response to joint attention (RJA) with 51 ASD-sibs at 14- and 24-months of age, and again at 30- to 36-months of age. Three groups were established: ASD (n = 16), 'broader autism phenotype' (BAP; n = 8), which comprised children who displayed language and/or social delays but were not given a classification of an ASD at 3 years, and non-BAP (n = 27), which included children who did not meet classification of BAP or an ASD at 3 years. Deficits in RJA were present by 14-months in the children later diagnosed with an ASD and BAP. However, while there were large improvements in RJA for the BAP and non-BAP groups at 24-months, there was minimal improvement for the ASD group. Moreover, as performance on RJA at 14-months predicted later language and ASD outcome, Sullivan et al. concluded that RJA is an important behaviour for the early screening of ASDs, and subsequent intervention.

Another prospective study investigating the broader autism phenotype was conducted by Cassel et al. (2007). In comparison to non-ASD siblings (n = 19), ASD-sibs (n = 12) were found to engage in lower rates of higher-level behavioural requests (i.e., pointing at, or giving the examiner a desired toy, with or without eye contact) at 12-months, lower rates of initiating joint attention (i.e., pointing at an object or event out of interest, with or without eye contact; holding up a toy to show it to the examiner) at 15-months, and lower rates of RJA (i.e., following the examiner's gaze or point) at 18-months. Although the diagnostic status of these infants has not

yet been determined, the results demonstrate the broader autism phenotype in both ASD-sibs who do not go on to receive a diagnosis of an ASD, and those who do.

Mitchell et al. (2006), in their prospective study of 97 ASD-sibs and 49 low risk controls, found that the children who received a diagnosis of an ASD at 24-months (n = 18) showed deficits in language and communication as early as 12-months of age. These infants understood fewer phrases and produced fewer gestures by 12-months (e.g., giving, pointing, showing, shaking and nodding head, holding arms up to be lifted, and knowledge of appropriate use of real and toy objects); at 18-months, they showed delays in their understanding of phrases and single words, use of gestures, and production of single words. As production and comprehension of words did not differ significantly between children with and without an ASD until 18-months, the authors argue that use of gestures may be more important in prospectively identifying ASDs in children less than 18-months of age.

In addition to the social and communication impairments that are consistently reported in infants with ASDs, behavioural reactivity, difficulties with transitions, and impaired motor control have also been found to account for unique variance in ASD risk in a sample of 115 18-month-old ASD-sibs (Brian et al., 2008). Furthermore, Ozonoff et al. (2008) found that 12-month-old ASD-sibs engaged in significantly more spinning, rotating, and unusual visual exploration of objects than the non-ASD-sibs. Thus, although social and communication impairments have been found to be the best predictors of ASDs in infancy, future research should focus on the subtle and very early behavioural manifestations *alongside* social and communication impairments.

Despite the recent surge of research with ASD-sibs, and the invaluable insights gained into their early development, some caution needs to be exercised when interpreting the results

from these studies. Firstly, many are designed to compare groups based on risk status and not on eventual diagnosis. If the ultimate aim in these prospective studies is to improve knowledge of the early signs of ASDs in infancy, and to use these signs to prospectively identify young children, then eventual diagnostic status of these ASD-sibs becomes critical (Zwaigenbaum et al., 2007). Secondly, high-risk samples are unique and are not representative of a 'true' prospective sample. Children who have grown up in an environment already affected by an ASD may have different symptomology in comparison to those children with an ASD who were not reared in that environment. Moreover, it has been found that children with an ASD from multiplex families are higher functioning in adaptive skills and cognitive development than those from singleton families (Pandey, 2008).

Thus, numerous factors need to be considered as possible influences contributing to differences in development, including alteration in parent-child interaction, early recognition of symptoms and subsequent intervention, affected parenting styles due to exposure to early intervention techniques, and parental stress (Zwaigenbaum et al., 2007). In addition, genetic expression of ASDs may differ in multiplex compared to singleton families, although there is little research to date investigating this possibility.

General population (Level 1) screening studies. Level 1 ASD screens are used to identify children for general developmental disability, with specific emphasis on the signs of ASDs. These screens are used in the general population, and are usually applied in community health services, such as in infant and child health centres or in general medical practice settings (Pinto-Martin & Levy, 2004; Volkmar et al., 2005). There are currently very few screening studies for ASDs that have been conducted in community-based settings, and many of these have used tools that screen for ASDs at only one specific age.

Baron-Cohen and colleagues conducted the first prospective study of ASDs. They developed the Checklist for Autism in Toddlers (CHAT; Baron-Cohen et al., 1992), designed to be administered in a primary health care setting to identify 18-month-old children at risk for an ASD. This brief observational tool was initially administered to 41 ASD-sibs and 50 TD children, all aged 18-months. Three key items (protodeclarative pointing, gaze monitoring, pretend play) were successful in identifying children who later received an ASD diagnosis at 36-months. Baron-Cohen et al. (1996) subsequently used the CHAT on 16,235 18-month-olds during their routine developmental check-up. Twelve children were identified as 'at risk', with 10 of these children receiving a diagnosis of an ASD, and two receiving a diagnosis of DD; these diagnoses remained stable at 3.5 years, giving a false positive rate of 16.6%. In a long-term follow-up study of this same population, Baird et al. (2001) found that although the CHAT had excellent specificity (.98), it lacked sensitivity (.38), as 50 additional children were identified at age 7 as having an ASD, none of whom had been identified as at risk at 18-months. The low sensitivity of the CHAT reduces its use as a screening instrument, as a large percentage of children with an ASD (around 60%) will not be identified by the CHAT at 18-months.

A modified version of the CHAT was developed in an attempt to increase the sensitivity of the tool. The M-CHAT (Robins, Fein, Barton, & Green, 2001) relies entirely on parental report and is designed for use with 24-month-olds; unlike the CHAT, it has a lower threshold for identifying ASDs. A non-selected population of 1,122 18- to 25-month-olds and a high-risk sample (referred from early intervention services) of 171 18- to 30-month-olds were screened using the M-CHAT. Six items in the areas of social relatedness and communication were found to best discriminate between children diagnosed with and without an ASD (protodeclarative pointing, response to name, interest in peers, bringing things to show parents, following a point,

imitation). Using various cut-off scores on the checklist, sensitivity ranged from .87 – .97, specificity ranged from .95 – .99, and PPV ranged from .36 – .80, depending on which cut-off scores were used, and whether the M-CHAT was followed-up with a scripted telephone interview. These preliminary data suggest that the M-CHAT is able to discriminate between ASDs and other DDs by 24-months, and has a higher sensitivity for detecting ASDs than the CHAT.

In a study by Ventola et al. (2007), 195 children (mean age: 24-months) who failed the M-CHAT were grouped into DD (n = 15), Developmental and Language Disorder (DLD; n = 30), and ASD (n = 150) to investigate differences in symptom presentation. Once overall language level was controlled for, only four items significantly differed between the DD/DLD and ASD groups. These were all joint attention and social responsiveness items (response to name, pointing for interest and to request, ability to follow a point), reinforcing past literature that social responsiveness and joint attention behaviours are core, and particularly unique, deficits in ASDs.

In order to address the usefulness of the M-CHAT as a screen for ASDs in a community-based sample, as well as to establish absolute sensitivity and specificity, Kleinman et al. (2008) screened 3,309 low-risk children (new cases) as part of their well-child care visits, and a further 484 high-risk children referred for early intervention. All children were screened at 16- to 30-months (Time 1), and followed-up at 42- to 54-months (Time 2). For the *total* sample, PPV at Time 1 was close to that of the original study (.36 – .74), again depending on whether a follow-up phone interview was used; PPV for the total sample at Time 2 was similar (.59 – .74). However, for the low-risk sample, PPV at Time 1 was extremely low (.11 ± .05) when the M-CHAT was used alone. When used in conjunction with a follow-up phone interview, it increased

to .65 ± .17. Thus, the PPV increases to an acceptable level, but only in conjunction with a follow-up phone interview, which is consistent with the findings of both Pandey et al. (2008) and Robins (2008) . These data suggest that the use of the M-CHAT alone as a screen for ASDs in a community-based sample is problematic. The M-CHAT may be useful in identifying children in need of further assessments, but should not be used as a screen to exclude the possibility of an ASD (Eaves, Wingert, & Ho, 2006).

The Q-CHAT (Allison et al., 2008), a quantitative version of the CHAT, marks a major revision of the instrument. Like the M-CHAT, it relies solely on parental report, and contains 25-items rated on a 5-point likert scale. Its test properties and clinical validity have not yet been established, although preliminary data on a sample of 779 children (unselected group: mean age 21-months; ASD group: mean age 44-months) has resulted in a range of scores that approximate a normal distribution. Thus, the Q-CHAT may be a useful instrument to measure trait differences in the general population, and not just in the ASD population. However, its revision into a parental report only measure lends itself to the problems associated with these types of measures, as discussed previously.

An ongoing longitudinal, prospective study, called the FIRST WORDS® project, uses the Communication and Symbolic Behaviours Scales (CSBS; Wetherby & Prizant, 2002) as a screen with children in the general population, recruited from health and childcare clinics (Wetherby et al., 2004). The CSBS comprises an Infant-Toddler Checklist (ITC) that parents complete when their child is below 24-months of age, and a Behaviour Sample, which is a direct evaluation of the child after 18-months of age by a clinician, which is videotaped for later analysis. Wetherby, Watt, Morgan, and Shumway (2007) examined the social and communication behaviours of 123 children (50 with an ASD, 23 with DD, and 50 TD children)

aged 18- to 26-months using the CSBS who were recruited from the FIRST WORDS® project. Compared to children with DD, who were matched on age and developmental level, the children with an ASD were found to display five core social and communication deficits. These included deficits in gaze shifts, following of gaze/points, rate of communicating, acts for joint attention, and inventory of conventional gestures.

In order to determine the efficacy of the ITC as a general population screening tool, 5385 children from the general population were administered this checklist between 6- to 24-months of age (Wetherby, Brosnan-Maddox, Peace, & Newton, 2008). Of the 60 children who went on to receive an ASD diagnosis, 56 (93%) screened positive between 9- to 24-months. However, although the sensitivity of the ITC between 9- to 24-months is excellent, it is unable to distinguish between children with an ASD and those with communication delays, as 813 children were identified on the ITC as needing further developmental surveillance.

Only one other community-based ASD screening study has been conducted to date. Swinkels et al. (2006) developed an instrument known as the Early Screening of Autistic Traits Questionnaire (ESAT). A population of 31,724 children aged 14- to 15- months were first pre-screened at well-baby clinics using a 4-item screening instrument, and screen positive infants were then evaluated using the 14-item ESAT. Eighteen children were found to have an ASD, indicating that it is possible to identify unrecognised cases of ASDs as early as 14-months. The items that were most predictive of ASDs were, once again, social-communicative in nature. ‘Stereotypical movements’ was least predictive, reinforcing the earlier suggestion that social-communicative behaviours are the strongest predictors of ASDs, and repetitive behaviours (or stereotypies) are, perhaps, more indicative of general intellectual disability (Osterling et al., 2002; Werner & Dawson, 2005).

The use of the ESAT as a general population screen in its current form would be problematic, as it was found to have a large number of false positives (42 in total); however, none of these were TD children. Although the authors could not determine overall sensitivity, they indicated that it would have been low as their number of identified cases of ASDs was low in comparison to current prevalence rates (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006).

Diagnosing ASDs in Toddlers: Instruments and Stability of Diagnosis

The findings from the screening studies reviewed above indicate that it is possible to identify ASDs in infancy and toddlerhood. It has also been shown that it is possible to accurately *diagnose* ASDs as early as 2 years of age with instruments such as the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), a standardised, semi-structured parental interview, and the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000; Lord, Rutter, DiLavore, & Risi, 1999), an observational instrument consisting of four modules devised for individuals with varying language abilities. However, it has been found that that ADOS sometimes has lower specificity and sensitivity for classification between AD and other ASDs (Bishop & Norbury, 2002; de Bildt et al., 2004; Gotham, Risi, Pickles, & Lord, 2007). Recently, Gotham et al. (2007) attempted to improve the sensitivity and specificity of the ADOS in differentiating the various ASDs, by altering the current algorithm. A 12-31% increase in specificity in differentiating between the ASDs was achieved with non-verbal children. Furthermore, a replication study by Gotham et al. (2008) found that the sensitivity and specificity of these revised algorithms approximated or exceeded those of the original algorithms (except for young children with PDD-NOS and phrase speech). These revised algorithms are yet to

replace the current algorithms, as these findings await further replication with other research samples.

Although the ADOS is the best available instrument for diagnosing ASDs in children as young as 2 years, its use with children younger than 2 is limited. A toddler version (the ADOS-T) was therefore developed by Luyster et al. (2009), with an algorithm developed for all children aged 12- to 20-months and non-verbal children aged 21- to 30-months, and another for verbal children aged 21- to 30-months. The data on 182 children (360 evaluations) aged 12- to 30-months of age produced excellent sensitivity and specificity values of 91% and 94%, respectively. Due to the variability in early development, the authors propose that the scores on the new algorithms should be used to indicate ranges of concern (i.e., little, moderate, significant concern), rather than using traditional 'cut-off' scores. The data await replication with a larger sample, and data on the stability of diagnosis using the toddler version are not yet available.

Given there are some problems associated with the ADOS in correctly differentiating the ASDs, and with the ADI-R in correctly diagnosing AD in children with mental ages below 18-months (Lord et al., 1997; Lord, Storoschuk, Rutter, & Pickles, 1993; Pilowsky, Yirmiya, Shulman, & Dover, 1998), it has been suggested that the two instruments be used together (de Bildt et al., 2004). Le Couteur, Haden, Hammal, and McConachie (2008) found good agreement between the instruments in a preschool sample aged 24- to 49-months, especially for those with 'classic autism' (AD). However, Ventola et al. (2006) found poor agreement with the ADOS and ADI-R in young children as they did not display enough repetitive behaviours and stereotyped interests to meet the cut-off for AD on the ADI-R. Therefore, Wiggins and Robins (2008) excluded the behaviour domain on the ADI-R when assessing toddlers at risk for an ASD, and found a significant improvement in agreement between the ADI-R and other measures (including

the ADOS). These findings indicate that it is advisable to use the ADI-R together with the ADOS, in conjunction with clinical judgment, when diagnosing very young children.

Reliability of Diagnosis at Age 2

Diagnoses of ASDs at around 2 years of age have been found to be accurate and stable over time (Chawarska, Klin, Paul, & Volkmar, 2007). Lord (1995), using clinical judgement, found that 27 children out of 30 retained their diagnostic classification of an ASD from 2 to 3 years of age. Eaves and Ho (2004) found that 79% of children given a diagnosis of an ASD at age 2½ years retained their diagnosis at age 4½ years. However, the stability of diagnoses for ASDs other than AD was not as stable across time. Turner, Stone, Pozdol, and Coonrod (2006) examined the developmental outcomes of 2-year-old children 7 years after they received a diagnosis of an ASD. It was found that 88% of the children who received an ASD diagnosis at age 2 years received the same diagnosis at 9 years of age. In their study of 77 children aged 16- to 35-months, Kleinman et al. (2008) reported that 80% remained in the same diagnostic category at 42- to 82-months of age. As with previous studies, a diagnosis of AD was more stable than that of a PDD-NOS diagnosis (85% versus 47%).

Charman et al. (2005), also investigating the outcome of children 7 years after their initial diagnosis at 2 years of age, found that 22 of the 26 children diagnosed with an ASD at 2 years (based on clinical judgement) continued to meet this diagnosis at 9 years of age. However, their findings on the stability of diagnosis based on psychometric and standardised tests, as opposed to clinical judgement, were not as clear, with children crossing diagnostic boundaries as they aged. Charman et al. concluded that the assessment of early social-communication behaviours (using, for example, the ADOS) gives a better indication of the diagnostic profile of young, non-verbal children than standard psychometric tests measuring IQ and language abilities.

In summary, the follow-up studies reviewed above indicate that the diagnosis of ASDs is reliable in children aged 2 years. However, it is imperative that the diagnostician has sufficient training and experience in the assessment and diagnosis of ASDs, and utilises appropriate tools for young, non-verbal children, which are used in combination with clinical judgement (Stone et al., 1999).

Summary and Future Directions

The prevalent finding from studies on ASDs in infancy and toddlerhood is that abnormalities in social attention and communication behaviours are evident from the first year of life, and are the most predictive early signs of an ASD diagnosis. In the area of social attention, these markers include a lack of eye contact, social interaction, social smiling, imitation, orienting to name call, appropriate facial expressions, and interest and pleasure in others. In the area of communication, these markers include a lack of vocal communication, joint attention skills (protodeclarative pointing, following a point, gaze monitoring, referencing objects/events), showing and requesting behaviours, and gestures. Impairments in imagination skills, such as the use of pretend play, have also been found to be important markers in late infancy/toddlerhood. Although sensory/motor behaviours and stereotypies are seen in some infants with an ASD, these behaviours may be more indicative of general intellectual disability (Osterling et al., 2002; Werner & Dawson, 2005), and these behaviours may not become apparent until at least 3 years of age in some children (Gray & Tonge, 2001; Young & Brewer, 2002). Currently, they may not serve as important *predictors* of ASDs in infancy.

Level 1 screening instruments, using social attention and communication behaviours as key items, have been able to prospectively identify previously unidentified cases of ASDs in community-based samples. A highly predictive, but brief, observational tool containing a

checklist of the behaviours that are absent in infants with an ASD would prove invaluable for the detection of these infants, as children that would previously go unrecognised could be identified though routine developmental monitoring, and reliably diagnosed at 2 years of age. This is important, as only 50% of parents of children with an ASD suspect a problem before 12-months (Osterling & Dawson, 1999; Werner et al., 2000). However, it is apparent from the studies reviewed here that, as acknowledged by Charman (2003), there are currently no instruments available with adequate sensitivity and specificity to recommend universal screening. Therefore, there remains a need for more prospective studies of infants conducted in community-based settings, as the few conducted to date have reported poor sensitivity on the measures used, or have high false positive rates.

The routine and repeated monitoring of behaviours throughout the infancy period, rather than a single screening at a given age, may prove more useful in detecting ASDs in infancy. The two large-scale prospective community-based studies reviewed here utilised a screening tool at a single given age. In contrast to this approach, the *repeated* monitoring of infant development will serve to increase the chances of identifying early manifestations of ASDs, consequently increasing the sensitivity of the screening tool utilised. In addition, repeated sampling will help to track the subtle changes that occur in infants with an ASD overtime (Yirmiya & Ozonoff, 2007), and aid investigation into what seems to be a critical period between 12- and 24-months of age, where a subset of children with an ASD progressively lose cognitive skills, while another maintains cognitive abilities (Bryson et al., 2007; Landa & Garrett-Mayer, 2006). Furthermore, the phenomenon of regression is well known to occur during this time period. Thus, future prospective studies should focus on systematically investigating not only the behavioural changes that occur during this important developmental period, but also the milestones that

children with an ASD reach in relation to those reached by their TD peers. In addition to aiding early identification, such a focus on the early development of the ASD phenotype will ultimately contribute to understanding the underlying neuropathology leading to the cognitive and behavioural deficits in ASDs.

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PAPER 2

DEVELOPMENTAL SURVEILLANCE OF ASDs IN INFANTS AND TODDLERS BY MATERNAL AND CHILD HEALTH NURSES

Running Head: DEVELOPMENTAL SURVEILLANCE OF ASDs IN INFANTS AND TODDLERS

Paper 2

Developmental surveillance of infants and toddlers by Maternal and Child Health nurses in an Australian community-based setting: Promoting the early identification of Autism Spectrum Disorders

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Abstract

Although signs of Autism Spectrum Disorders (ASDs) are evident during the first year of life, few children are diagnosed prior to 3 years. The objective in this article is to highlight the role that primary health care professionals can play in the early identification of ASDs by briefly outlining the successful implementation of The Social Attention and Communication Study. Maternal and Child Health nurses were trained on the early signs of ASDs, which enabled them to identify these children prior to 2 years. The training procedure utilised will be outlined, and the early signs that were monitored will be explained in detail. It is recommended that routine monitoring for ASDs in infancy and toddlerhood become standard practice amongst all primary health-care professionals.

Key Words: Autism Spectrum Disorders; infants; toddlers; Maternal Child Health nurses; developmental surveillance; screening

Developmental surveillance of infants and toddlers by Maternal and Child Health nurses in an Australian community-based setting: Promoting the early identification of Autism Spectrum Disorders

Primary health care workers, particularly Maternal and Child Health (MCH) nurses, can play a central role in the early identification of Autism Spectrum Disorders (ASDs). Evidence for their central role comes from the successful implementation of a developmental surveillance program designed to identify infants and toddlers 'at risk' for an ASD in a large community-based sample. The different types of ASDs will be discussed first, with attention to the similarities and differences between these related conditions. The Social Attention and Communication Study (SACS), conducted in Melbourne, Australia, will then be described in order to illustrate how ASDs can be monitored in infants and toddlers during well-baby checks, which are routinely conducted by MCH nurses in a community-based setting. Each of the key behaviours that should be used to identify 'at risk' infants and toddlers will be explained in turn, highlighting how developmental surveillance can lead to effective early identification of ASDs.

An evidence-base for the implementation of the developmental surveillance program will be provided by 1) briefly outlining the rate of ascertainment of ASDs in the referred sample, and 2) inclusion of MCH nurses' evaluation of its implementation. The SACS was undertaken with the ultimate aim of lowering the age at which ASDs are diagnosed, so that intervention can begin earlier, leading to better outcomes for the developing child and his/her family. The findings from the SACS and the nurses' evaluations lead to the conclusion that routine monitoring for ASDs should become standard practice amongst all primary health care professionals.

Introduction to Autism Spectrum Disorders

Autism Spectrum Disorder is an umbrella term used to describe a group of Pervasive Developmental Disorders characterised by a triad of impairments, including qualitative impairments in 1) social interaction, 2) verbal and non-verbal communication, and 3) a restricted repertoire of activities and interests combined with repetitive behaviours and stereotypies (Diagnostic and Statistical Manual of Mental Disorders-IV-TR; DSM-IV-TR; APA, 2000). Autism Spectrum Disorders are lifelong neurodevelopmental disorders, with current prevalence rates estimated at 1 in 91 in the USA (Kogan et al., 2009), 1 in 100 in the UK (Baird et al., 2006), and 1 in 160 in Australia (Williams, MacDermott, Ridley, Glasson, & Wray, 2008). The last four decades have seen a vast worldwide increase in the number of individuals diagnosed with an ASD (Wing & Potter, 2002), which is partially attributable to lowering the age of diagnosis, as well as to the broadening of diagnostic criteria to include 'milder' cases of ASDs (Gernsbacher et al., 2005).

The term 'ASD' includes Autistic Disorder (AD), Asperger's Disorder (AspD), and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Autistic Disorder involves profound deficits in all three areas of the triad, and is associated with a wide range of cognitive functioning (APA, 2000). Approximately three-quarters of individuals with AD have an associated intellectual disability (i.e., IQ < 70, APA, 2000). Those individuals without a co-morbid intellectual disability are classified as having 'high-functioning autism' (HFA; Tager-Flusberg et al., 2001). Individuals with AspD closely resemble those with HFA, but they do not show evidence of significant delays in language development that characterises AD/HFA (APA, 2000). Thus, language is the main criterion differentiating AspD and HFA. However, despite their absence of language delays, individuals with AspD do have problems in communication, failing to use and understand language in the typical way (APA, 2000). Individuals who do not fulfil the DSM-IV-TR (APA, 2000) criteria for a

diagnosis of AD or AspD, but who show some of the specified symptoms, are given a diagnosis of PDD-NOS. These individuals may have a late age of onset, atypical or sub-threshold symptomatology, or they may display all of these (APA, 2000).

Males are at an increased risk of having an ASD, with the ratio of males to females being 4:1 (Yearing-Allsopp et al., 2003). Although the underlying neuropathology of the ASDs remains unknown, there is much evidence to suggest strong genetic involvement in these conditions. Twin studies indicate that monozygotic twins have a 60% concordance rate for AD, and a 71% concordance rate for all ASDs (Bailey et al., 1995). The recurrence rate of ASDs in siblings of affected individuals is estimated to be 2-8% (Rutter et al., 1999), which is approximately 20-80 times higher than the risk among the general population (Fombonne, 2005; O'Roak & State, 2008).

Although most children with an ASD show problems in development prior to 12-months, 20% to 30% are reported by their parents to develop 'typically' in the first 15- to 21-months of life. These infants reach language and social skill milestones at age appropriate levels, but then progressively 'lose' these skills. The most frequently reported skill loss is language, followed by social skills (Davidovitch et al., 2000; Siperstein & Volkmar, 2004; Werner & Dawson, 2005). However, it is important to note that most cases of regression do not involve *completely* normal development prior to regression (Richler et al., 2006; Werner et al., 2005), with some children having lower language abilities than their typically developing peers (Siperstein & Volkmar, 2004).

The phenomenon of regression, along with the increase in prevalence rates discussed earlier, led to a prolonged debate regarding the causative role of the Measles-Mumps-Rubella (MMR) immunisation that infants typically receive between 12- and 18-months of age. Despite the media popularity of this supposed 'link', empirical studies have shown

unequivocally that there is no association between the MMR injection and ASDs (DeStefano et al., 2004; Fombonne et al., 2006; Richler et al., 2006).

Importance of Early Detection and Diagnosis

Early identification of ASDs is the first step to facilitating referral and diagnosis. Early diagnosis is crucial as it provides the best opportunity for specialised early intervention, which serves to maximise developmental outcomes for affected children and their families. The benefits of early intervention for children with an ASD are now unquestionable (see Dawson, 2008; Rogers & Vismara, 2008, for an overview) and, if instituted early enough, can serve to move the young child toward a more typical developmental trajectory. Early intervention can also prevent the onset of secondary manifestations of the disorder, which appear later in childhood, such as aggressive or self-harming behaviours, restricted rituals or routines, and severe difficulties socialising with peers (Dawson 2008; Young & Brewer, 2002). Importantly, if a child is referred before a loss in language and social skills, as reported earlier, the impact of early intervention is even greater, as it may prevent some of these losses (Dawson, 2008).

Early detection and diagnosis also means that the frustrating delays and the resulting distress that families often face when trying to obtain a diagnosis for their child are avoided or minimised (Siperstein & Volkmar, 2004). Indeed, the main factor associated with parental satisfaction in the diagnostic process is early diagnosis (Goin-Kochel et al., 2006; Howlin & Moore, 1997). Thus, it is no surprise that parents want to be told at the earliest possible opportunity if there is any concern about their child's development or well-being, and are more satisfied if their early concerns are accepted and addressed by health care professionals (Brogan & Knussen, 2003).

Monitoring for ASDs in the Community

There is currently no universally recommended screening program for detecting ASDs, despite the American Academy of Pediatrics (AAP, 2007; Johnson & Myers, 2007) calling for routine screening for signs of ASDs in the second year of life. The American Academy of Neurology (Filipek et al., 2000) recommends a 2-step process whereby all children undergo developmental surveillance at every well-child visit, and if identified as 'at risk' for an ASD, an ASD specific screen and follow-up diagnostic testing are recommended. The importance of developmental surveillance over developmental screening, which is a broader concept, has been advocated since the 1980s (Dworkin, 1989). With developmental surveillance, one does not administer a set screen, which rapidly gives an estimate as to a child's risk status. Rather, the skilled observer's judgement about the child is incorporated with any parental concerns about the child's development each time the practitioner comes into contact with the child, not just at set health checks (Curry & Duby, 1994). Dworkin refers to this as "opportunistic surveillance", and the importance of this concept in monitoring early signs of ASDs in the community is emphasised throughout this paper.

There is general consensus that MCH nurses and related practitioners (e.g., Nurse Practitioners, paediatric, 'well-baby', and community nurses) are well placed to undertake developmental surveillance of young children to identify those showing early signs of ASDs (Curry & Duby, 1994; Dworkin, 1989; Halpin & Nugent, 2007; Nadel & Poss, 2007; Pinto-Martin et al., 2005). In fact, Chakrabarti and Fombonne (2001), in their study of referrals for possible ASDs, found that two-thirds of all children diagnosed with an ASD over the period of two years were first identified by their health visitor.

In the UK, there has been a move away from using health visitors to conduct routine developmental surveillance of children up to 3½ years, which has raised concerns as to possible lost opportunities to detect ASDs at an earlier age (Halpin & Nugent, 2007;

Tebruegge et al., 2004). Tebruegge et al. (2004) suggest that if developmental surveillance is no longer implemented by health nurses, suitable methods to detect children at risk of developmental disorders, including ASDs, are needed. Sole reliance on the implementation of tools such as the Parents' Evaluation of Developmental Status (PEDS; Glascoe, 1998), which rely on parents raising concerns with their practitioner, is therefore problematic. Although the recommendation is that the PEDS is used as a supplemental assessment during well-baby checks, there is the danger that some health professionals will not undertake further developmental monitoring of a child by using skilled clinical observations if the parents do not raise concerns with them. Young children's development needs to be closely monitored for developmental anomalies despite a lack of parental concern, as many parents and family members do not recognise developmental concerns with their young children, especially in the first year of life (Werner et al., 2000). Therefore, lack of, or failure to report, parental concerns does not necessarily imply typical development. Pinto-Martin et al. (2008) have found that the PEDS misses the majority of children who screen positive for an ASD on an ASD specific tool, with Glascoe et al. (2007) also stating that the PEDS alone is not useful in identifying ASDs, and must be used in conjunction with an ASD specific tool.

Maternal and Child Health nurses, who routinely see children at key stages in their development, are not only the best placed to monitor abnormal development, but are also the most expert to do so, given their extensive knowledge and training on developmental milestones (Curry & Duby, 1994; Halpin & Nugent, 2007). With a firm knowledge in early child development, the MCH nurse can, through routine developmental surveillance and monitoring, identify potential problems via observation of the child's responses, interactions and play, and can thus serve as leaders in the identification of ASDs in infancy (Curry & Duby, 1994; Nadel & Poss, 2007).

The Maternal and Child Health Service

In the State of Victoria, Australia, infant and child development is monitored through the universal MCH service, which is offered free of charge to all families with children under 6 years of age (Department of Education and Early Childhood Development; DEECD, 2007a). The major provider of MCH services is local government, which is responsible for the provision of service to metropolitan, rural and remote areas of the State (DEECD, 2007a). The MCH service program standards identify their role as one of surveillance, screening and assessment to enable "early detection of, and intervention for, physical, emotional and social factors affecting young children and their families" (DEECD, 2009, p. 5).

The primary aims in this service are to monitor children's growth and development, to promote the health and wellbeing of families with young children, and to provide anticipatory guidance and support to parents (Australian Nursing Federation; ANF, 1999). The MCH nurses within the service are highly trained, with qualifications in general nursing and midwifery, as well as the Child, Family and Community nursing specialty. As part of the universal MCH service, well-baby checks are scheduled at key ages from birth to 3½ years of age. Given that 98% of Victorian babies access the MCH service soon after birth, and attendance remains relatively high within the first two years (DEECD, 2007b), this universal service has enormous potential to identify infants at risk of a host of developmental disorders, including ASDs.

Implementation of Developmental Surveillance in a Community-Based Setting

Pinto-Martin et al. (2005), in arguing for the importance of routine screening for ASDs in pediatric primary care, cited various barriers to standardised screening, including costs, large patient volumes, diminished reimbursements for staff, and failure to attend appointments by parents. Issues with screening tools themselves included length, variety, lack of uniformity in regards to their properties, and lack of formal training for practitioners in

administration and scoring of the tools. They argue that if developmental screening is to be universal, these issues need to be addressed. Furthermore, it is also recognised that scientific research vastly precedes current practice and that "Integration of routine developmental screening into pediatric primary care is still an unrealized goal" (Pinto-Matrin et al., 2005b, p. 1932). It is for this reason that The Social Attention and Communication Study (SACS) was launched in metropolitan Melbourne, Victoria, in 2006.

The overall objective of the SACS was to determine whether routine and repeated monitoring, within the MCH service, of key markers of ASDs in infancy[1] could be used to prospectively identify infants who will receive a diagnosis of an ASD, in a community based sample. Many of the issues raised by Pinto-Martin et al. (2005) were addressed in designing the SACS, which utilised a developmental surveillance approach, rather than a screening approach. Relying on a screening tool, which is administered at one point in development, leads to many missed opportunities for identifying 'at risk' children (e.g., Baird et al., 2000; Dietz et al., 2006; Swinkels et al., 2006).

The approach used in the SACS was a low-cost one, and designed to be implemented in centres with large volumes of children as *part of*, rather than *in addition to*, the well-baby check. The procedure was therefore brief and only added time to the consultation if there was a concern with the child's development.

Training Procedure and Results of the SACS

A cohort of 22,168 children was monitored though 184 MCH centers in 17 local government areas (LGAs) in metropolitan Melbourne, over a 6-month period, between September 2006 and June 2007. The LGAs were chosen based on proximity to facilitate ease of referral, with most centres within a 20 kilometer radius of a Melbourne University, where the study was conducted.

[1] See Barbaro & Dissanayake (2009) for a review

Each child was monitored by their MCH nurse from 8- to 24-months of age; however, children were only referred to the SACS team at the Child Development Unit (CDU) at the University from 12-months of age. The nurses in each LGA received a 2½ hour training workshop. Two hundred and forty one nurses were trained from September to December 2006 to monitor infants' development for the early signs of ASDs during four routine consultations undertaken at 8-, 12-, 18-, and 24-months of age. The workshops focused on typical and atypical social-communicative development, the early (and later) signs of ASDs, as well as the particular items within the MCH record at each age, which were relevant to the detection of ASDs. Items that were most relevant to ASDs, and developmentally appropriate for the age being monitored, were underlined and considered 'KEY' items. Children were considered 'at risk' for an ASD only if they showed a 'pattern' of failure on the items of interest; for example, by failing three of the four 'KEY' items. These behaviours, and the criteria for a pass/fail, are detailed in Appendix A.

The nurses were instructed to re-administer 'failed' items a maximum of three times, and were specifically trained to identify when a behaviour was *atypical*, as opposed to present or absent. Video clips showing examples of children with and without an ASD were used as part of the training for the behaviours of interest. Nurses were also trained on how to raise concerns with parents of children identified as 'at risk'.

Two hundred and sixteen 'at risk' children were referred by the nurses to the SACS team at the CDU for a developmental and behavioural assessment. Children 'at risk', whose caregivers agreed to participate in the study, were initially seen and followed-up by the team at 6-monthly visits, until s/he was 24-months old, when a diagnostic assessment was undertaken using the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000), and the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994).

One hundred and ten children, whose parents consented to participation, were assessed at the CDU. Of these, 89 children met criteria for an ASD, resulting in an ascertainment rate (Positive Predictive Value; PPV) of 81%. Only one typically developing child was referred to the SACS, with the remaining 20 children (18%) meeting criteria for a developmental and/or language (DD/LD) delay. Importantly, 9 out of the 10 12-month olds (PPV: 90%), and 30 of the 38 18-month-olds (PPV: 79%) who were referred to the SACS, met criteria for an ASD. The estimated sensitivity and specificity of the SACS, based on the current prevalence rates of 1 in 100 in the UK (Baird et al., 2006), is 83.8% and 99.8%, respectively. The prevalence rates of the UK were used as this was the closest to that found in the SACS of 1 in 119 children. Further discussion of the SACS, including how specificity, sensitivity and prevalence rates were estimated is beyond the scope of this paper, and is detailed in Barbaro and Dissanayake (2010).

These data show, without question, that it is not only possible to monitor for ASDs in the community, but that MCH nurses are able to *correctly* identify and refer infants and toddlers with an ASD as a result of their training on the early signs of ASDs. The remaining children who do not meet criteria for an ASD nonetheless have other developmental problems. The nurses' knowledge of early child development clearly facilitated their ability to successfully monitor signs of ASDs in these very young children. The results strongly indicate that MCH nurses have a key role to play in the early identification of ASDs and other developmental anomalies. The behaviours used to identify ASDs in infants and toddlers in the SACS will be described individually to assist all primary health care professionals, including MCH nurses, to monitor the development of these behaviours.

Early Signs of ASDs

Social Attention and Communication Behaviours

Delayed, absent or abnormal development in the behaviours listed below should be considered 'red flags' for an ASD. It is important to note that the presence of any of these behaviours does not exclude the possibility of an ASD. Rather, it is paramount that the *quality* of these behaviours be monitored in addition to their presence or absence. Furthermore, the behaviours listed should not be used in isolation to identify whether a child is 'at risk' for an ASD, but should, instead, be considered in combination to indicate 'risk'. A reference table, summarising the information below, is provided in Appendix B to enable practitioners to quickly refer to it during their busy consultations. Practitioners can then use this information to fill out the SACS checklists in Appendix A.

Social games - peek-a-boo (8-months): When engaging in a game such as peek-a-boo, look for use of eye contact, reciprocal social smiles, anticipatory postures, or imitation of the actions. Many children with ASDs will not engage in many or all of these behaviours during this game with adults.

Eye contact (8- to 24-months): Eye contact should be monitored not only for its presence/absence, but also for its quality. Signs of atypical eye contact include a lowered frequency, inconsistency of use (e.g., not making eye contact when giving objects), and the fleeting nature of the contact. Abnormal eye contact is perhaps *the* most important behaviour to look for when considering if a child has an ASD.

Turning to name call (8- to 24-months): Does the child turn to look at others when his/her name is called out? If so, consideration should be given to the number of prompts required for a response, or the consistency of the response. Children with ASDs often do not respond when their name is called, *especially* if it is someone other than their parents calling them.

Social smiling (8- to 24-months): Monitoring children as they enter a room is useful to check for spontaneous social smiles. Smiles without directed eye contact are not social, and tend to be more typical of children with an ASD.

Imitation (8- to 24-months): If a child is not copying things others do, such as poking one's tongue out, waving or clapping, and other common activities, this is a cause for concern. However, some children with an ASD may imitate, so the *presence* of imitation does not exclude a child from having an ASD.

Use and understanding of language (8- to 24-months):

Use of language: Is the child using single syllables and combining these into babble such as gaga/mama/dada by 8-months? Does s/he babble in a conversational manner? Does s/he use 1 to 3 words by 12-months, 5 to 10 words by 18-months, and 20 to 50 words by 24-months? S/he should also be combining 2-words together by 2 years of age.

Understanding of language: Infants should be able to understand "Give me" by 12-months, obey simple instructions (e.g., "Give me the block", without using gestures) by 18-months, and follow simple commands (e.g., "Go and get your shoes", again without using gestures) by 24-months. If a child presents with *both* receptive and expressive language delays, as opposed to an expressive delay alone, they are at a higher risk of having an ASD.

Pointing (12- to 24-months): The failure to point (with an extended index finger) by at least 15-months is a strong sign of developmental concern. If the child does point, it must be *combined with* eye contact to be communicative. Some children with an ASD will point to things, but will not combine this with eye contact, or may only point to *request* things (e.g., a drink, an unreachable object), rather than to 'share' or 'show' things (e.g., a bird, a plane).

Joint attention – following another's point and gaze (12- to 24- months): Many children with an ASD fail to *follow* another's point and gaze by either not looking at the target or, instead, looking at the person's hand/finger. Furthermore, they may not alternate their gaze between a person and an object or event for the purpose of *sharing attention* (not requesting).

Social gestures (12- to 24-months): Children with ASDs typically use fewer social gestures such as clapping and waving. If the child does wave or clap, look for an absence of other gestures like nodding for 'yes' or shaking his/her head for 'no' (for 18- to 24-month olds).

Showing; social communication (18- to 24-months): Does the child show things to others by holding them up or giving them, *combined* with eye contact? This behaviour is distinct from giving something as a request; for example, giving a container to be opened, or a book to be read. Showing behaviours are very rarely seen in children with ASDs.

Pretend play (18- to 24-months): Children begin to engage in pretend play at around 15-months and should be doing so by *at least* 18-months. Although some children with ASDs engage in pretend play, they rarely 'share' this experience with others, or try to incorporate others into their play. When assessing a child's pretend play skills (such as their ability to feed a 'teddy') the behaviour should not be modeled, as you want to assess *spontaneous* pretend play. It is important to note that many children with ASDs will engage in functional play (such as pushing a toy car or using a toy phone).

Interest in other children – parallel play (24-months): Does the child play near (not necessarily with) other children? Do they show an interest in other children by watching them play, approaching them, or giving them objects such as toys? Typically developing children will usually show an interest in other children by 24-months, but this is less frequently seen in children with an ASD.

Aberrant Behaviours

Abnormal behaviours are not useful *predictors* of ASDs in infancy and toddlerhood. Firstly, not all children with ASDs will exhibit aberrant behaviours, or if they do, they differ greatly between children. Secondly, although some of these behaviours can occur at any age (e.g., sensory behaviours and interests, and subtle repetitive and stereotyped behaviours can occur prior to 12-months, such as hand flapping or prolonged visual examination of lights), they typically emerge after 2 to 3 years of age (Young & Brewer, 2002). Thus, it is important to note that an absence of atypical behaviours in infancy and toddlerhood *does not* exclude the possibility of an ASD. However, knowing what common abnormal behaviours are sometimes seen in very young children with ASDs can assist in identifying these children, especially if they also exhibit deficits in social attention and communication behaviours, as described above.

It should also be noted that many of the aberrant behaviours described below may sometimes be seen in typically developing children. However, typically developing children may not become as invested or preoccupied in these behaviours, so consideration should be given to the amount of time engaged in these behaviours, and their intensity. A quick reference table is provided in Appendix C.

Using another's hand/body as a tool: Young children with an ASD will sometimes manipulate another's hand as if it was a tool. For example, they may pick up someone's hand and *place* it on an object, such as a container, to request it be opened. Or the child may use another person's finger to point to pictures in a book.

Repetitive behaviours: The most common repetitive behaviours include lining up objects and toys and/or sorting them (sometimes arranged according to colour, shape, or type); spinning objects such as wheels, lids, toy rings on a table (may be observed in children as young as 12-months); placing their head on the floor or table to observe toys with wheels

being rolled from side to side; continuously holding an object in one or both hands; obsession with particular objects or toys and frequently seeking them out, or holding them (e.g., circular objects, lights, balls, cars); repeatedly flicking switches such as lights and power points; repeatedly pushing buttons; opening and closing objects, or repeatedly throwing objects.

Stereotyped behaviours: Flapping of the hands or arms is commonly seen in some children with ASDs when they are excited and/or frustrated. Children with ASDs may also walk on tiptoes, spin their body on the spot, or shake/vibrate their body while completing activities or when excited. This latter behaviour may also occur with clenched fists and gritted teeth.

Sensory behaviours and interests: The most commonly observed sensory behaviours include visual examination of objects by: holding them up and peering at them, using their peripheral vision, or placing them very close to the face; smelling or licking objects; sensitivity to everyday sounds such as a music box, blender, vacuum cleaner etc. and becoming distressed and/or placing their hands over their ears; repeatedly exploring the tactile properties of objects and surfaces by, for example, feeling materials in-between their fingers such as tags on clothes or people's hair, or running sand or dirt though their fingers.

Ritualistic behaviours and routines: Parents may report that their child: has to drink from a specific bottle; does not like different foods to touch each other on the plate; will only eat certain coloured or textured foods; has to put things in certain places; must have all the lights switched on or off, or have all the doors in the house opened or closed etc. Any other rituals or routines that seem fixed and that the child seems under pressure to complete are also important to note.

Echolalia: Verbal toddlers with an ASD may display echolalia, where they repeat what is said to them. For example, when asked "Can you stack these blocks?" the child repeats, "Stack these blocks". These words are typically repeated with the same intonation as originally said.

Loss of skills: Skill loss is an important marker for developmental concern. Many children with an ASD may not show typical 'regression' as was explained earlier, but may, instead, show more subtle losses. Many parents report that their child said "mama/dada" or other first words early on (8- to 12-months of age), made more eye contact, used to smile more, or wave bye-bye etc., but subsequently lost these skills, or currently uses them less frequently. Thus, if *any* loss of language or social skills occurs, other signs of ASDs described here should be explored.

Evaluation of the SACS Implementation by MCH Nurses

The MCH nurses who participated in the SACS were asked to evaluate its implementation at three time points: immediately after the initial training workshop (Time 1), 6 to 9 months after commencement of the study (Time 2), and immediately after completion of the study (Time 3). Nurses rated items on a 5-point likert scale from 'Strongly Agree' to 'Strongly Disagree'. All nurses (241) completed the evaluation at Time 1, 83% of nurses completed the evaluation at Time 2, and 68% of nurses completed the evaluation at Time 3 (the nurses from two councils did not complete an evaluation at the last time point due to non-participation).

Summary data from the evaluation administered after the initial training workshop are presented in Figure 1. On the basis of their training, nurses reported that they felt able to monitor the early signs of ASDs between 8- to 24-months of age, and included comments such as: "…will be more diligent in looking at development at 8-, 12-, 18- and 24-months"; "helped me understand at a deeper level the importance and relevance of social attention and

communication signs". They also felt confident in being able to refer infants at risk of an ASD, and reported that the training will have a positive impact on their work: "…the study will not to be difficult to incorporate into practice"; "…a great opportunity to participate in evidence based practice".

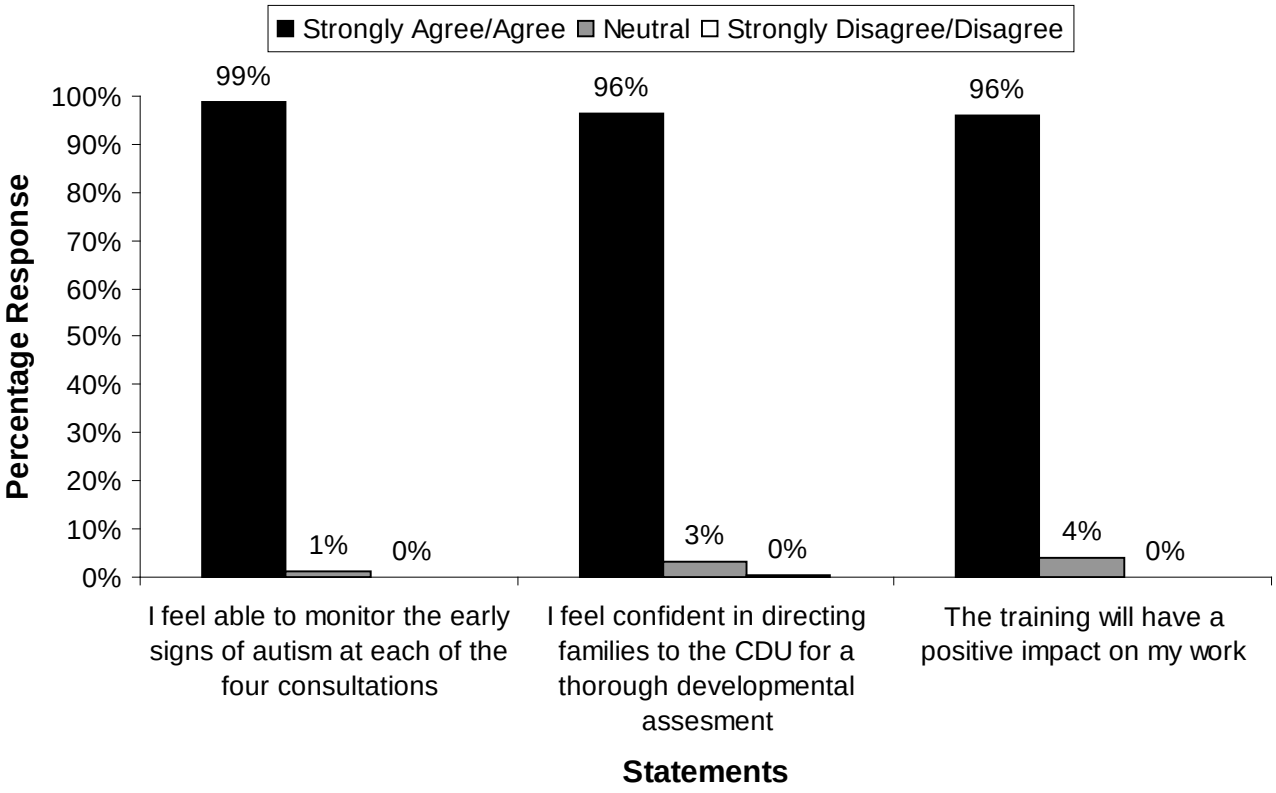

Figure 1. Percentage response by MCH nurses at the initial training evaluation – Time 1

At the 6 to 9 month evaluation (see Figure 2), the large majority of nurses reported that the SACS was easy to implement into their current practice, had a positive impact on their current practice, and reported that it did not take much additional time to include as part of their regular checks, with most nurses agreeing that additional time was added only in instances where a child was showing problems in their development: "If a child has a developmental problem, the consult takes longer but not because we are using SACS." The majority of parents were also reported as being comfortable with the SACS being undertaken

at their centres: “Parents are interested and fascinated with this – has led to healthy discussion”; “…my ability to discuss concerns with parents has been enhanced”.

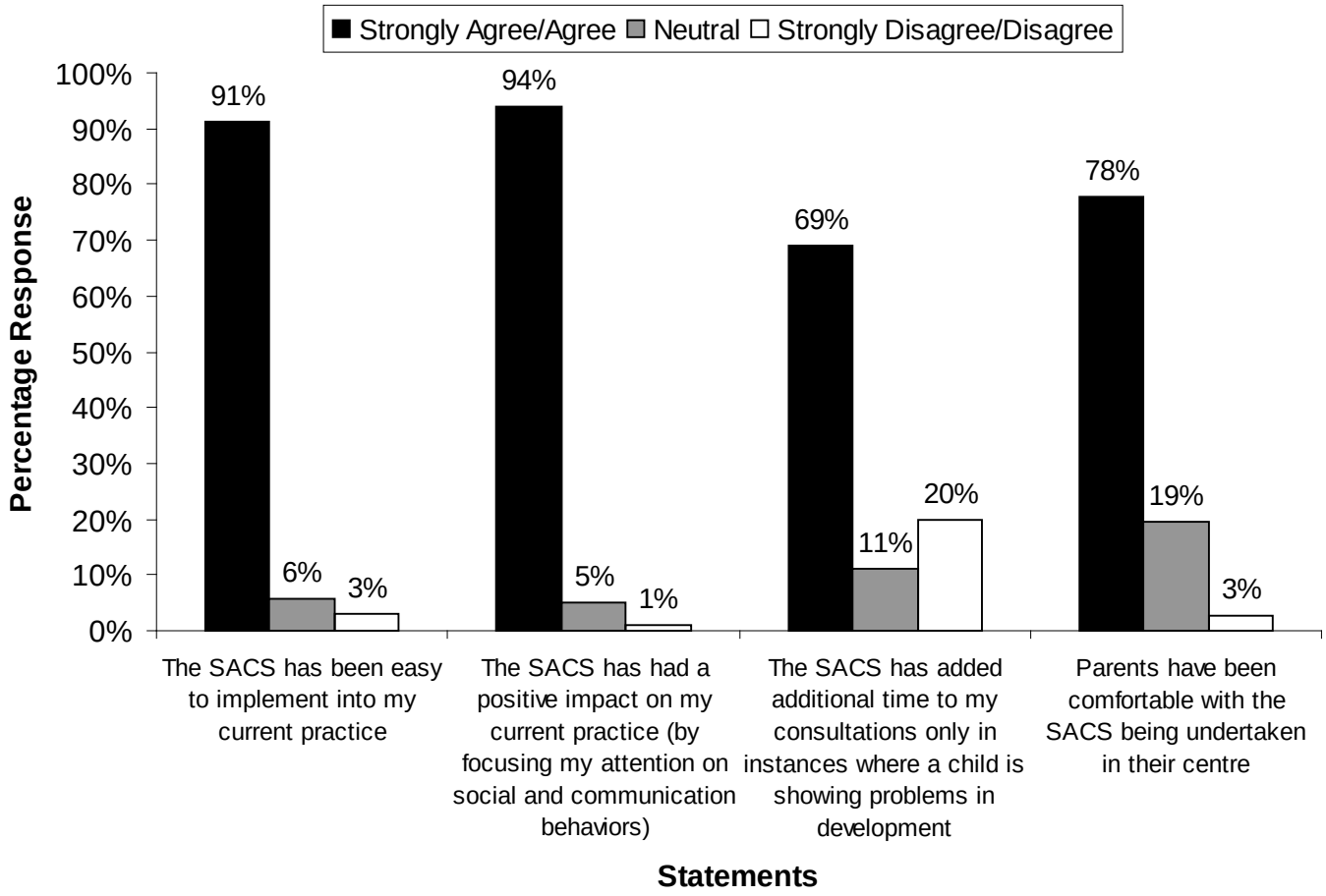

Figure 2. Percentage response by MCH nurses at the 6 to 9 month evaluation – Time 2

At the completion of the study, the nurses reported that the SACS helped them to understand the presentation of ASDs in infancy and toddlerhood (see Figure 3). For those nurses who referred children to the SACS, the majority reported that parents felt being part of the SACS was a positive experience: “Excellent study. My knowledge was reinforced and I’m now more confident in handling this with parents. Parents have also become more aware of necessity for diagnosis and help in looking for concerns”.

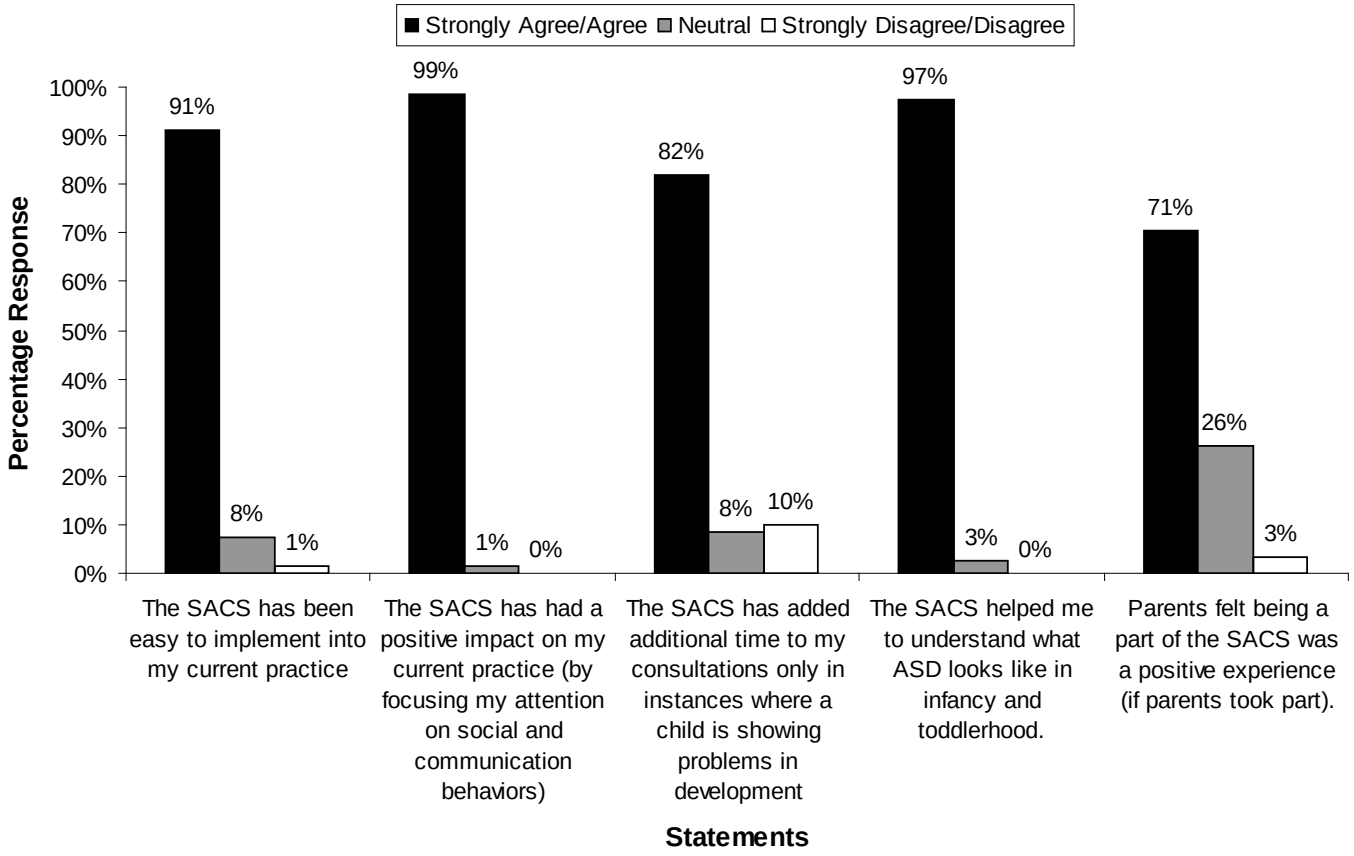

Figure 3. Percentage response by MCH nurses at the final evaluation – Time 3

Figure 4 indicates that the nurses were very confident in looking for signs of ASDs at each of the consultations at both the 6 to 9 month evaluation and the final evaluation: “I cannot thank you enough for the knowledge and confidence I have gained in picking up the children”; “This study has been empowering to help me look for signs of ASD. I am much more confident in looking for the signs”. Finally, the nurses reported that they would like to see the model implemented permanently to help identify ASDs as early as possible: “I wish we had this type of training regularly throughout our practice”; “The best tool and the best study I have ever been involved with”.

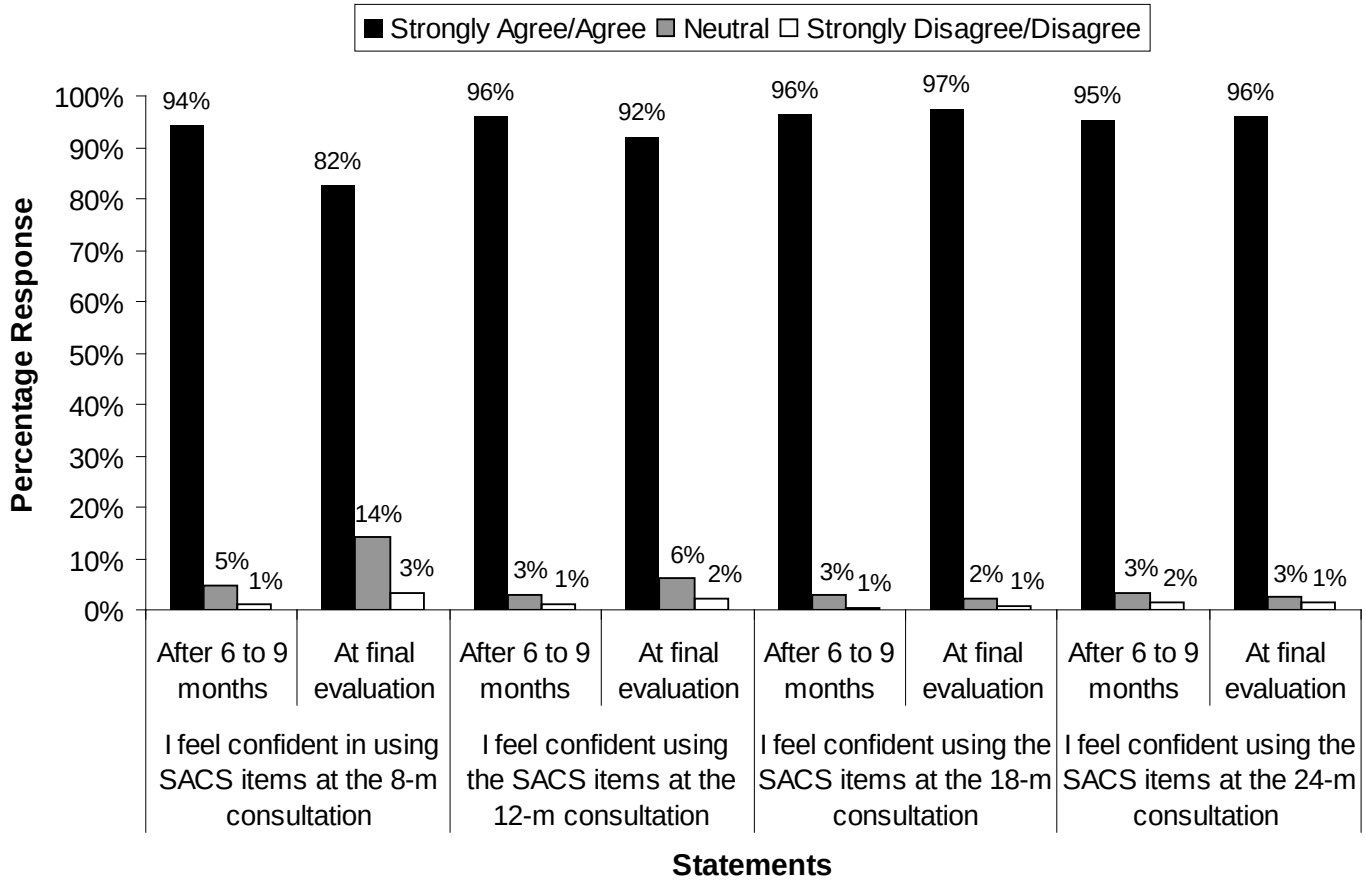

Figure 4. Percentage response by MCH nurses of their confidence in looking for signs of ASDs at each age – Time 2 and 3.

Future Directions

Implementation of Developmental Surveillance of Social Attention and Communication Behaviours

On the basis of the results from the SACS, and the nurses' evaluations of its implementation, it is argued here that developmental surveillance of social attention and communication behaviours should be undertaken universally and preferably within children's regular health checks during their second year of life (Curry & Duby, 1994; Dworkin, 1989; Filipek et al., 2000; Pinto-Martin et al., 2005). By training MCH nurses on the early signs of

ASDs, it has been possible to prospectively identify infants with an ASD in a community-based setting as early as 12-months of age.

Although the Victorian MCH service differs from other Australian and international early childhood services, the SACS procedure could be easily incorporated into well child checks carried out by other primary health care workers; for example health visitors in the UK or paediatricians and paediatric nurses in the USA. The SACS utilised behaviours already monitored as part of the health checks by MCH nurses, and these are behaviours which are universally monitored by primary health care workers (i.e., eye contact, social smiling, imitation, etc.). Thus, any primary heath care worker involved with infants and toddlers could monitor the behavioural items utilised in the SACS to identify risk for an ASD.

The repeated monitoring of children from 8-months of age makes it possible to identify more children at risk for an ASD, rather than relying on "once-off" screening of children at a given age. The latter approach has been adopted in other large-scale community based studies (Baron-Cohen et al., 1992; Dietz et al., 2006; Swinkels et al., 2006) with limited success. A move away from a 'screening' model and towards a 'developmental surveillance' model is recommended here, whereby all children are monitored by primary health care workers for signs of abnormal development, focusing on the early signs of ASDs. The importance of education about the early characteristics of ASDs, and the value of early identification and intervention, cannot be underestimated.

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Appendix A

SACS items completed by MCH nurses when a child was identified as 'at risk' for an ASD

8-MONTHS: If answer NO to BOTH underlined items, child is 'AT RISK'	
Social games – peek-a-boo	
Start a game of peek-a-boo with the child. Does the child reciprocate?	YES / NO
Eye contact	
Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?	YES / NO
Turning to name call	
Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you)	YES / NO
Social smiling	
Has the child smiled while making eye contact with you? If not, smile at the child. Does s/he smile back? (Do not use physical contact to elicit a smile)	YES / NO
Imitation	
Get the child's attention and clap your hands in front of the child *OR* 'Smack' your lips in front of the child. Does s/he imitate you?	YES / NO
Use of language	
• Does the child use syllables (e.g., ba, da, ra)?	YES / NO
• Does s/he combine these sounds into babble (e.g., saying agaga, adaba, mama, dada)?	YES / NO
Does the child enjoy cuddles with the parent?	*YES / NO*
Has the child been attending to / seem interested in sounds during the session?	*YES / NO*

Note. **Items in italics were monitored as part of the SACS, but are not described in the text as they have subsequently been found not to be important markers of ASDs in infancy and toddlerhood.**

12-MONTHS: If answer NO to 3 of the 4 underlined items, child is 'AT RISK'

Eye contact
Has the child spontaneously made eye contact with you during the session?
If not, interact with the child to elicit eye contact.
Does s/he make eye contact with you? YES / NO

Turning to name call
Call the child's name. Does s/he turn to look at you?
(Make sure child is not already looking at you) YES / NO

Social smiling
Has the child smiled while making eye contact with you?
If not, smile at the child. Does s/he smile back?
(Do not use physical contact to elicit a smile) YES / NO

Imitation
Get the child's attention. Use a brush/comb on your hair.
Give it to the child and say 'your turn'. Does s/he imitate you? YES / NO

Use of language
- Does the child babble (e.g. saying agaga, adaba, mama, dada) in a conversational like manner? YES / NO
- Does the child speak 1-3 recognisable words? YES / NO

Understanding of language
Show the child a block and place it beside him/her.
Then ask, "Give me the block". Does s/he give you the block? YES / NO

Pointing
Get a teddy bear, show it to the child and say "This is teddy".
Then put the bear across the room (where the child can see it) and say,
"Where's teddy?" Does the child point to the bear and look at your face? YES / NO

Joint attention: following another's point and gaze
Get the child's attention and then point to an object across the room and say 'WOW, look at that!' Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)? YES / NO

Social gestures
Elicit the social routine of waving bye-bye
(e.g., pretend to leave room and wave bye-bye to the child).
Does s/he wave back? YES / NO

Does the child enjoy cuddles with the parent? *YES / NO*

Has the child been attending to / seem interested in sounds during the session? *YES / NO*

Note. **Items in italics were monitored as part of the SACS, but are not described in the text as they have subsequently been found not to be important markers of ASDs in infancy and toddlerhood.**

18-MONTHS: If answer NO to 3 of the 4 underlined items, child is 'AT RISK'

Eye contact
Has the child spontaneously made eye contact with you during the session?
If not, interact with the child to elicit eye contact.
Does s/he make eye contact with you? YES / NO

Turning to name call
Call the child's name. Does s/he turn to look at you?
(Make sure child is not already looking at you) YES / NO

Social smiling
Has the child smiled while making eye contact with you?
If not, smile at the child. Does s/he smile back?
(Do not use physical contact to elicit a smile) YES / NO

Imitation
Get the child's attention. Use a brush/comb on your hair.
Give it to the child and say 'your turn'. Does s/he imitate you? YES / NO

Use of language
- Does the child use 5-10 words? YES / NO
- Does the child understand many more words? YES / NO

Understanding of language
- Show the child a block and place it beside him/her.
  Then ask, "Give me the block". Does s/he give you the block? YES / NO
- Get the child's attention. Say 'point to your eyes/nose/mouth'.
  Does s/he point to his/her eyes/nose/mouth? YES / NO

Pointing
Get a teddy bear, show it to the child and say "This is teddy".
Then put the bear across the room (where the child can see it) and say,
"Where's teddy?" Does the child point to the bear and look at your face? YES / NO

Joint attention: following another's point and gaze
Get the child's attention and then point to an object across the room
and say 'WOW, look at that!' Does s/he look at where you are pointing
at (as opposed to just looking at your hand/arm)? YES / NO

Social gestures
Elicit the social routine of waving bye-bye
(e.g., pretend to leave room and wave bye-bye to the child).
Does s/he wave back? YES / NO

Showing: social communication
Does the child try to communicate with the parent in a SOCIAL manner?
(i.e., not just to request food or an object – ask parent) YES / NO

Pretend play
Give the child a toy cup and pot. Say "Can you pour a drink and drink it"?
Does the child pretend to pour a drink and/or drink it? (Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy) YES / NO
Loss of skills
Ask the parent if the child has lost ANY language or social skills at ANY age.
Has the child lost any skills? YES / NO
Does the child ever come to the parent for affection or comfort? (ask parent) YES / NO
Does the child enjoy cuddles with the parent? YES / NO

Note. **Items in italics were monitored as part of the SACS, but are not described in the text as they have subsequently been found not to be important markers of ASDs in infancy and toddlerhood.**

24-MONTHS: If answer NO to 3 of the 5 underlined items, child is 'AT RISK'

Eye contact
Has the child spontaneously made eye contact with you during the session?
If not, interact with the child to elicit eye contact.
Does s/he make eye contact with you? YES / NO

Turning to name call
Call the child's name. Does s/he turn to look at you?
(Make sure child is not already looking at you) YES / NO

Social smiling
Has the child smiled while making eye contact with you?
If not, smile at the child. Does s/he smile back?
(Do not use physical contact to elicit a smile) YES / NO

Imitation
Get the child's attention. Use a brush/comb on your hair.
Give it to the child and say 'your turn'. Does s/he imitate you? YES / NO

Use of language
- Does the child use 20 – 50 words? YES / NO
- Does the child use some two-word phrases (e.g., want drink)? YES / NO

Understanding of language
Show child a teddy bear and place it beside him/her.
Then ask, "Give me teddy". Does s/he give you the teddy? YES / NO

Pointing
Get a teddy bear, show it to the child and say "This is teddy".
Then put the bear across the room (where the child can see it) and say,
"Where's teddy?" Does the child point to the bear and look at your face? YES / NO

Joint attention: following another's point and gaze
Get the child's attention and then point to an object across the room
and say 'WOW, look at that!' Does s/he look at where you are pointing
at (as opposed to just looking at your hand/arm)? YES / NO

Social gestures
Elicit the social routine of waving bye-bye
(e.g., pretend to leave room and wave bye-bye to the child).
Does s/he wave back? YES / NO

Showing: social communication
Does the child try to communicate with the parent
in a SOCIAL manner? (i.e., not just to request food or an object – ask parent) YES / NO

Pretend play
Give the child a toy cup and pot. Say "Can you pour a drink and drink it"?
Does the child pretend to pour a drink and/or drink it? (Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy) YES / NO
Interest in other children (parallel play)
Does the child play near (not necessarily with) other children? (ask parent) YES / NO
Loss of skills
Ask the parent if the child has lost ANY language or social skills at ANY age.
Has the child lost any skills? YES / NO
Does the child ever come to the parent for affection or comfort? (ask parent) YES / NO

Note. **Items in italics were monitored as part of the SACS, but are not described in the text as they have subsequently been found not to be important markers of ASDs in infancy and toddlerhood.**

Appendix B

Checklist of Social Attention and Communication Behaviours

CHILD ID: **AGE (in months):**

Behaviour	***Age to look for***	***Atypical behaviours to look for***	***Typical (+) or Atypical (-)?***
Social games: peek-a-boo	8-months	Lack of eye contact, social smiles, imitation, anticipatory postures	
Eye contact	8- to 24-months	Absent, lowered frequency, inconsistent, fleeting	
Turning to name call	8- to 24-months	Doesn't/rarely turns when you or parent calls name	
Social smiling	8- to 24-months	Doesn't/rarely smiles in response to another person	
Imitation	8- to 24-months	Doesn't/rarely imitates others	
Use of language	8- to 24-months	Hasn't reached appropriate milestones for expressive language	
Understanding of language	8- to 24-months	Doesn't follow instructions appropriate for his/her age	
Pointing	12- to 24-months	Doesn't/rarely points with an index finger while combining this with eye contact	
Joint attention: following another's point or gaze	12- to 24-months	Doesn't/rarely looks to where you are pointing or looking	
Social gestures	12- to 24-months	Doesn't/rarely uses gestures, e.g., nodding or shaking head	
Showing: social communication	18- to 24-months	Doesn't/rarely shows other people toys / objects.	
Pretend play	18- to 24-months	Doesn't pretend to feed a teddy bear or pour a drink	
Interest in other children (parallel play)	24-months	Doesn't seem interested in other children	

Appendix C

Checklist of Aberrant Behaviours

CHILD ID: **AGE (in months):**

Behaviour	***Atypical behaviours to look for***	***Present (+) or Absent (-)?***
Using another's hand/body as a tool	Places another's hand on an object to request; using another's finger to point	
Repetitive behaviours	- Lining up / sorting / spinning objects	
	- Places head on the floor/table to observe toys rolled side to side	
	- Continuously holds object/s in one or both hands	
	- Obsession with particular objects: frequently seeks them out, or holds them	
	- Repeatedly: flicks switches / pushes buttons / opens and closes objects / throws objects	
Stereotyped behaviours	- Flaps hands/arms	
	- Walks on tiptoes	
	- Spins body on spot	
	- Shakes/vibrates body (can occur with clenched fists and gritted teeth)	
Sensory behaviours and interests	- Visual examination of objects (peering, using peripheral vision, placing very close to face)	
	- Smells / licks objects	
	- Distress to everyday sounds, hands over ears	
	- Feels materials in-between fingers	
Ritualistic behaviours and routines	- Has to drink from a specific bottle	
	- Does not like different foods to touch	
	- Will only eat certain coloured / textured foods	
	- Has to put things in certain places	
	- Must have all lights switched on/off, or have all the doors opened/closed	
	- Any other rituals/routines that seemed fixed and the child seems under pressure to complete	
Echolalia	Repeats words/sentences that other people have said. May be same intonation.	
Loss of skills	Loss of ANY language of social skills	

PAPER 3

PROSPECTIVE IDENTIFICATION OF ASDs IN INFANCY AND TODDLERHOOD

Paper 3

Prospective identification of Autism Spectrum Disorders in infancy and toddlerhood using developmental surveillance: The Social Attention and Communication Study (SACS)

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Abstract

Objective: Despite behavioural markers of Autism Spectrum Disorders (ASDs) being evident within the first year of life, there remains little research on the prospective identification of these children in a community-based setting prior to 18-months. The aim in the Social Attention and Communication Study (SACS) was to identify infants and toddlers at risk of an ASD during their first 2 years. **Methods:** A total of 241 Maternal and Child Health (MCH) nurses were trained on the early signs of ASDs at 8-, 12-, 18- and 24-months. Utilising a developmental surveillance approach with a community-based sample, a cohort of 20,770 children was monitored on early social attention and communication behaviours. Those infants/toddlers identified as 'at risk' were referred to the SACS team from 12-months for developmental and diagnostic assessments at 6-monthly intervals, until 24-months. **Results**: A total of 216 children were referred, with 110 being assessed by the SACS team. Of these, 89 children were classified with an ASD at 24-months, and 20 children had developmental and/or language delays, resulting in a Positive Predictive Value of 81%. The estimated rate of ASDs in the SACS cohort ranged from 1:119 to 1:233 children. Estimated sensitivity ranged from 69% to 83.8%, and estimated specificity ranged from 99.8% to 99.9%. **Conclusion:** Developmental surveillance of social and communication behaviours, which differ according to the age at which the child is monitored, enables the accurate identification of children at risk for ASDs between 12- to 24-months. Education on the early signs is recommended for all primary health-care professionals in order to facilitate early identification of ASDs.

Key words: autism spectrum disorders; developmental surveillance; screening; infants; toddlers; prospective identification; community-based.

Prospective identification of Autism Spectrum Disorders in infancy and toddlerhood using developmental surveillance: The Social Attention and Communication Study (SACS)

Autism Spectrum Disorders (ASDs) are among the most severe and debilitating neuro-developmental disorders affecting children, and include individuals who meet criteria for Autistic Disorder (AD), Asperger's Disorder (AspD), or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS; DSM-IV-TR; American Psychiatric Association, 2000). Current prevalence rates of the combined ASDs are currently 1 in 160 in Australia (Williams, MacDermott, Ridley, Glasson, & Wray, 2008), 1 in 100 in the UK (Baird et al., 2006), and 1 in 91 in the USA (Kogan et al., 2009). Retrospective videotape analyses and parental report studies provide valuable evidence that symptoms of ASDs are present during infancy. Indeed, nearly 50% of parents of children with an ASD report having concerns prior to 12-months of age, with many more reporting recognition of abnormalities between 12- to 24-months (Rogers & Di Lalla, 1990; Werner, Dawson, Osterling, & Dinno, 2000; Young, Brewer, & Pattison, 2003).

The signs of ASDs in infancy and toddlerhood consistently identified from these retrospective studies fall within the realm of social attention and communication. These 'red flags' include lack of: eye contact, social smiles, imitation, response to name call, interest and pleasure in others, emotional expression, directed vocalisations, joint attention skills (pointing to 'show', following a point, monitoring others' gaze, referencing objects/events), requesting behaviours, and gestures (e.g., waving, clapping, nodding, shaking head etc.). Imagination skills, such as pretend play, have also been found to be deficient in late infancy and toddlerhood for many children with an ASD (see Barbaro & Dissanayake, 2009, for a review). Although sensory and motor behaviours and stereotypies are seen in some infants with an ASD, they are also indicative of general intellectual disability (Osterling, Dawson, &

Munson, 2002; Werner & Dawson, 2005), with many children not showing these behaviours until around 3 years of age (Gray & Tonge, 2001; Young & Brewer, 2002).

Despite knowledge of the early signs of ASDs, the average age of diagnosis is 3.1 years for AD, 3.9 years for PDD-NOS, and 7.2 years for AspD (Mandell, Novak, & Zubritsky, 2005). Screening tools have therefore been developed to identify ASDs in infancy and toddlerhood to facilitate early referral, diagnosis and, most importantly, intervention, as this provides the best opportunity to promote positive developmental outcomes for affected children and their families (Dawson, 2008; Shonkoff & Phillips, 2000).

Prospective Studies

Prospective studies attempt to identify children with ASDs who have not previously been identified with developmental problems. They are highly desirable as the researcher can attempt to elicit the behaviours of interest identified as early markers at a particular age and under standardised conditions, allowing comparison between different groups and at different time points in the child's life. Furthermore, these behaviours can be studied longitudinally, so that the relationship between early deficits and later behavioural manifestations can be examined. Few prospective studies have been conducted in the general population (Level 1 screening studies), with many more focusing on the siblings of children with an ASD (ASD-sibs), as they are at a genetically increased risk of developing an ASD (Bailey et al., 1995; O'Roak & State, 2008; Rogers, 2009).

High-risk sibling studies have been an invaluable source of information on the very early development of ASDs. Capable of investigating the early ASD phenotype, risk markers of ASDs have been found from 12-months of age, and include: a combination of impaired language and social-communicative development; abnormal visual tracking, attention and sensory-orienting behaviours; behavioural manifestations such as behavioural reactivity, difficulties with transitions and impaired motor control, and subtle stereotyped behaviours

such as spinning, rotating, and unusual visual exploration of objects (Barbaro & Dissanayake, 2009; Rogers, 2009).

Although many recent studies have been conducted with ASD-sibs, high-risk samples are unique, as siblings have grown up in an environment already affected by ASDs. Indeed, children with ASDs from multiplex families are higher functioning in cognitive and adaptive skills than those from singleton families (Pandey, 2008). Thus, numerous factors need to be considered as possible influences contributing to developmental differences, including early symptom recognition, intervention, affected parenting styles due to exposure to intervention techniques, and parental stress (Zwaigenbaum et al., 2007).

Prospective studies conducted in community-based samples are therefore preferable for investigating the early ASD phenotype. They typically utilise a Level 1 screening tool at a single age in a community health service or general medical practice setting (see Barbaro & Dissanayake, 2009, for a review). Unfortunately, few have been conducted, and the large-scale screening studies using the Checklist for Autism in Toddlers (CHAT) at 18-months (Baird et al., 2000; Baron-Cohen et al., 1996) and the Early Screening of Autistic Traits Questionnaire (ESAT) at 14/15-months (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006; Swinkels et al., 2006) have poor sensitivity. Although the CHAT's specificity was excellent (98%) at 18-months, its sensitivity was only 38%, missing over 60% of children diagnosed with an ASD at 7 years. The sensitivity of the ESAT was unable to be estimated, but would have been low based on current prevalence rates, as only 18 children with ASDs were identified out of 31,724 children at 14/15-months.

Smaller community-based studies, utilising the M-CHAT (Kleinman et al., 2008) and Infant-Toddler Checklist (ITC; Wetherby, Brosnan-Maddox, Peace, & Newton, 2008) have also reported problems. The Positive Predictive Value (PPV) of the M-CHAT between 16- to 30-months was only 11% when used alone, and 65% when used with a follow-up phone

interview. The ITC, although having excellent sensitivity between 9- to 24-months (93%), identified 813 children as needing further developmental surveillance out of a sample of 5385 children. Only 56 of these children received a diagnosis of an ASD, indicating that the ITC was unable to distinguish between children with ASDs from those with developmental or language delays. Therefore, although the American Academy of Pediatrics (AAP, 2007) recommends routine screening for ASDs in the second year of life, there are currently no tools with sufficient specificity *and* sensitivity available for universal use.

The less than optimal outcomes to date from the large-scale screening studies may be because the screening tools (CHAT; ESAT) were administered at a single age, leading to many missed opportunities for identifying 'at risk' children. Furthermore, the smaller community-based screening studies (using M-CHAT; ITC), in an attempt to increase sensitivity, identified many children without ASDs, albeit with other general developmental and language problems. In contrast to this approach, the *routine and repeated* monitoring of key behaviours throughout infancy and toddlerhood may serve to improve the identification of ASDs, consequently increasing sensitivity whilst decreasing the number of false positive cases.

Developmental Surveillance Through the Maternal and Child Health (MCH) Service

Primary health-care professionals, such as MCH nurses and related practitioners, are the best placed and most expert to undertake developmental surveillance of young children to identify those showing early signs of ASDs, given their extensive knowledge and training on developmental milestones (Halpin & Nugent, 2007; Pinto-Martin, Souders, Giarelli, & Levy, 2005). Parental report, although useful for informing professionals about infrequent behaviours, is prone to incorrect memory recall, recall biases, distortion of events, and other problems (Zwaigenbaum et al., 2005). It thus remains important that all health-care

professionals, particularly early childhood nurses, monitor children for abnormal development through *skilled observations*, as well as though parental report.

In the State of Victoria, Australia, infant and early child development is monitored through the MCH service by trained MCH nurses. The Social Attention and Communication Study (SACS) reported here was conducted through this universal service, and utilised a developmental surveillance approach. The MCH service is offered free of charge to all families with children under 6 years of age, with an emphasis on child and maternal health surveillance and screening. As part of this service, well-baby checks are scheduled at key ages from birth to 3½ years, and key developmental milestones are routinely monitored and recorded at these consultations. Given that 98% of Victorian babies access the MCH service soon after birth, with attendance remaining relatively high within the first 2 years (Department of Education and Early Childhood Development; DEECD, 2007), this service has enormous potential to identify infants at risk of ASDs.

The aim in the SACS was to determine whether routine and repeated monitoring of social attention and communication behaviours, previously found to be key markers of ASDs in infants and toddlers, could be used to prospectively identify children with an ASD in a community-based sample. It was hypothesised that these behaviours will serve to identify infants with ASDs via their routine MCH assessments by at least 18-months. However, it was anticipated that detection may even be possible at 12-months. It was also hypothesised that utilising a developmental surveillance approach would increase the chances of accurately identifying children with ASDs at 2 years of age and younger.

Method

Participants

A total of 22,168 children were monitored though 184 MCH centers in 17 local government areas (LGAs) in metropolitan Melbourne, between September 2006-2008. Fourteen centers (including a whole LGA) were subsequently excluded due to non-compliance, with the final number of monitored participants included in the data analyses being 20,770 children. The number of children initially monitored at each age was: 5723 8-month-olds, 5286 12-month-olds, 5334 18-month-olds, and 4427 24-month-olds. The cohort initially monitored at 8-months (n = 5723) was monitored by the nurses at all ages (i.e., 8-, 12-, 18-, and 24-months). Similarly, those that were initially monitored at 12-months (n = 5286) were monitored at 12-, 18-, and 24-months, and so on.

The LGAs were chosen based on proximity to facilitate ease of referral, with most centers within a 20 kilometer radius of La Trobe University, Bundoora Campus. The Socio Economic Status of the LGAs was mostly high, with the mean Socio-Economic Indexes for Areas (SEIFA) score for the LGAs in the SACS (M = 1066) being slightly higher than the mean SEIFA score in metropolitan Melbourne (M = 1033). The centers included in the SACS were therefore comparable to those not included in metropolitan Melbourne.

Procedure

Maternal and Child Health nurse training and SACS items. Following approval from the Victorian Department of Human Services (DHS) and the La Trobe University Human Ethics Committees, the coordinators of the MCH centers in each LGA were invited to participate in the study. Local Government Areas were only included if the MCH coordinators consented to participation in the study (see Appendix A for the MCH coordinators consent form). A pilot phase was implemented at an LGA local to the University for one month.

The nurses in each LGA (N = 241) received a 2½ hour training workshop, held between September to December 2006, to monitor children's development using skilled observations during their routine consultations at 8-, 12-, 18-, and 24-months. The workshops focused on typical and atypical social-communicative development, the early (and later) signs of ASDs, and the particular items within the MCH record which were relevant to the detection of ASDs.

Behavioural items for monitoring were selected on the basis of the literature on the signs of ASDs in infancy and toddlerhood, the majority of which were already part of the routine MCH consultations. Items most relevant to ASDs, and developmentally appropriate for the age being monitored, were underlined and considered 'KEY' items. Children were considered 'at risk' for an ASD only if they showed a 'pattern' of failure on the items of interest; for example, by failing three of the four 'KEY' items. Important markers of ASDs, which were not part of the MCH consultations at the age being assessed, were added to these checks as 'Extra Items' and only monitored if a child was identified as 'at risk'. A summary of the behaviours monitored, highlighting the 'KEY' and 'Extra' items, are outlined in Table 1.

Table 1
Behaviours Monitored at Each Age, Including 'KEY' (K) and 'Extra' (E) Items

	Age at which behaviour was monitored			
Behaviour	8-months	12-months	18-months	24-months
Social games – peek-a-boo	✓			
Interest in sounds	✓	✓		
Eye contact	✓(K)	✓(K)	✓(K)	✓ (E)
Turning to name call	✓(K)	✓(K)	✓ (E)	✓ (E)
Use/understanding of language	✓	✓	✓	✓
Imitation	✓ (E)	✓ (E)	✓ (E)	✓(K)
Social smiling	✓ (E)	✓ (E)	✓ (E)	✓ (E)
Enjoys & seeks cuddles/ affection/comfort	✓	✓	✓	✓
Pointing		✓(K)	✓(K)	✓(K)
Gestures – Waving		✓(K)	✓(K)	✓(K)
Joint attention – following point		✓ (E)	✓ (E)	✓ (E)
Pretend play			✓(K)	✓(K)
Social communication ('showing behaviours')			✓	✓(K)
Loss of skills			✓ (E)	✓ (E)
Parallel Play				✓

Note. Pass/Fail Criteria: 8-months: Fail 2 KEY items; 12- & 18-months: Fail 3 out of 4 KEY Items; 24-months: Fail 3 out of 5 KEY items.

The nurses were provided with a sheet detailing how each specific item was to be monitored at each age (these are detailed in Barbaro, Ridgway, & Dissanayake, 2010, and are available on request). For example, "Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?" Nurses were instructed to re-administer 'failed' items a maximum of three times, and were trained to identify when a behaviour was *atypical*, as opposed to present/absent. For example, nurses were trained to identify when eye contact was atypical due to its absence, inconsistency, infrequency, or when it was not used in combination with other behaviours such as pointing or giving objects when requesting. Video clips of children with and without an ASD were utilised in training the behaviours of interest.

In instances where the nurse was unable to elicit a particular behaviour due to the child being ill, unhappy or asleep, parental/caregiver report was used. Nurses were required to probe for specific and detailed examples of the behaviour, to make a judgment as to whether the behaviour was, in fact, typical or atypical.

Reliability of training. To determine reliability of the nurses' monitoring of the behavioural items, the first author visited 27 of the MCH centers (~10%) participating in the study to co-monitor these items during routine child check-ups. Fifty-two items were assessed across the four ages. Percentage agreement, calculated for items assessed at each age, was .90 or higher for *all* the items, and .83 or higher for each individual item, with the exception of three items, which ranged between .59 and .70[1].

Protocol for referrals. Nurses were instructed to only refer children from 12-months onwards. Thus, no 8-month data will be presented in this paper. Once identified 'at risk' for an ASD, the nurses administered the 'extra items', and counseled parent/s about concerns regarding the child's development in social attention and communication. The nurses were instructed to refrain from using the terms autism or ASD. Parents were told that the monitored behaviours were important developmental milestones, and were referred to the SACS team for a thorough developmental and behavioural assessment to clarify the child's developmental status (see Appendix B for the flow chart MCH nurses were required to follow for referrals). They were then given an informed consent form for completion, to be sent to the team (See Appendix C for the MCH informed consent form).

[1] These three were 'Extra items', and the lower reliability scores were due to a large percentage of nurses not scoring these items. This is not problematic for the data reported in this paper as they were not used to refer children to the SACS.

Assessment protocols for 'at risk' children. Children identified by their nurse as 'at risk', whose parent/s consented to participate in the study, were initially seen and then followed-up at the CDU at 6-monthly visits, until 24-months of age (see Appendix D for the CDU informed consent form). All children were assessed in a laboratory playroom: one researcher conducted the assessment, while the other operated three video cameras remotely from an observation room. The videotapes were used to assist in scoring the assessments. Children were either seated at a table or brought to the floor on a play mat, as determined by the activity, and a parent was present during the assessments. These assessments, undertaken at each age, are outlined in Table 2.

Table 2

Assessments Undertaken at the CDU at Each Age

12-18 month visits	24-month visit
Administered assessments:	Administered assessments:
- Mullen Scales of Early Learning (Mullen, 1995) - Early Social and Communication Scales (Mundy, Hogan, & Doehring, 1996) - Imitation / name call / spontaneous play tasks. Empathy tasks (18m only). - CHAT-23 (18m only; Wong et al., 2004)	- Mullen Scales of Early Learning - Autism Diagnostic Observation Schedule (Lord et al., 2000; 1999) - Imitation/empathy tasks
Parental Questionnaires:	Parental Questionnaires:
- Demographic Questionnaire - Infant-Toddler Checklist-CSBS-DP (Wetherby & Prizant, 2002) - The Early Development Interview (re-formatted into questionnaire; Werner & Dawson, 2006) - CHAT-23 (18m only)	- Demographic Questionnaire - Autism Diagnostic Interview-Revised (Lord, Rutter, & Le Couteur, 1994)

Note. The data from many of these assessments will be presented in subsequent papers

On the basis of the assessments undertaken at the CDU, children were classified as AD (those children showing signs of 'classic' autism); ASD (children showing signs of an ASD, but who did not meet criteria for Autistic Disorder); DD/LD (children showing signs of developmental and/or language delay, but not AD or ASD), and TD (typically developing), which was confirmed at their 24-month assessment. A child was classified as 'AD/ASD' at 18-months only if s/he showed very clear signs. This classification was made based on clinical judgment using developmental history, data from all assessments, and parental questionnaires.

At 24-months, a diagnostic assessment was undertaken using the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000; Lord et al., 1999), an observational instrument consisting of four modules devised for individuals with varying language abilities. Module 1, designed for pre-verbal children, was used. The Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994), which is standardised, semi-structured parental interview, was also used. The first author, J.B., was trained to research reliability on both instruments. Research has shown that it is possible to accurately diagnose ASDs as early as 2 years of age using the ADI-R and the ADOS *together*, and in combination with clinical judgment (de Bildt et al., 2004; Le Couteur, Haden, Hammal, & McConachie, 2008). Furthermore, diagnoses at 24-months have been found to be *stable* over time (Barbaro & Dissanayake, 2009; Charman et al., 2005; Lord, 1995; Stone et al., 1999; Turner, Stone, Pozdol, & Coonrod, 2006).

Detailed reports were written on the basis of each of the assessments and parental questionnaires completed at each age, with copies sent to parents and, with parental permission, to the MCH nurses (see Appendix E for example reports from 12-, 18-, and 24-month assessments). All children who showed developmental and/or language delays at *any age*, and/or met criteria for an ASD, were referred to government Specialist Children's

Services teams for early intervention and a full diagnostic work-up, and speech pathology services if they also had language delays.

Results

Sample Characteristics

A total of 216 'at risk' children were referred by their MCH nurse to the SACS team. Of these, 124 consent forms were received. As 14 children were either withdrawn from the study by their parents prior to their visit to the CDU, or did not attend their scheduled assessment, a total of 110 children were assessed. There were 10 12-month assessments conducted (two children assessed at 12-months only; eight children assessed at 12-, 18- and 24-months); 46 18-month assessments conducted (eight children assessed at 18-months only; 30 children assessed at 18- and 24-months; eight children assessed at 12-, 18-, and 24-months), and 100 24-month assessments (62 children assessed at 24-months only; 30 children assessed at 18- and 24-months; eight children assessed at 12-, 18-, and 24-months). In total, 156 assessments were conducted at the CDU. The average time between referral and assessment at the CDU was just over 3 weeks for all the children.

Of the 110 children assessed, 89 were classified with an ASD (39 AD and 50 ASD), which was confirmed at their 24-month assessment[2]. Only one TD child was referred (at 18-months of age) to the CDU[3], with the remaining 20 children meeting criteria for DD/LD. The SACS therefore has an overall PPV of 81%.

[2] Ten children did not return for their 24-month assessment (2 children at 12-months and 8 children at 18-months). In these cases, a best estimate classification (BEC) was made based on clinical judgment using developmental history, and all assessments and parental questionnaires conducted to date (detailed in Method). We have been informed by their MCH nurses that two of the children given a BEC of an ASD (first seen at 12- and 18-months, respectively) have subsequently been diagnosed with an ASD or are receiving intervention for an ASD. No information is currently available on the remaining 8 children.

[3] This child was seen at 18- and 24-months, but was omitted from all analyses

At each of the ages, the SACS has a PPV of: 90% at 12-months, 79% at 18-months, and 81% at 24-months. Tables 3 to 5 present the characteristics of the samples assessed at each age.

Table 3

Sample Characteristics – 12m CDU Assessment (N = 10)

	Group					
	AD (*n* = 3)		ASD (*n* = 6)		DD/LD (*n* = 1)	
	M (*SD*)	95% CI	M (*SD*)	95% CI	M (*SD*)	95% CI
Age in months						
Chronological	13.7 (1.2)	-	12.7 (0.5)	-	15.0 (-)	-
Non-verbal	12.0 (4.3)	± 4.9	11.5 (2.2)	± 1.8	16.5 (-)	-
Verbal	9.2 (2.9)	± 3.3	9.0 (2.5)	± 2.0	8.0 (-)	-
Overall mental	10.6 (3.6)	± 4.1	10.3 (2.2)	± 1.8	12.3 (-)	-
T score						
Visual Reception	29.7 (6.5)	± 7.4	37.0 (9.2)	± 7.4	47.0 (-)	-
Fine Motor	43.7 (20.1)	± 22.8	44.7 (10.8)	± 8.7	53.0 (-)	-
Receptive Language	28.0 (5.2)	± 5.9	30.8 (7.3)	± 5.9	20.0 (-)	-
Expressive Language	31.3 (3.8)	± 4.3	38.2 (10.6)	± 8.5	28.0 (-)	-
Gender (Male – Female)	2 – 1		5 – 1		1 – 0	

Note. CDU = Child Development Unit; M = Mean; *SD* = Standard Deviation; CI = Confidence Interval; AD = Autistic Disorder; ASD = Autism Spectrum Disorder; DD/LD = Developmental and/or Language Delay

Table 4

Sample Characteristics – 18m CDU Assessment (N = 45)*

	Group					
	AD (*n* = 16)		ASD (*n* = 21)		DD/LD (*n* = 8)	
	M (*SD*)	95% CI	M (*SD*)	95% CI	M (*SD*)	95% CI
Age in months						
Chronological	19.2 (1.0)	-	19.1 (1.2)	-	19.9 (1.6)	-
Non-verbal	17.3 (2.3)	± 1.1	17.5 (2.9)	± 1.2	17.4 (1.9)	± 1.3
Verbal	9.2 (2.2)	± 1.1	12.0[b] (1.5)	± 0.6	13.4[b] (2.0)	± 1.4
Overall mental	13.2 (1.9)	± 0.9	14.8[a] (1.8)	± 0.8	15.4[a] (1.5)	± 1.0
T score						
Visual Reception	37.6 (8.5)	± 4.1	39.0 (9.7)	± 4.2	37.0 (7.5)	± 5.2
Fine Motor	44.0 (10.9)	± 5.3	44.9 (11.8)	± 5.0	42.1 (6.5)	± 4.5
Receptive Language	20.6 (2.5)	± 1.2	24.4[a] (5.0)	± 2.1	25.5[a] (4.5)	± 3.1
Expressive Language	26.3 (4.6)	± 2.2	31.4[b] (4.9)	± 2.1	35.0[b] (4.3)	± 3.0
Gender (Male – Female)	12 – 4		20 – 1		5 – 3	

Note. CDU = Child Development Unit; M = Mean; *SD* = Standard Deviation; CI = Confidence Interval; AD = Autistic Disorder; ASD = Autism Spectrum Disorder; DD/LD = Developmental and/or Language Delay

*TD child excluded

[a] Significantly different from AD, $p < .05$; [b] $p < .01$

Table 5

Sample Characteristics – 24m CDU Assessment (N = 99)*

	Group					
	AD (*n* = 37)		ASD (*n* = 42)		DD/LD (*n* = 20)	
	M (*SD*)	95% CI	M (*SD*)	95% CI	M (*SD*)	95% CI
Age in months						
Chronological	25.2 (1.6)	-	25.6 (2.2)	-	25.8 (2.7)	-
Non-verbal	19.1 (2.9)	± 0.9	21.4[b] (2.7)	± 0.8	21.3[a] (3.6)	± 1.6
Verbal	11.0 (2.7)	± 0.9	15.8[b] (4.1)	± 1.2	17.6[b] (3.5)	± 1.5
Overall mental	15.1 (2.5)	± 0.8	18.6[b] (2.9)	± 0.9	19.5[b] (3.3)	± 1.4
T score						
Visual Reception	30.9 (7.6)	± 2.5	35.8[a] (8.1)	± 2.5	36.6[a] (9.9)	± 4.3
Fine Motor	36.0 (11.1)	± 4.0	40.7 (9.0)	± 2.7	37.8 (11.0)	± 4.8
Receptive Language	20.3 (1.6)	± 0.5	26.3[b] (9.2)	± 2.8	32.2[b c] (10.4)	± 4.5
Expressive Language	23.9 (4.1)	± 1.3	31.7[b] (7.4)	± 2.2	32.5[b] (6.5)	± 2.8
Gender (Male – Female)	27 – 10		34 – 8		14 – 6	

Note. CDU = Child Development Unit; M = Mean; *SD* = Standard Deviation; CI = Confidence Interval; AD = Autistic Disorder; ASD = Autism Spectrum Disorder; DD/LD = Developmental and/or Language Delay

*TD child excluded

[a]Significantly different from AD, $p < .05$; [b] $p < .01$

[c] Significantly different from ASD, $p < .05$

Developmental status was assessed using the Mullen Scales of Early Learning (Mullen, 1995). Means and standard deviations of the standardised scores were calculated for each of the scales, and are presented in Tables 3-5. However, comparison of performance between each of the groups is better illustrated using age-equivalent scores, as many T scores across each of the assessments (21%) were three or more standard deviations below the mean (i.e., T = minimum score of 20; Akshoomoff, 2006). Verbal mental age was therefore calculated by combining age equivalent scores from the receptive and expressive language scales, and non-verbal mental age was calculated by combining age equivalent scores from the visual reception and fine motor scales.

Both verbal and non-verbal mental ages are lowest in children who met criteria for AD in comparison to the ASD and DD/LD groups. Moreover, more males than females were identified as 'as risk', with an overall ratio of approximately 3:1, with the ratios being highest amongst the AD/ASD groups.

Prevalence of ASDs in SACS Cohort

The rate of ASDs in the SACS sample, using *just those children that were assessed* and given a classification of an ASD (i.e., 89 out of 20,700), is 1:233. Combining the number of children assessed who had a classification of an ASD, with 81% of those who were referred as 'at risk' and *not assessed,* results in an estimated rate of 1:119 children for ASDs in the sample monitored for the SACS (a figure of 81% was used as this was the ascertainment rate – PPV – for ASDs in the assessed sample). Taking a more conservative approach and using only 50% of the referred but not assessed sample results in a rate of 1:146 cases of ASDs, which is still lower than current Australian prevalence rates of 1:160 (Williams et al., 2008). Figure 1 details the calculation of the rate of ASDs in the SACS sample.

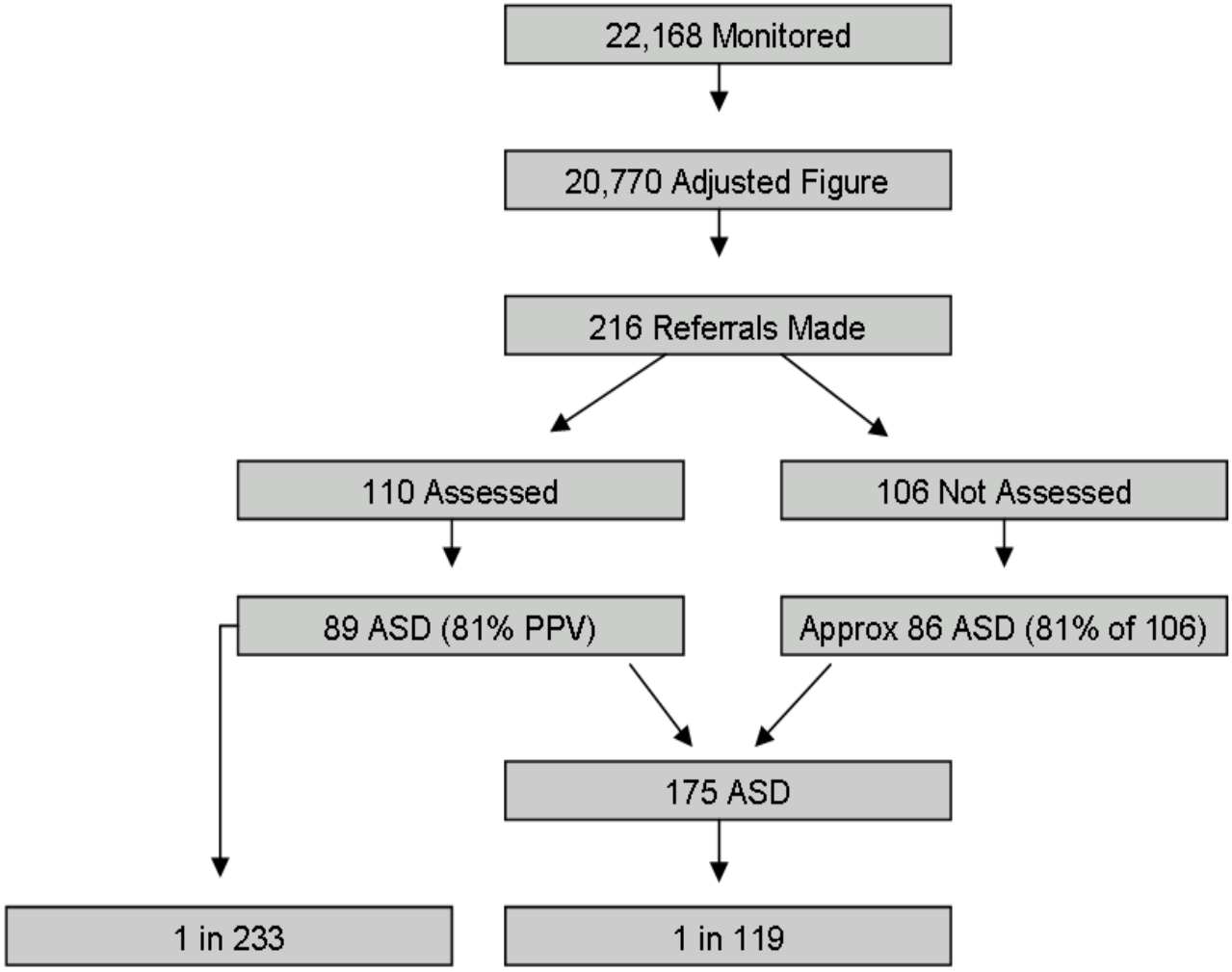

Figure 1. Flow chart detailing calculation of the rate of ASDs in the SACS sample.

Specificity and Sensitivity

As the entire cohort of children initially monitored could not be followed up, the 'true' specificity and sensitivity of the SACS cannot be calculated at this stage. It is possible, however, to estimate these figures based on current prevalence rates for the combined ASDs. Using the assessed sample only (n = 110) and the current prevalence rates in Australia of 1:160 (Williams et al., 2008), the estimated sensitivity and specificity is 69.0% and 99.9%, respectively. Using the *entire referred sample* of children (N = 216), sensitivity is improved. As the estimated rate of ASDs using this sample (1:119) is higher than current Australian prevalence rates (1:160), estimated sensitivity cannot be calculated based on this rate. Thus, using the UK rate of 1:100, which is closest to the estimated rate of 1:119, the estimated sensitivity of the SACS is 83.8%, and estimated specificity is 99.8%.

Discussion

This is the first large-scale study to demonstrate that it is possible to prospectively identify infants at risk of ASDs in a community-based sample from 12- to 24-months of age. The social attention and communication behaviours, previously found to be key markers of ASDs in infants and toddlers (Barbaro & Dissanayake, 2009), served to prospectively identify these infants via their routine MCH assessments from 12-months, supporting the first hypothesis. The repeated monitoring of children from 8-to 24-months, unlike previous studies that have screened children at only one time point, has resulted in a high ascertainment rate with few false positives. Thus, the second hypothesis, that utilising a developmental surveillance approach will increase the accuracy of identifying children with an ASD at 2 years of age and younger, was supported.

The implementation of developmental surveillance of social attention and communication behaviours, across four routine consultations, to identify infants at risk of ASDs in a community-based setting resulted in a PPV of 81%. The rate of ASDs found in the

SACS for all children assessed was 1:233, which is lower than the current Australian prevalence rate of 1:160 (Williams et al., 2008). However, estimating the prevalence on the entire referred sample results in a rate of 1:119 children, which more closely approximates that of the UK rate of 1:100 (Baird et al., 2006). The estimated specificity and sensitivity of the assessed sample was 69% and 99.9%, respectively. Inclusive of *all* referrals made to the CDU and calculated using prevalence data from the UK (Baird et al., 2006), which was closest to the estimated rate of ASDs in the SACS sample (1:119), the estimated sensitivity was 83.8%, and estimated specificity was 99.8%.

The SACS did not have a large number of false positives, and had an excellent PPV, which contrasts with the findings following use of the M-CHAT (Kleinman et al., 2008) and ITC (Wetherby et al., 2008) in community-based samples. Importantly, with one exception, all children who did not meet criteria for an ASD (19%) had either developmental and/or language delays. The high PPV found here indicate that the nurses did effectively observe and record infants' behavioural responses on the items of interest, and selectively referred 'at risk' infants and toddlers to the SACS team. The training received by the nurses on the early signs of ASDs clearly contributed to the high PPV. The SACS not only *accurately* identified children 'at risk' of ASDs in a community-based sample, but was able to do so from as early as 12- to 18-months for some children. Thus, very early identification is not limited to those already at risk of an ASD, such as ASD-sibs, but is possible at a universal level with adequate education of health-care professionals on the early signs.

The current results indicate that primary health-care professionals, such as MCH nurses, are able to correctly identify and refer infants and toddlers with an ASD with a high level of accuracy as a result of their training on the early signs of ASDs. With one exception, the remaining children that they referred also have developmental problems, therefore benefiting from earlier identification. The nurses' extensive knowledge of early child

development clearly facilitated their ability to successfully monitor signs of ASDs in very young children, following training on these signs. The results strongly indicate that child health nurses and related professionals have a central role to play in the early identification of ASDs and other developmental anomalies. Furthermore, given the similarity in mean SEIFA scores in the 17 LGAs included in the SACS to that reported for the greater metropolitan Melbourne area, the findings reported here are likely to be generalisable to the LGAs not included in this study.

Given the high level of accuracy, it is unfortunate that only a few 12-month-olds were referred to the SACS team. There are three possible reasons for this low referral rate at 12-months: 1) nurses were hesitant about raising concerns with parents at this early age; 2) many children were not yet showing social and communication deficits; 3) the behavioural items were not sufficiently sensitive at 12-months. On the strength of the findings from retrospective studies indicating that some deficits are apparent as early as 6-months, more extensive training and reassurance of the nurses about their level of accuracy may lead to higher identification rates at 12-months. However, surveillance at 18- and 24-months is especially important as reliance on very early signs alone will fail to identify those children who subsequently regress, as well as those with few, mild or subtle symptoms at 12-months.

These results highlight the importance of repeated monitoring of children across ages, rather than the administration of a single screen at a given age. Zwaigenbaum et al. (2009), when reporting on the properties of the M-CHAT, also emphasised the importance of repeated assessment. When used in a community-based sample *with* a follow-up phone interview, the PPV of the M-CHAT was lower for younger children (28% for 16- to 23-month-olds) and increased for those older than 24-months (61%; Pandey et al., 2008).

A developmental surveillance approach, rather than reliance on screening for ASDs at one age, is advocated here on the basis of the combined findings. Furthermore, the repeated monitoring of children for ASDs should be completed with a tool that is designed to monitor different behaviours that are developmentally appropriate for the age at which it is administered. The approach utilised in the SACS allowed nurses to monitor the progress of children on the same items previously monitored, as well as assessing their performance on behaviours that were not monitored in the past, but that were presently developmentally appropriate.

Limitations

Despite its obvious strengths, the limitations of the SACS should be noted. Foremost amongst them was that sensitivity and specificity were each estimated based on the current prevalence rates reported in other studies as it was not possible to calculate 'true' specificity and sensitivity. In order to do so, the entire sample of 20,770 children would need to be followed-up. Due to the enormity of this task, we are currently planning a study where children from a subset of the LGAs will be monitored at school entry for an ASD diagnosis. This approach will identify which, if any, children were missed in the SACS in these specific LGAs, thereby providing additional information on sensitivity and specificity, as well as prevalence rates. Furthermore, as ~50% of children referred to the SACS team were not seen as their parents did not provide consent for a developmental assessment, the rate of ASDs in the SACS sample was *estimated* based on all referrals, rather than just those who were assessed at the CDU. This is, necessarily, a limitation of community-based studies. However, estimating ASD prevalence was not a focus within the SACS, and the prevalence rate estimated here should be treated with caution.

Another possible limitation is that our conclusions are based on diagnostic classifications at 24-months of age. However, as mentioned previously, research shows that

an ASD diagnosis at this age is both accurate and stable across time, given the diagnostician has sufficient training and experience in the assessment and diagnosis of ASDs, and utilises appropriate tools for young, non-verbal children, which are used in combination with clinical judgment (Stone et al., 1999). Lord (1995), using clinical judgment, found that 90% of children retained their diagnostic classification of an ASD from 2 to 3 years of age. Turner et al.(2006) found that 88% of the children who received an ASD diagnosis at age 2 years received the same diagnosis at 9 years of age. Charman et al. (2005) found that approximately 85% of children diagnosed with an ASD at 2 years (based on clinical judgment) continued to meet this diagnosis at 9 years of age. Most recently, Paul, Chawarska, Cicchetti, and Volkmar (2008) found that *all* of the 37 15- to 25-month-olds who received a clinical diagnosis of an ASD retained this diagnosis 2 years later. We are currently following-up all children assessed at the CDU when they are between 4 to 5 years of age, with the aim of further establishing the stability of an ASD classification at 2 years of age.

Future Directions

The success of the SACS in identifying children with an ASD, *as well as* children with a DD/LD, indicates that the behavioural items utilised are applicable during Level 1 developmental surveillance. Analyses are now underway to identify which of these items best predicts a diagnosis of an ASD at 24-months (Barbaro & Dissanayake, in preparation[4]). These specific items could then be used during Level 2 surveillance, to more accurately identify those children with ASDs as opposed to other developmental disorders. It is at this stage that tools like the Autism Detection in Early Childhood (ADEC; Young, 2007) and the Screening Tool for Autism in Two-Years-Olds (STAT; Stone & Ousley, 1997) should be implemented, prior to referral, for a full diagnostic work-up.

[4] *Paper 4*

Conclusion

Previous attempts to develop a universal ASD screening tool, to prospectively identify ASDs in community-based samples, have been unsuccessful as a result of the single administration of a tool at a single age, or the administration of the *same tool* at different ages. In contrast, the SACS, in utilising a developmental surveillance approach, *repeatedly* monitored *different,* developmentally appropriate, behaviours in a large cohort of infants from 8-months of age. This approach, combined with the training of MCH nurses on the early signs of ASDs, served to increase the chances of accurately identifying early manifestations of the disorder.

It is argued here that developmental surveillance of social attention and communication behaviours should be undertaken universally and preferably within children's regular health checks during their second year of life. By training MCH nurses on the early signs of ASDs, which, importantly, differ at each age, it has been possible to prospectively identify infants with an ASD in a community-based setting from 12- to 24-months of age. This *developmental* approach to the identification of ASDs is recommended, as it recognises the ever changing and dynamic nature of children's early social and communication skills.

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Appendix A

Maternal and Child Health Coordinators Information Sheet and Informed Consent Form Filled out by Maternal and Child Health Coordinators

INFORMATION SHEET FOR PARTICIPATION
IN THE SOCIAL ATTENTION AND COMMUNICATION STUDY (SACS)

Dear

Toward the end of 2005 we gave a presentation at your Maternal and Child Health (MCH) coordinators meeting about a study on the "Prospective Identification of Autism in Infancy: The Social Attention and Communication Study (SACS)". This study is being conducted by Dr Cheryl Dissanayake and her PhD student, Ms Josephine Barbaro, at the School of Psychological Science, La Trobe University, Bundoora, and Ms Lael Ridgway, at the School of Nursing and Midwifery.

The Department of Human Services Office for Children has provided strong support for this study, which has received approval from the La Trobe University Human Ethics Committee. The SACS is also endorsed by Autism Victoria, and is funded by a grant received from the Telstra Foundation Community Development Fund.

The aim of the SACS is to prospectively identify infants who will receive a diagnosis of an Autism Spectrum Disorder (ASD) through routine assessments undertaken at MCH centres. This aim will be achieved by firstly training MCH nurses to monitor infants' development on key items within the MCH record during four of their routine check-ups (8-, 12-, 18-, and 24-months). Any infants who show an absence of key behaviours at these assessments will be referred by the MCH nurse to the Child Developmental Unit at La Trobe University, Bundoora. We will undertake a thorough developmental assessment of the infants, who will be followed up until 24-months of age.

As the key items (see Attachment A) are within the standard MCH protocols, *no extra time* will be needed to monitor a child who is developing normally. If a child is identified as 'at risk' on the key items, the nurse will be asked to administer a few extra items to gather more information on the child, and we do not foresee that this will take any longer than 10 minutes.

We have developed a clear referral pathway to be used by the nurses when the infant is identified as 'at risk' (see Attachment B). Given that the estimated prevalence rate of ASD is 1-2 in 500, we do not anticipate that your nurses will have to refer many children to us. Prior to commencement of the SACS, we will provide training for all MCH nurses in your Local Government Area (LGA) on the early signs of ASD and on the key items of interest within the MCH record. We will also provide administrative support for your nurses as required, and we will visit each centre during the course of the study (approximately 2-years).

If you agree to participate in this study, approximately 1-2 in 500 young children within your LGA will receive an earlier diagnosis of ASD, thereby ensuring earlier intervention, which we know will promote positive developmental outcomes for these youngsters and their families.

We will contact you to discuss the study further, to answer any questions you may have, and to ascertain your LGA's participation. If you agree to the MCH centres within your LGA participating in this study, we require you to sign the Informed Consent Form on the last page and send it to:

Josephine Barbaro
School of Psychological Science
La Trobe University, Bundoora
3083, Victoria

Upon receipt of the consent form, we will contact you to organise training for the MCH nurses within your LGA. Prior to commencement of the study, a poster about the SACS (see Attachment C) will be placed at each MCH centre to inform parents and caregivers that the centre is participating in the SACS.

If you have any questions or queries regarding this study that you would like to discuss prior to us contacting you, or would like some more information, please do not hesitate to contact Dr Cheryl Dissanayake at the School of Psychological Science, La Trobe University, Bundoora, Victoria, 3083 (Tel: 03 9479 1162; Fax: 03 9479 1829; email: c.dissanayake@latrobe.edu.au) or Ms Josephine Barbaro (Tel: 03 9479 1767; email: j.barbaro@latrobe.edu.au). In the event that we are unable to satisfy your queries, you may contact The Secretary of the University Human Ethics Committee, La Trobe University, Bundoora, Victoria, 3083 (Tel: 03 9479 1443; email: humanethics@latrobe.edu.au).

Sincerely,

Dr Cheryl Dissanayake, PhD; MAPS

INFORMED CONSENT FORM FOR PARTICIPATION IN THE SOCIAL ATTENTION AND COMMUNICATION STUDY (SACS)

Please complete and sign the following:

I, _____,
consent to the participation of the Maternal and Child Health centres within my jurisdiction in the SACS, realising that I may withdraw my permission at any time. I have read and understood the information above, and any questions I have asked have been answered to my satisfaction.
I agree that the data will be used for research purposes, including writing up a PhD thesis and for publication in journal articles on the condition that all personal details of all nurses, caregivers and children will remain confidential. The data will be kept in secure storage at LTU as it may be used in future research and follow-up studies.

_____
(Name of Maternal and Child Health Coordinator) (Block Letters)

_____ ___ / ___ / ___
(Signature of Maternal and Child Health Coordinator) (Today's Date)

_____
(Local Government Area of Maternal and Child Health Coordinator)
(Block Letters)

Office Use Only

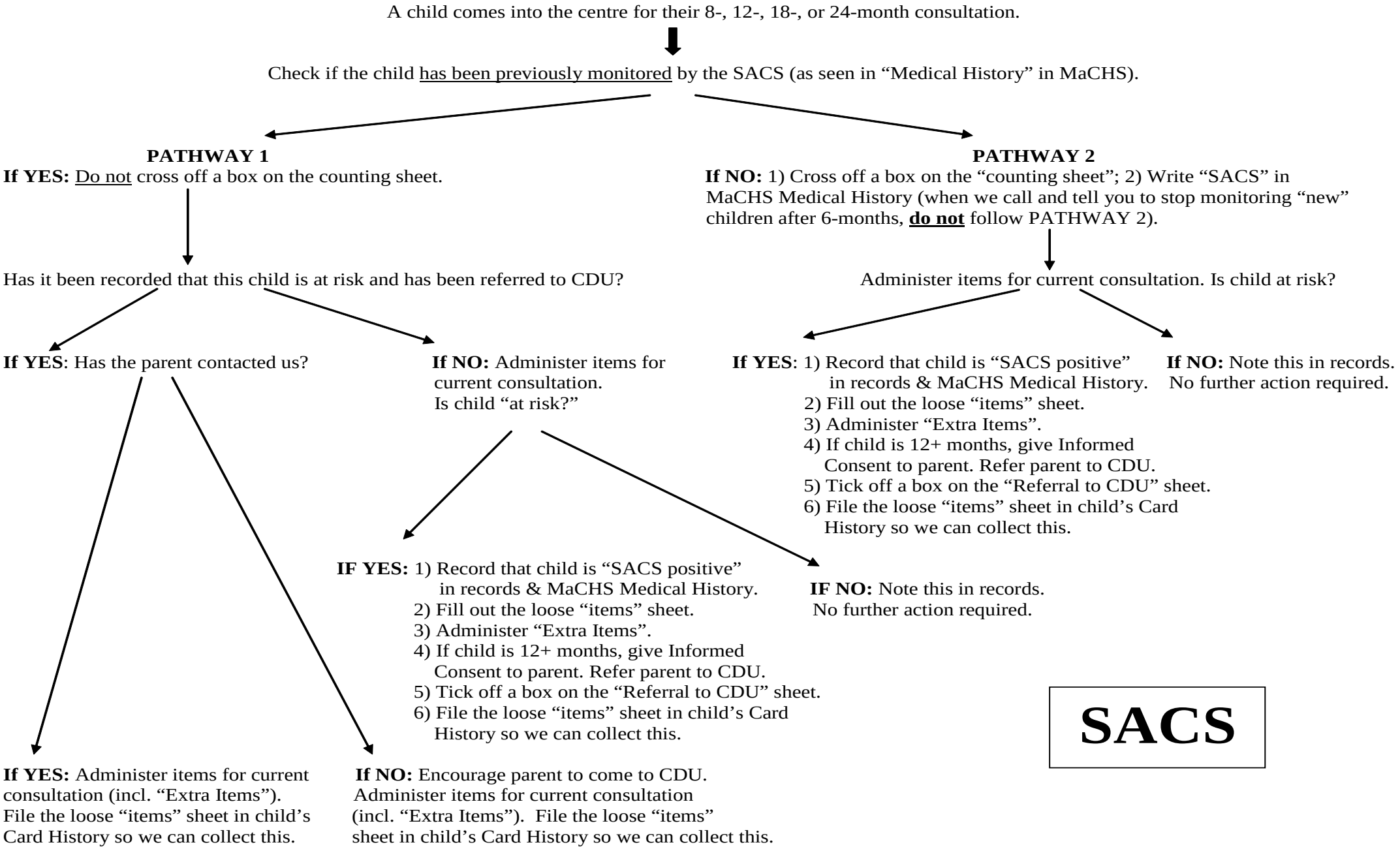
_____
(Name of Investigator) (Block Letters)

_____ ___ /___ / ___
(Signature of Investigator) (Today's Date)

_____
(Name of Student Supervisor) (Block Letters)

Appendix B

Flow Chart Used by Maternal and Child Health Nurses to Refer a Child to the Child Development Unit



Appendix C

Maternal and Child Health Information Sheet and Informed Consent Form Filled out by Parents/Caregivers

INFORMATION STATEMENT

NAME OF STUDY: The Social Attention and Communication Study (SACS)
NAME OF RESEARCHERS: Dr Cheryl Dissanayake (Supervisor)
Ms Josephine Barbaro (PhD Candidate)
Ms Lael Ridgway (MCH Nurse and Educator)

You are invited to take part in this study being conducted in the School of Psychological Science. The purpose of the study is to promote the early identification of problems in social attention and communication behaviours in children, which represent important developmental milestones. It is funded by a grant received from the Telstra Foundation Community Development Fund.

Your Maternal and Child Health (MCH) nurse has identified that your child may be experiencing some difficulty in his/her social attention and communication from key items in the MCH record. As a result, we would like to undertake a thorough developmental assessment of your child's social attention and communication abilities at the Child Development Unit at La Trobe University, Bundoora. This consultation will be free-of-charge.

The benefit of participation is that we will be able to detect if your child is having any problems with his/her development and if this is the case, we will refer your child for further assessments. The early detection of any developmental problems in your child is important for maximising his/her developmental opportunities.

The results of all developmental assessments undertaken of your child will be available to you on request (free-of-charge). A summary of the results of this study will also be available on request at the conclusion of the project. All data collected will be kept in secure storage at the Child Development Unit as it may be used in future research and follow-up studies.

By signing this consent form, you allow us to view your child's MCH records, and allow us to contact you in the coming weeks to arrange an appointment for your child at the Child Development Unit.

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Questions regarding this study can be directed to Dr Dissanayake at the School of Psychological Science, La Trobe University, Bundoora, 3083 (Tel: 03 9479 1162; email: c.dissanayake@latrobe.edu.au) or Ms Barbaro (Tel: 03 9479 2151; email: j.barbaro@latrobe.edu.au).

In the event that we are unable to satisfy your queries, or should you have comments on this study, you may contact Ms Mira Junge, Secretary of the University Human Ethics Committee, La Trobe University, Bundoora, 3083 (Tel: 03 9479 1443; email: humanethics@latrobe.edu.au). Alternatively, you may contact Ms Genevieve Nolan, Executive Officer of the Department of Human Services Human Research Ethics Committee, 50 Lonsdale Street, Melbourne, 3000 (Tel: 03 9096 5239; email: genevieve.nolan@dhs.vic.gov.au).

INFORMED CONSENT FORM FOR PARTICIPATION IN THE SOCIAL ATTENTION AND COMMUNICATION STUDY (SACS)

Please complete and sign the following on behalf of your child:
I, _____, consent to participate in this study with my child, realising that I may withdraw at any time. I have read and understood the information above, and any questions I have asked have been answered to my satisfaction.
I agree that the data will be used for research purposes, including writing up a PhD thesis and for publication in journal articles, on the condition that all personal details will remain confidential. The data will be kept in secure storage at the Child Development Unit as it may be used in future research and follow-up studies.

_____ ___ / ___ / ___
(Name of Child) (Block Letters) Child's DOB

_____
(Name of Caregiver) (Block Letters)

_____ ___ / ___ / ___
(Signature of Caregiver) (Today's Date)

Contact Details

Address: _____ Postcode: _____

Telephone Number/s: _____

Maternal & Child Health Centre: _____

PLEASE SEND THIS COMPLETED FORM IN THE STAMPED, SELF-ADDRESSED ENVELOPE PROVIDED

OFFICE USE ONLY

_____
(Name of Investigator) (Block Letters)

_____ ___ / ___ / ___
(Signature of Investigator) (Today's Date)

_____
(Name of Student Supervisor) (Block Letters)

Appendix D

Child Development Unit Information Sheet and Informed Consent Form Filled out by Parents/Caregivers

LA TROBE UNIVERSITY

INFORMATION STATEMENT

NAME OF STUDY: The Social Attention and Communication Study (SACS)

NAME OF RESEARCHERS: Dr Cheryl Dissanayake (Supervisor)
Ms Josephine Barbaro (PhD Candidate)
Ms Lael Ridgway (MCH Nurse and Educator)

AIM

The purpose of this study is to promote the early identification of problems in social attention and communication behaviours in infants, which represent important developmental milestones. The study is being conducted at the School of Psychological Science and is funded by a grant received from the Telstra Foundation Community Development Fund.

BACKGROUND INFORMATION

Social attention and communication skills include regular eye contact with people, interest in other people, smiling at others, sharing interest in an object or event with others, and communicative vocalisations. The frequent occurrence of these behaviours during infancy and toddlerhood indicate healthy development, and are thus being examined in 3 ways; via: 1) assessment of your child's social attention and communication behaviours during routine Maternal and Child Health check-ups; 2) direct observation of your child at the Child Development Unit (CDU) during administration of various tasks designed to assess social attention and communication; 3) caregiver interviews and completion of questionnaires about your child.

The number of sessions you and your child are required to attend will depend on the age of your child on your first visit to the CDU. We would like to see your child at 6-monthly intervals until s/he is 2-years of age.

During each visit to the CDU, your child will be administered various social attention and communication tasks. These include assessing your child's imitation abilities (for example, imitation of facial gestures, sounds, and actions on objects), response to his/her name being called out, response to spontaneous games like playing peek-a-boo, and his/her empathic responsiveness (for example, observing your child's response to the experimenter knocking her knee on the table). A developmental assessment will also be conducted to assess your child's cognitive and language abilities. Each of the testing sessions will take approximately 1-1 ½ hours to complete, and each session will be videotaped for later analysis. If you provide us with a videotape, we will be happy to make a copy of the sessions for you.

During the initial session, you will be given a general background information sheet to complete, which inquires about marital status, education level, and annual income. You have the right to refuse to answer any questions that you do not wish to answer. At the first and subsequent sessions, you will be interviewed and given questionnaires about your child's social attention and communication. A caregiver interview conducted when your child is 24-months old can be completed over the phone (as its duration is approximately 2 hours) or you can return to the CDU to complete the interview in person.

The benefit of participation is that we will be able to detect if your child is having any problems with his/her development, and if this is the case, we will refer your child for further assessments. The early detection of any developmental problems in your child is important for maximising his/her developmental opportunities.

The results of all developmental assessments undertaken of your child will be available to you on request (free-of-charge). A summary of the results of this study will also be available on request at the conclusion of the project.

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Questions regarding this study can be directed to Dr Dissanayake at the School of Psychological Science, La Trobe University, Bundoora, 3083 (Tel: 03 9479 1162; email: c.dissanayake@latrobe.edu.au) or Ms Barbaro (Tel: 03 9479 2151; email: j.barbaro@latrobe.edu.au).

In the event that we are unable to satisfy your queries, or should you have comments on this study, you may contact Ms Mira Junge, Secretary of the University Human Ethics Committee, La Trobe University, Bundoora, 3083 (Tel: 03 9479 1443; email: humanethics@latrobe.edu.au). Alternatively, you may contact Ms Genevieve Nolan, Executive Officer of the Department of Human Services Human Research Ethics Committee, 50 Lonsdale Street, Melbourne, 3000 (Tel: 03 9096 5239; email: genevieve.nolan@dhs.vic.gov.au).

INFORMED CONSENT FORM FOR PARTICIPATION IN THE SOCIAL ATTENTION AND COMMUNICATION STUDY (SACS)

Please complete and sign the following on behalf of your child:

I, _____,
consent to participate in this study with my child, realising that I may withdraw at any time. I have read and understood the information above, and any questions I have asked have been answered to my satisfaction.

I agree that the data will be used for research purposes, including writing up a PhD thesis and for publication in journal articles on the condition that all personal details will remain confidential. The data will be kept in secure storage at the Child Development Unit as it may be used in future research and follow-up studies.

I agree to allow the report to be made available to my Maternal and Child Health nurse(s).....YES ☐ NO ☐

_____
(Name of Child) (Block Letters)

_____
(Name of Caregiver) (Block Letters)

_____ ___ /___/___
(Signature of Caregiver) (Today's Date)

Office Use Only

_____
(Name of Investigator) (Block Letters)

_____ ___ /___/___
(Signature of Investigator) (Today's Date)

_____
(Name of Student Supervisor) (Block Letters)

Appendix E

Sample 12-month Assessment Report

School of Psychological Science
Faculty of Science, Technology and Engineering

0/0/2007

Dear ---,

Please find attached a report (and 2 copies) on our assessment of --- at the Child Development Unit (CDU). We recommend that you send the enclosed copies of this report to your paediatrician and any early intervention workers involved with ---.

On the basis of our assessment, and your reports on ---, he is not displaying some social attention and communication behaviours appropriate for his age, which are detailed in the report below. Furthermore, --- is performing below average on his Receptive and Expressive Language skills, and would benefit from help in these areas. However, he is performing at age appropriate levels on his Visual Reception and Fine Motor skills.

We strongly recommend that you seek early intervention for ---. **The relevant central intake number for early intervention in the Northern Region is 1300 664 977.** --- may also benefit from speech pathology, and we can recommend **Spectrum Speech Pathology in Pascoe Vale (Ph: 9350 1920).**

A particularly useful resource for parents to encourage language in their young children is a book called **'It Takes Two to Talk' (order form enclosed).** We have also included sheets with some suggested activities that you can undertake with --- to facilitate his Expressive and Receptive Language skills, as well as his social attention and communication skills.

In addition to seeing your paediatrician, we encourage you to attend your next MCH appointment for ---, in particular his 18-month consultation. The nurse will continue to monitor his social attention and communication behaviours, in addition to his overall development.

We would also like to see --- again at 18-months at the CDU. We will call closer to the date (in --- 2007) to confirm a time and day for this assessment.

Thank you for attending the CDU with ---. Please feel free to contact us at the CDU (9479 2151) should you need any further information.

Kind regards,

Cheryl Dissanayake, PhD, MAPS. Josephine Barbaro, BBSc (Hons.)

Assessment Report on --- (DOB: 00-00-0000)

--- was assessed at the Child Development Unit (CDU) in the School of Psychological Science, La Trobe University, Bundoora, on --, 2007, at 12-months of age. He was referred to the CDU as he showed some deficits within the areas of social attention and communication during his 12-month Maternal and Child Health (MCH) assessment. The MCH centre --- attends is part of the Social Attention and Communication Study being undertaken at La Trobe University.

--- was administered the **Mullen Scales of Early Learning** (Mullen, 1995), which is a standardised developmental test for children aged 3- to 68-months, and contains the subtests of Gross Motor, Fine Motor, Visual Reception, Receptive Language, and Expressive Language. This assessment was undertaken by Ms. Josephine Barbaro (BBSc, Hons; PhD candidate) under the supervision of Dr. Cheryl Dissanayake. --- was not administered the Gross Motor scale.

Visual Reception Scale

---'s Visual Reception Scale accomplishments place him at the 13-month level and in developmental stage 4. Milestones at this stage include understanding the concept of object permanence, associating objects with their functions, and demonstrating early spatial awareness and visual memory. He has a T score of 36 and a percentile rank of 8 for this Scale and is functioning in the Below Average range for his age.

--- did not match one set of objects or put nesting cups in proper order. However, he looked for a toy that was covered and then displaced and placed one shape out of four in a form-board.

Fine Motor Scale

--- has a T score of 66 and a percentile rank of 95 on the Fine Motor Scale. He is functioning in the Above Average range for this Scale. He performed at a 21-month level, developmental stage 6, which focuses on use of alternate bilateral hand patterns and increased control and strength in the arm, wrist, and hand.

--- could not make a four-block train (imitating a model) or unscrew and screw a nut and bolt. However, he could draw a horizontal line (imitating a model) and stack up to six blocks.

Receptive Language Scale

--- is functioning in the Below Average range on the Receptive Language Scale at a 13-month level, in developmental stage 4. At this level, children typically identify objects that have labels and give objects on verbal request. His T score on this Scale is 34 and his percentile rank is 5.

--- gave a toy in response to a verbal request and a gesture, and understood the question “Where’s the light?” He had difficulty following the direction "Give me the block" without use of gestures, and pointing to named body parts, such as nose and hair.

Expressive Language Scale

---'s Expressive Language Scale T score is 34 and his percentile rank is 5. He is functioning in the Below Average range on skills for his age. At the 12-month level, developmental stage

4, expressive language abilities include the spontaneous use of single words and words or sounds with gestures.

As reported by his mother, --- says “No” and jabbers with inflection. --- could not communicate intentions by using jargon combined with gestures or combine a word and a gesture to make a request.

Scale Summary
---'s strengths are in Visual Reception and Fine Motor. He showed a weakness in Receptive Language and Expressive Language. He may benefit from parental or caretaker activities in these areas (please see last page of report for a score summary).

Early Learning Composite
The Early Learning Composite is a measure of general cognitive ability and includes scores from the four cognitive Scales. ---'s Early Learning Composite standard score is 85 and his percentile rank is 16, which falls in the Average range.

--- was also administered **The Early Social and Communication Scales (ESCS**; Mundy, Hogan, & Doehring, 1996; Seibert, Hogan & Mundy, 1982) by Mrs. Irene Giaprakis (BA, LLB (Hons), BBSc) to obtain a behavioural measure of nonverbal communicative abilities. --- displayed social turn-taking behaviours such as rolling a ball to the examiner, but this was not coordinated with eye contact. --- did not use joint attention skills by alternating his gaze between an object and the examiner, and although he sometimes gave objects to the examiner and his mother, he did not coordinate this with eye contact or vocalisations. --- followed the examiner’s points while looking at a book together, but he did not look to where the examiner was pointing at a distance, and did not point to any objects. --- did not respond to his name being called, or use any gestures during the session.

--- showed functional play by combing his hair with a comb, and showed some nice social interaction with his mother by combing her hair and smiling (without coordinated eye contact). He also showed pleasure in a song and tickle game by directing some smiles to the examiner. This was an improvement from the beginning of the session as he was initially uncomfortable at being touched by the examiner. --- did not imitate the examiner’s actions on objects, but he did briefly imitate her facial expression (tongue protrusion).
When excited, --- would flap his hands/arms, and also showed some finger flicking. He displayed some odd breathing, as if he was hyperventilating, and reacted aversively to some sounds during the session (e.g., to wind-up and vibrating toys). --- displayed generally flat or unhappy affect throughout session.

---’s parents completed **The Communication and Social Behaviour Scales – Developmental Profile (CSBS DP;** Wetherby & Prizant, 2002) which is designed to identify communication and symbolic deficits in children aged 6- to 24-months of age. This scale comprises three subscales: the social composite scale, which consists of the use of emotion, eye gaze, communication, and gestures; the speech composite scale, which consists of sounds and word use, and the symbolic composite scale, which consists of understanding and object use. --- scored in the low range on each of these subscales, indicating that his social, language, and symbolic behaviours should be closely monitored, as there is concern regarding his use of these behaviours.

The First Year Inventory (Baranek, Watson, Crais, & Reznick, 2003), was also completed by ---'s parents, which is designed to identify deficits in social attention and communication in the first year of life.
It was reported that --- never:

- tries to get his parents' attention to play games like peek-a-boo
- tries to get his parents' attention to play physical games like swinging, tickling, or being tossed in the air
- seems interested in other babies his age

It was reported that --- seldom:

- tries to get his parents' attention to show them something interesting
- copies or imitates his parents when making sounds or noises with their mouths
- tries to get his parents' attention by making sounds and looking at them at the same time
- communicates by using his finger to point at objects or pictures

---'s parents have also indicated that they are concerned that:

- he is behind in his speech development
- he is afraid to socialise with other children, especially children his age
- he does not respond to his name
- he does not want to listen and does not want to pay attention most of the time
- he does not make much eye contact
- he does not like people touching him

Overall Assessment Summary and Recommendations

On the basis of our assessments, and parental reports on ---, he is not displaying social attention and communication behaviours appropriate for his age. Furthermore, --- is performing below average in his Receptive and Expressive Language skills, and would benefit from help in these areas. However, he is performing at age appropriate levels on his Visual Reception and Fine Motor skills. We recommend that --- receive early intervention for his language and social and communication skills. We would also like to see --- again when he is 18-months of age to re-assess his language, as well as his social attention and communication skills.

Sample 18-month Assessment Report

School of Psychological Science
Faculty of Science, Technology and Engineering

0/0/2007

Dear ---,

Please find attached a report (and 2 copies) on our assessment of --- at the Child Development Unit (CDU). We recommend that you send the enclosed copies of this report to your paediatrician and any early intervention workers involved with ---.

On the basis of our assessments, and your reports on ---, he is not displaying some social attention and communication behaviours appropriate for his age, which are detailed in the report below. His use of these skills should thus be closely monitored. Furthermore, --- is performing below average on his Receptive and Expressive Language skills, and would benefit from help in these areas.

We recommend that you seek early intervention for ---. **The relevant Specialist Children's Services number for early intervention in the Western Region is 9275 7500.** --- may also benefit from speech pathology, and we can recommend **Spectrum Speech Pathology in Pascoe Vale (Ph: 9350 1920).** Furthermore, you are entitled to 5 Medicare funded sessions per year for any health professional in the Allied Health Sciences, including speech pathology. Please take the enclosed forms to your GP to access these 5 sessions for ---.

A particularly useful resource for parents to encourage language in their young children is a book called **'It Takes Two to Talk' (order form attached).** We have also included sheets with some suggested activities that you can undertake with --- to facilitate his Expressive and Receptive Language skills, as well as his social attention and communication skills.

In addition to seeing your paediatrician, we encourage you to attend your next MCH appointment for ---, particularly his 24-month consultation. The nurse will continue to monitor his social attention and communication behaviours, in addition to his overall development.

Given that --- is not showing some social attention and communication behaviours, and your concerns regarding Autism, we would like to see --- again at 24-months at the CDU to undertake a diagnostic assessment for Autism. We will call closer to the date (in -- 2008) to confirm a time and day for this assessment.

Thank you for attending the CDU with ---. Please feel free to contact us (9479 2151) should you need any further information.

Kind regards,

Cheryl Dissanayake, PhD, MAPS. Josephine Barbaro, BBSc (Hons.)

Assessment Report on --- (DOB: 00-00-0000)

--- was assessed at the Child Development Unit (CDU) in the School of Psychological Science, La Trobe University, Bundoora, on --, 2007, at 19-months of age (18-months corrected). He was referred to the CDU as he showed some deficits within the areas of social attention and communication during his 18-month Maternal and Child Health (MCH) assessment. The MCH centre --- attends is part of the Social Attention and Communication Study being undertaken at La Trobe University.

--- was administered the **Mullen Scales of Early Learning** (Mullen, 1995), which is a standardised developmental test for children aged 3- to 68-months, and contains the subtests of Gross Motor, Fine Motor, Visual Reception, Receptive Language, and Expressive Language. This assessment was undertaken by Ms. Josephine Barbaro (BBSc, Hons; PhD candidate) under the supervision of Dr. Cheryl Dissanayake. --- was not administered the Gross Motor scale.

Visual Reception Scale

---'s Visual Reception Scale accomplishments place him at the 17-month level and in developmental stage 5. Milestones at this stage include demonstration of spatial awareness and form perception, as well as rapid development in visual organisation. He has a T score of 44 and a percentile rank of 27 for this Scale and is functioning in the Average range for his adjusted age.

--- did not match by shape or match two sets of pictures. However, he put three out of four nesting cups in proper order and sorted spoons and blocks into separate containers.

Fine Motor Scale

--- has a T score of 39 and a percentile rank of 14 on the Fine Motor Scale. He is functioning in the Below Average range for this Scale. He performed at a 16-month level, developmental stage 5, which focuses on unilateral hand patterning as shown in the graded release and placement of blocks and the unrefined crayon grasp.

--- could not stack up to three blocks or make a four-block train (imitating a model). However, he could turn pages in a book a few at a time and put 5c coins in a horizontal slot.

Receptive Language Scale

--- is functioning in the Very Low range on the Receptive Language Scale at an 11-month level, in developmental stage 4. At this level, children typically identify objects that have labels and give objects on verbal request. His T score on this Scale is 26 and his percentile rank is 1.

As reported by his mother, --- understands simple verbal input such as "bye-bye" without use of gestures, and he gives a toy in response to a verbal request and a gesture. He had difficulty touching or pointing to an object after hearing it named and giving a toy in response to a verbal request without gestures.

Expressive Language Scale

---'s Expressive Language Scale T score is 33 and his percentile rank is 4. He is functioning in the Below Average range on skills for his age. At the 13-month level, developmental stage

4, expressive language abilities include the spontaneous use of single words and words or sounds with gestures.

As reported by his mother, --- says “bye” and “dada” (but not mamma) and jabbers with inflection. --- could not communicate intentions by using jargon combined with gestures or combine a word and a gesture to make a request.

Early Learning Composite

The Early Learning Composite is a measure of general cognitive ability and includes scores from the four cognitive Scales. ---'s Early Learning Composite standard score is 73 and his percentile rank is 3, which falls in the Below Average range.

Scale Summary

---’s strength is Visual Reception skills. He showed a weakness in his Receptive and Expressive Language skills, and a slight weakness in Fine Motor. He may benefit from parental or caretaker activities in these areas (please see last page of this report for a score summary).

--- was also administered **The Early Social and Communication Scales (ESCS**; Mundy, Hogan, & Doehring, 1996; Seibert, Hogan & Mundy, 1982) by Mrs. Irene Giaprakis (BA, LLB (Hons), BBSc) to obtain a behavioural measure of his nonverbal communicative abilities. --- sometimes used joint attention skills by referencing objects (i.e., alternative his gaze between an object and the examiner). However, his use of these skills, and his overall use of eye contact, was infrequent and inconsistent. He did not look to where the examiner was pointing, and did not point to objects out of interest or to request them.

--- enjoyed participating in a turn-taking game by rolling a toy truck to the examiner, with some use of eye contact. He sometimes gave objects to the examiner when requested, but this was rarely coordinated with eye contact. --- displayed social overtures to the examiner and his mother by attempting to put a pair of glasses on the examiner, and spontaneously putting a hat on the examiner and his mother. He used eye contact and directed smiles to the examiner during a song and a tickle game, which he enjoyed very much, and participated in a game of peek-a-boo with the examiner by placing his hands over his face. --- briefly used one gesture during the sessions by clapping, but he did not respond to his name being called by the examiner and his mother.

--- did not imitate the examiner’s facial expressions or her actions directed towards objects. However, he imitated the examiner placing her hand on her nose and her head. --- did not show any use of pretend play with a toy tea set or teddy bear, and displayed some repetitive behaviours and visual interests by rolling a ball and a truck from side to side to while watching them.

---’s mother completed **The Communication and Social Behaviour Scales – Developmental Profile (CSBS DP;** Wetherby & Prizant, 2002) which is designed to identify communication and symbolic deficits in children aged 6- to 24-months of age. This scale comprises three subscales: the social composite scale, which consists of the use of emotion, eye gaze, communication, and gestures; the speech composite scale, which consists of sounds and word use, and the symbolic composite scale, which consists of understanding and object use. --- scored in the low range on each of the four subscales, indicating that there is concern regarding his use of these behaviours.

---'s mother also completed **The Early Development Interview** (Werner & Dawson, 2006), which is designed to identify deficits in social attention and communication from birth to 24-months.

It was reported that --- sometimes:

- does not orient to his name being called
- has poor eye contact
- fails to follow his parents' finger point and gaze
- fails to initiate simple, ritualised social interaction

It was reported that --- definitely:

- does not point to express interest in objects or events
- places an adult's hand on a desired object to move an adult's hand (as opposed to using eye contact, gestures, or vocalisations to communicate intent)

---'s mother also reports he has possibly failed to increase vocabulary/language from a previous time-point, she has concerns regarding his lack of speech and understanding of language, and feels he is busy in solitary play in "his own world".

Overall Assessment Summary and Recommendations

The results of these assessments indicate that --- is performing below average in his use and understanding of language, and is not showing some social attention and communication skills appropriate for his age. Thus, on the basis of our current assessments, we recommend that --- seek early intervention and speech pathology, and have referred his parents to the appropriate services. Given that --- is not showing some social attention and communication behaviours, and his mother's concerns regarding Autism, we would like to see --- again at 24-months at the CDU to re-assess his language, and undertake a diagnostic assessment for Autism.

Sample 24-month Assessment Report

School of Psychological Science
Faculty of Science, Technology and Engineering

-- October 2007

Dear ---,

Please find attached a report (and 2 copies) on our assessment of --- at the Child Development Unit (CDU). We recommend that you send the enclosed copies of this report to your paediatrician and any early intervention workers involved with him.

Our assessment of --- indicates that he is showing signs of Autistic Disorder with associated language delay. On the basis of our assessments, we strongly recommend that you seek early intervention for him. **As you will be moving to the Eastern Region, the relevant central intake number for early intervention in the Eastern Region is 1300 662 655.**

--- may also benefit from speech pathology, and we can recommend **Spectrum Speech Pathology in Ashwood (Ph: 9886 9130) or Pascoe Vale (Ph: 9350 1920).** Furthermore, you are entitled to five Medicare funded sessions per year for any health professional in the Allied Health Sciences, including speech pathology. Please take the enclosed forms to your GP to access these five sessions for ---.

We also encourage you to access a highly recommended resource book **(More Than Words – order form attached)** for working with --- within the home. This book will provide helpful information for you on how to interact with --- in order to facilitate the development of his social and communication skills. We have also included sheets with some suggested activities that you can undertake with --- to facilitate his Expressive and Receptive Language skills, his Visual Reception skills, as well as his social attention and communication skills.

In addition to seeing your paediatrician, we encourage you to attend your next MCH appointment for ---. The nurse will continue to monitor his social attention and communication behaviours, in addition to his overall development.

If you would like to receive some direction and support with regards to your child's developmental concerns, we encourage you to contact the Psychology Clinic within the School of Psychological Science at La Trobe University. The cost of attendance is $10 per hour (see enclosed brochure).

Thank you for attending the CDU with ---. Please feel free to contact us at the CDU (9479 2151) should either you or your physician need any further information.

Kind regards,

Cheryl Dissanayake, PhD, MAPS. Josephine Barbaro, BBSc (Hons.)

Assessment Report on --- (DOB: 00-00-0000)

--- was assessed at the Child Development Unit (CDU) in the School of Psychological Science, La Trobe University, Bundoora, on --, 2007, at 2-years of age. He was referred to the CDU as he showed some deficits within the areas of social attention and communication during his 24-month Maternal and Child Health (MCH) assessment. The MCH centre --- attends is part of the Social Attention and Communication Study being undertaken at La Trobe University.

The standardised assessments were undertaken by Ms. Josephine Barbaro (BBSc, Hons; PhD candidate), under the supervision of Dr. Cheryl Dissanayake.

--- was administered the **Mullen Scales of Early Learning** (Mullen, 1995), which is a standardised developmental test for children aged 3- to 68-months, and contains the subtests of Gross Motor, Fine Motor, Visual Reception, Receptive Language, and Expressive Language. He was not administered the Gross Motor scale.

Visual Reception Scale

---'s Visual Reception Scale accomplishments place him at the 19-month level and in developmental stage 5. Milestones at this stage include demonstration of spatial awareness and form perception, as well as rapid development in visual organisation. He has a T score of 38 and a percentile rank of 12 for this Scale and is functioning in the Below Average range for his age.

--- placed all four shapes in a form-board and matched one set of objects (shoes). However, he did not put nesting cups in proper order or sort spoons and blocks into separate containers.

Fine Motor Scale

--- has a T score of 56 and a percentile rank of 73 on the Fine Motor Scale. He is functioning in the Average range for this Scale. He performed at a 26-month level, developmental stage 6, which focuses on use of alternate bilateral hand patterns and increased control and strength in the arm, wrist, and hand.

--- could not unscrew and screw a nut and bolt, or string three or more beads on a shoelace. However, he could stack up to eight blocks, and make a four-block train (imitating a model).

Receptive Language Scale

--- is functioning in the Very Low range on the Receptive Language Scale at an 11-month level, in developmental stage 4. At this level, children typically identify objects that have labels and give objects on verbal request. His T score on this Scale is 20 and his percentile rank is 1.

--- gave a toy in response to a verbal request and a gesture by the examiner, and gave a toy in response to a verbal request only by his mother. He had difficulty understanding the question such as "Where's the door?" and other simple questions, and following the direction "Give me the block".

Expressive Language Scale

---'s Expressive Language Scale T score is 22 and his percentile rank is 1. He is functioning in the Very Low range on skills for his age. At the 12-month level, developmental stage 4,

expressive language abilities include the spontaneous use of single words and words or sounds with gestures.

--- said “mama” during the assessment, and is reported by his mother to say “papa” and jabber with inflection. --- could not communicate intentions by using jargon combined with gestures, or combine a word and a gesture to make a request.

Early Learning Composite

The Early Learning Composite is a measure of general cognitive ability and includes scores from the four cognitive Scales. ---'s Early Learning Composite standard score is 70 and his percentile rank is 2, which falls in the Very Low range.

Scale Summary

---’s strength is in Fine Motor. He showed a weakness in Visual Reception, and Receptive and Expressive Language. He may benefit from parental or caretaker activities in these areas (please see last page of report for a score summary).

--- was also assessed on the Autism Diagnostic Observation Scale-Generic (ADOS-G; Lord et al., 2000; Lord, Rutter, DiLavore, & Risi, 1999). A related instrument, the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), was also administered to his mother, ---, and Father, ---, on ---, 2007. These instruments were used as a result of ---’s deficits in the areas of social attention and communication displayed during his 24-month MCH assessment.

The ADOS-G is a semi-structured, standardised assessment administered directly to the child, and it complements the ADI-R in classifying Autistic Disorder. The ADOS-G uses developmentally appropriate social and play-based interactions designed to elicit spontaneous behaviours across the following areas: reciprocal social interaction; language and communication; play and imagination, and stereotyped, repetitive and restrictive behaviours. One of the important features of the ADOS-G algorithm is that it discriminates between the narrower definition of Autistic Disorder and the broader definition of Autism Spectrum Disorder (ASD), which is a milder form of Autistic Disorder. The ASD diagnosis is appropriate when thresholds are generally lower than the cut-off for Autistic Disorder, or when not all cut-offs are met.

The ADI-R is a semi-structured, standardised parent interview that assesses the presence and severity of early symptoms of autism across the three main domains: impairments in reciprocal social interaction; impairments in communication, and restricted, repetitive and stereotyped patterns of behaviour. This detailed interview about the child is approximately 2 hours in duration. The ADI-R employs an algorithmic scheme, combining scores for those items found to be most discriminating of autism, providing an overall classification of Autistic Disorder based on reaching cut-offs for these three domains.

Autism Diagnostic Observation Scale-Generic (ADOS-G)

Reciprocal Social Interaction

---'s use of eye contact was fleeting and used very infrequently. He directed some facial expressions to others, such as smiling during a game of peek-a-boo with his mother, but he mostly displayed neutral affect throughout the session. --- did not share enjoyment in his interactions with the examiner and he did not show objects to others. He sometimes referenced objects by alternating his gaze between the examiner and an object, but this behaviour was also infrequent and inconsistent. He also did not look to where the examiner was looking or pointing.

--- displayed some social overtures to his mother and the examiner by pretending to give them a drink and food, which he did throughout the session. However, these overtures were rarely coordinated with eye contact. He also gave objects to the examiner and his mother to request them. --- did not respond to his name being called by the examiner or his mother.

--- scored 11 on the Social Interaction scale, with the Autism cut-off at 7, and the Autism Spectrum Disorder cut-off at 4.

Language and Communication

--- directed an occasional vocalisation to his mother ("mama") but he did not direct any other vocalisations to her or the examiner. He did not point to anything during the session, or use any gestures such as clapping or waving. --- grabbed the examiner's hand on numerous occasions and placed it on an object that he wanted activated, and this was not coordinated with eye contact or vocalisations.

--- scored 8 on the Communication scale, with the Autism cut-off at 4, and the Autism Spectrum Disorder cut-off at 2.

Play

--- displayed some spontaneous pretend play by feeding a doll with a spoon, and showed functional use of cups, plates and cutlery. --- also imitated the examiner with a clapper, and toy zebra and dowel.

--- scored 2 on the Play scale (maximum score = 4)

Stereotyped Behaviours and Restricted Interests

--- briefly displayed an unusual sensory interest by picking at the examiner's fingernails, and displayed some repetitive behaviours by repeatedly flicking the light switch on and off. He also repeatedly sought out the examiners pen, which had to be hidden as a result.

--- scored 2 on the Stereotyped Behaviours and Restricted Interests scale (maximum score = 6).

Summary

On the ADOS-G Algorithm, combining scores from the Communication and Social Interaction scale, --- scored a total of 19, with the Autism cut-off at 12, and the Autism Spectrum Disorder cut-off at 7. *On the ADOS-G, --- is a given classification of Autistic Disorder.*

Autism Diagnostic Interview-Revised (ADI-R)

The ADI-R, administered to ---'s mother, ---, and father, ---, confirmed that --- displays repetitive behaviours and interests. He is reported to flick light switches and rotate door knobs continuously, which he can do for up to 2-minutes at a time. --- will also pick up wooden objects and move them from one place to another, which can keep him occupied for hours, and continuously presses buttons on his toys. These behaviours started at around 18-20-months of age. Within the past month, --- has started to line up objects, but will not become distressed if the line is disturbed.

--- has a ritual of stepping on sewage lids when walking past them, and will stand there for a few minutes if allowed, which began at 15-months of age. However, he does not become distressed if he is unable to perform this activity.

--- displays sensory interests, such as feeling and smelling his blanket, and smelling his mother's hair, which started at 20-months of age. He will also tilt his head while watching the TV, and will sometimes tilt his head and examine objects he has put on the table. He also enjoys watching the sun shine through the leaves in the trees.

--- displays sensitivity to noise: he puts his hands to his ears if the TV is too loud, and in unfamiliar situations, he puts his fingers in his ears if sounds are too loud for him. He also displays anger and aggression when his baby brother cries.

--- spins on the spot when upset or bored, but will only do 2 or 3 rotations. He currently does this about 7-8 times per week, but when younger, he used to do this behaviour 2 to 3 times a day. He also displays some stereotyped body movements, and walks on his toes when upset. ---'s gait is reported to be unusual when running, and his parents feel he is clumsy.

--- displays aggression towards other people if they approach him; he will grab their face and try to scratch them if they get in his 'personal space', and will scratch himself and bang his head on the ground when he is not allowed to watch TV.

---'s parents report that he is very good at shapes and numbers, and can recognise and say the numbers and letters off registrations plates on cars.

The social and communications behaviours reported by ---'s parents during the ADI-R interview were consistent with the behaviours observed during the assessment at the CDU.

ADI-R Diagnostic Algorithm

Qualitative Abnormalities in Reciprocal Social Interaction
--- scored a total of 19, with the Autism cut-off at 10.

Qualitative Abnormalities in Communication
--- scored a total of 11, with the Autism cut-off at 7.

On Restricted, Repetitive, and Stereotyped Patterns of Behaviour
--- scored a total of 5, with the Autism cut-off at 3.

Abnormality of Development
Scored as evident before 12-months of age.

On the ADI-R, --- is given a classification of Autistic Disorder.

Overall Assessment Summary and Recommendations

Our assessment of --- indicates that he is showing signs of Autistic Disorder with associated language delay. On the basis of our assessments, we strongly recommend that --- receive early intervention and speech pathology, and have referred his parents to the appropriate services.

PAPER 4

EARLY MARKERS OF ASDs IN INFANTS AND TODDLERS PROSPECTIVELY IDENTIFIED BY THE SACS

Paper 4

Early markers of Autism Spectrum Disorders in infants and toddlers prospectively identified by the Social Attention and Communication Study (SACS)

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This paper has been submitted for publication

Abstract

Barbaro and Dissanayake (2010) successfully implemented developmental surveillance of the early markers of Autism Spectrum Disorders (ASDs) in a community-based setting, with the majority of infants and toddlers identified as having an ASD. However, there were also a small percentage of children with developmental and/or language delays (DD/LD) identified. Thus, the objective in this study was to determine the most discriminating and predictive markers of ASDs used by Barbaro and Dissanayake at 12-, 18-, and 24-months of age, so that these could be used to identify children across the spectrum of autism with greater accuracy. The percentage of 'yes/no' responses for each behaviour was compared between children with Autistic Disorder (n = 39), broader ASD (n = 50), and DD/LD (n = 20) from 12- to 24-months of age, with a logistic regression also conducted at 24-months. Across all ages, the recurring key markers of autism (both AD and ASD) were deficits in *Eye Contact* and *Pointing*, and from 18-months of age, deficits in *Social Communication* ('showing' behaviours) became an important marker of autism. In combination, these behaviours, along with *Pretend Play*, were found to be the best group of predictors for a diagnostic classification of autism (both AD and ASD) at 24-months of age. As the key markers of autism were found to differ across the ages, and many children later diagnosed with 'milder' or 'broader' ASD passed some of the key items at each age, it was argued that the monitoring of the markers identified in this study must be undertaken repeatedly across the second year of life. Screening tools developed for administration at only one age will continue to result in poor sensitivity, particularly for children with broader ASD.

Early markers of Autism Spectrum Disorders in infants and toddlers identified by the Social Attention and Communication Study (SACS)

Once considered a "rare" disorder, Autism Spectrum Disorders (ASDs) are now amongst the most common neuro-developmental disorders affecting children, with between 1 in 91 to 1 in 160 individuals in the general population affected (Baird, et al., 2006; Centers for Disease Control and Prevention (CDC), 2009; Kogan, et al., 2009; Williams, MacDermott, Ridley, Glasson, & Wray, 2008). As it is increasingly apparent that very early intervention is critical in promoting better developmental outcomes for children and their family (Dawson, 2008), early identification of these disorders is paramount. However, the average age of diagnosis is 3 to 4 years for Autistic Disorder (AD) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and 7 years for Asperger's Disorder (AspD; Mandell, Novak, & Zubritsky, 2005). The past two decades have thus seen a growing body of literature on the early signs of ASDs, with screening tools developed on the basis of these signs to identify ASDs at the earliest possible opportunity. However, despite our growing knowledge of the early signs, there is currently no recommended universal tool for early detection, as the tools available to date lack sufficient specificity and sensitivity. Therefore, research needs to focus on pinpointing behaviours that will successfully identify all children across the spectrum of autism, and encompass those children with more subtle or milder presentations to increase sensitivity of the tools used in early identification.

Early Markers of ASDs

Investigations of the early markers of ASDs began with retrospective videotape investigations and parental report (e.g., Adrien, et al., 1993; Baranek, 1999; Rogers & Di Lalla, 1990; Werner & Dawson, 2005; Werner, Dawson, Osterling, & Dinno, 2000; Young, Brewer, & Pattison, 2003). These studies have provided invaluable insight into the early signs apparent between 12- to 24-months, and have consistently indicated deficits in social

attention (eye contact, social smiles, imitation, response to name, interest/pleasure in others, and expression of affect) and communication (directed vocalisations, social gestures such as waving and clapping, requesting behaviours, and joint attention skills, i.e., pointing to 'show', following others' point/gaze, referencing objects/events). Deficits in pretend play has also been identified as a key marker in toddlers (see review by Barbaro & Dissanayake, 2009).

Prospective studies of infant siblings of children with an ASD (ASD-sibs), who are at a genetically increased risk of developing an ASD (Bailey, et al., 1995; O'Roak & State, 2008; Rogers, 2009), have also been useful in charting the very early development of autism, with risk markers identified from 12-months of age. Although there have been some subtle regulatory and stereotyped behaviours identified, the majority of markers have been within the social-communicative realm (Barbaro & Dissanayake, 2009; Rogers, 2009). The Autism Observation Scale for Infants (AOSI; Bryson, Zwaigenbaum, McDermott, Rombough, & Brian, 2008), developed to investigate behavioural manifestations of ASDs between 6- to 18-months in sample of ASD-sibs, was successful in prospectively identifying infants by 12-months who were later diagnosed with an ASD. The behavioural markers included abnormal eye contact, visual tracking, disengagement of visual attention, orienting to name, imitation, social smiling, reactivity, social interest, and sensory-orienting behaviours (Zwaigenbaum, et al., 2005).

Mitchell et al. (2006) found that ASD-sibs who received a diagnosis of an ASD at 24-months understood and produced fewer phrases and gestures by 12-months such as giving, pointing, showing, shaking and nodding head, holding arms up to be lifted, and knowledge of the appropriate use of real and toy objects. By 18-months, these toddlers showed delays in their use of gestures and in the understanding and production of phrases and single words. Furthermore, response to joint attention skills, consistently found retrospectively to be an

important marker, was also found by Sullivan et al. (2007) to be an important prospective marker for the screening of ASDs in the latter part of the 2nd year of life.

In their prospective study of ASD-sibs from 14- to 24-months, Landa, Holman, and Garrett-Mayer (2007) found that a subset of children later diagnosed with an ASD did not display social and communication deficits until 24-months of age. Children in their "early diagnosis" group (i.e., those identified at 14-months of age) showed abnormalities in all aspects of joint attention, initiation of communication, and variability in expressive communicative initiations at 14-months, which persisted to 24-months. However, toddlers in the "later diagnosis" group, (i.e., after 14-months of age) were deemed initially to be more or less indistinguishable from those without an ASD on the social and communication variables examined (such as gaze shifts, shared positive affect, gestures, initiation of joint attention etc.). Children in this latter group exhibited a shift away from typical social and communication behaviour between 14- to 24-months. Consequently, by 24-months, both the early and later diagnosis groups showed persistent impairments in triadic gaze, response to joint attention, and initiation of joint attention (Landa, et al., 2007).

Landa et al.'s (2007) data suggests that, in many cases, ASD has a progressive phase involving developmental arrest, slowing, or even regression in social and/or language behaviours, which has been found in previous studies during the second year of life (e.g., Interactive Autism Network, 2008; Lord, Shulman, & DiLavore, 2004; Richler, et al., 2006; Werner & Dawson, 2005). In their review, Yirmiya and Charman (2010) conclude that regression is relatively specific to "narrowly defined autism" (i.e., AD). They cite Pickles et al (2009), who found that regression occurred in only 1% of children with Specific Language Impairment compared to 15% of children with autism or broader ASD. Baird et al. (2008), investigating the same group of children, found regression in 30% of children with AD, 8% of children with ASD, and 3% of controls with intellectual disability, learning, or behaviour

difficulties. However, these studies relied on retrospective parental report, thus limiting confidence of these conclusions until these findings are replicated in prospective studies (Yirmiya & Charman, 2010).

It is evident from these findings that some toddlers later diagnosed with ASDs are likely to remain undetected via early ASD specific screening in the early part of their second year of life. Landa et al. (2007) therefore proposed a continuum of impairment, where children reach the threshold for diagnosis at different times in their early years. Hence, it is of utmost importance to repeatedly monitor the early signs throughout the first 2 years of life.

Prospective, community-based, studies have also provided evidence of early behavioural markers. The earliest signs identified were through the Early Screening of Autistic Traits Questionnaire (ESAT) at 14/15-months of age (Swinkels, et al., 2006). The items most predictive of ASD were a lack of *bringing/showing objects, smiling,* and *reacts when spoken to*, and items most sensitive were a lack of *eye contact*, and *interest in people* and the presence of *stereotypical movements*. Of these behaviours, *stereotypical movements* was the least predictive item (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006). The key markers found at 18-months using the Checklist for Autism in Toddlers (CHAT; Baron-Cohen, Allen, & Gillberg, 1992), which successfully identified children who later received an ASD diagnosis at 36-months, were protodeclarative pointing, gaze monitoring, and pretend play (Baron-Cohen, et al., 1996). Unfortunately, the use of both the ESAT and CHAT with community-based samples has resulted in poor sensitivity, consequently missing many of the children later diagnosed with an ASD (Baird, et al., 2000; Dietz, et al., 2006).

Using the Infant-Toddler Checklist (ITC), Wetherby, Watt, Morgan, and Shumway (2007) compared children with developmental delay and ASD aged 18- to 26-months and found five core social and communication deficits in the ASD group (gaze shifts, following of gaze/points, rate of communicating, acts for joint attention, and inventory of conventional

gestures). However, when later used with a community-based sample, the ITC was unable to distinguish between children with ASDs from those with developmental or language delays, despite having excellent sensitivity between 9- to 24-months of age (93%; Wetherby, Brosnan-Maddox, Peace, & Newton, 2008).

The M-CHAT (Robins, Fein, Barton, & Green, 2001), designed for use with 24-month-olds, identified six key items in the areas of social relatedness and communication that best discriminated between children diagnosed with and without an ASD. These were: protodeclarative pointing, response to name, interest in peers, bringing things to show parents, following a point, and imitation. The M-CHAT was also later used in a community-based sample of 16- to 30-month olds, but resulted in low Positive Predictive Value (PPV) when used alone (11%; Kleinman, et al., 2008), consequently identifying many children without an ASD.

Problems with Current Screening Tools

It can be seen that in an attempt to increase sensitivity, the ITC and M-CHAT identified many children without ASDs, albeit with other general developmental and language problems. Furthermore, the low sensitivity reported in the large-scale screening studies (using CHAT, ESAT) may be because these tools were administered at a single age, leading to many missed opportunities for identifying ‘at risk’ children. It is also likely that these tools have low sensitivity because the behavioural markers used to identify children with ASDs are heavily based on those related to ‘classic’ autism, rather than the broader spectrum. Many of the retrospective and parental report studies, which identified the early markers later incorporated into these tools, focused on children with Autistic Disorder. Consequently, many children with milder or atypical presentation of symptoms were not identified by these tools (Baird, et al., 2000; Dietz, et al., 2006). The latest study using the ESAT is testament to this (Oosterling, et al., 2009). Utilising a high-risk population referred

for clinical psychiatric evaluation, the ESAT was only able to detect children with ASD with low IQ, and not those with higher IQ and perhaps 'milder' or atypical symptom presentation.

Matson and colleagues (Fodstad, Matson, Hess, & Neal, 2009; Matson, Boisjoli, Hess, & Wilkins, 2010; Matson, et al., 2009) acknowledge that most scales measuring symptoms of ASD do not differentiate between AD and 'broader' ASD. They have recently developed a screening tool, the 'Baby and Infant Screen for Children with aUtIsm Traits-Part 1' (BISCUIT-Part 1), and developed cut-off scores for autism, PDD-NOS, and non-autism. It is reported to have higher sensitivity, comparable specificity, and a higher overall classification rate than the M-CHAT. However, the mean age of identification was 27-months for both AD and PDD-NOS using a high-risk sample, and its utility has thus not been demonstrated for younger children in community-based samples (Matson, et al., 2009).

Other problems with current early screening tools, identified by Landa (2008), is the use of "lack of" terminology such as "lack of pointing". Many toddlers with ASDs do, in fact, exhibit these behaviours, but do so less often or inconsistently and may therefore pass the screen but still possess atypical behaviours. Consequently, most children with classic autistic symptoms will be identified with these tools, but those with mild or less severe symptoms may be missed. The focus should therefore be on whether a particular behaviour is typical or atypical, rather than present or absent. A revision of the CHAT, the Quantitative-CHAT (Q-CHAT; Allison, et al., 2008), is currently addressing this issue by utilising a 5 point scale on their 25 item parent report measure, and we are currently awaiting the results of their screening study on 20,000 18- to 30-month-olds.

The Current Study

The monitoring of reduced or poorly developed social attention and communication behaviours should be undertaken within the realm of services that have a skilled workforce in early child development, such as Maternal and Child Health (MCH) nurses and related

practitioners. They are the best placed to determine, through skilled observations, whether a behaviour is typical or atypical in young children, given their extensive knowledge and training on developmental milestones (Halpin & Nugent, 2007; Pinto-Martin, Souders, Giarelli, & Levy, 2005). Barbaro and colleagues (Barbaro & Dissanayake, 2010; Barbaro, Ridgway, & Dissanayake, 2010) utilised the MCH service in Victoria, Australia, to conduct a large-scale, prospective, longitudinal study in a community-based sample. In the Social Attention and Communication Study (SACS), they recently demonstrated that routine and repeated monitoring of social attention communication behaviours by MCH nurses can accurately identify children across the spectrum of autism from 12- to 24-months. However, the specific early behavioural markers (used in the SACS) that were the most predictive of a diagnosis of an ASD at 24-months of age were not reported, and is therefore the focus of the current study.

The overall aim was to identify the earliest and most predictive markers of ASDs, used in the SACS, at 12-, 18-, and 24-months of age, so that these may be used in community-based centres to identify children across the spectrum of autism. It was hypothesised that children with 'AD' would show pervasive and severe deficits in most of the social attention and communication behaviours monitored from 12- to 24-months of age. Those with 'mild' or 'broader' autism (here on in referred to as 'ASD') were hypothesised to also show impairments in the same areas. However, it was expected that they would display a less pervasive and severe presentation of impairment, which would manifest later in the second year of life for some children. Concomitantly, it was expected that children showing signs of a developmental and/or language delay without an ASD would not show marked impairment in social attention and communication behaviours, but would instead mainly show impairments on relevant language variables.

Few researchers have attempted to distinguish between symptoms indicative of both AD and ASD versus developmental and/or language delays in infants and toddlers, and no prospective study to date conducted with a community-based sample has done so. It is important to identify markers of autism for children across the autism spectrum, as those children with a higher functioning form of autism or Asperger's Disorder also need intervention at an early age, but are traditionally diagnosed much later (Mandell, et al., 2005). As a result, these 'higher-functioning' children are not receiving intervention in their early and most critical years.

Method

Participants

Participants in the current study were drawn from the larger pool of participants monitored in the community as part of the SACS (Barbaro & Dissanayake, 2010; Barbaro, et al., 2010). The original cohort comprised 20,770 children monitored by their MCH nurse for signs of an ASD from 8- to 24-months of age[1]. Children deemed to be 'at risk' for an ASD by the MCH nurses, based on the SACS behavioural items (detailed in 'Procedure'), were referred to the SACS team at the La Trobe University Child Development Unit (CDU) for a thorough developmental and behavioural assessment. Children were only referred from 12-months onwards, and were assessed at 6-monthly intervals until 24-months of age.

A total of 110 'at-risk' children were assessed at the CDU, and are the focus of this study. To maximise sample numbers, a cross-sectional approach was taken in the current study; the 12-month sample consists of all of the children assessed at 12-months (n = 10), the 18-month sample consists of those that were assessed only once at 18-months, or at both 18-

[1] A detailed description of this cohort can be found in Barbaro and Dissanayake (2010).

and 24-months (n = 37)[2], and the 24-month sample consists of only those children that were assessed once at 24-months (n = 62). Although the majority of children assessed at 12- and 18-months were also assessed at 18- and 24-months of age, respectively, these data were excluded at each subsequent age due to the cross-sectional nature of this study[3].

Children's diagnostic status was determined at 24-months using a combination of Module 1 (pre-verbal) of the Autism Diagnostic Observation Schedule (ADOS; Lord, et al., 2000; Lord, Rutter, DiLavore, & Risi, 1999) and the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), as well as clinical judgment by the authors. The first author (J.B.) was trained to research reliability on both instruments. Diagnosis of ASDs at 24-months has been found to be both accurate and stable over time using the ADI-R and the ADOS together, and in combination with clinical judgment (Charman, et al., 2005; Chawarska, Klin, Paul, Macari, & Volkmar, 2009; de Bildt, et al., 2004; Le Couteur, Haden, Hammal, & McConachie, 2008; Lord, 1995; Stone, et al., 1999; Turner, Stone, Pozdol, & Coonrod, 2006). Children were classified as 'AD', broader 'ASD', 'DD/LD' (developmental and/or language delay), or 'TD' (typically developing). The term "autism" will be used throughout this paper to refer to both children with AD and ASD.

Children's developmental status was assessed using the Mullen Scales of Early Learning (MSEL; Mullen, 1995). Age equivalent scores were combined from the MSEL's Receptive and Expressive Language subscales, and the Visual Reception and Fine Motor subscales, to form verbal and non-verbal mental ages, respectively. Table 1 presents the characteristics of the samples assessed at each age, grouped according to their diagnostic

[2] One typically developing child, referred and assessed at both 18- and 24-months, has been excluded from this sample.

[3] These data have been examined and are deemed to be comparable to the cross-sectional data presented in this paper.

status, which was determined at 24-months. At each age, both verbal and non-verbal mental ages were lowest in children who met criteria for AD in comparison to ASD and DD/LD[4].

Table 1

*Sample Characteristics (Mean, SD, 95% CIs) at the 12-, 18-, and 24-month Assessments (N = 109)**

	Group		
	AD (*n* = 39)	ASD (*n* = 50)	DD/LD (*n* = 20)
Age in Months			
12m assessment	*n* = 3	*n* = 6	*n* = 1
Chronological	13.7 (1.2)	12.7 (0.5)	15.0 (-)
Non-verbal	12.0 (4.3) ± 4.9	11.5 (2.2) ± 1.8	16.5 (-)
Verbal	9.2 (2.9) ± 3.3	9.0 (2.5) ± 2.0	8.0 (-)
Overall mental	10.6 (3.6) ± 4.1	10.3 (2.2) ± 1.8	12.3 (-)
18m assessment	*n* = 13	*n* = 17	*n* = 7
Chronological	19.4 (1.0)	19.2 (1.3)	20.1 (1.6)
Non-verbal	17.4 (2.3) ± 1.3	17.5 (2.7) ± 1.3	17.4 (2.0) ± 1.5
Verbal	8.9 (2.0) ± 1.1	11.9[b] (1.6) ± 0.8	13.6[bc] (2.1) ± 1.6
Overall mental	13.2 (1.9) ± 1.0	14.7[a] (1.8) ± 0.9	15.5[b] (1.6) ± 1.2
24m assessment	*n* = 23	*n* = 27	*n* = 12
Chronological	25.8 (1.8)	26.2 (2.6)	26.8 (3.1)
Non-verbal	18.9 (3.4) ± 1.4	21.5[b] (3.0) ± 1.1	21.5[a] (3.8) ± 2.2
Verbal	11.1 (3.2) ± 1.3	15.8[b] (4.4) ± 1.7	16.9[b] (4.0) ± 2.3
Overall mental	15.0 (3.0) ± 1.2	18.7[b] (3.2) ± 1.2	19.2[b] (3.6) ± 2.0
Gender (M – F)	28 – 11	41 – 9	14 – 6

Note. SD = Standard Deviation; CIs = Confidence Intervals; AD = Autistic Disorder; ASD = Autism Spectrum Disorder; DD/LD = Developmental and/or Language Delay

*The one typically developing child, referred and assessed at 18- and 24-months, has been excluded
[a]Significantly different from AD, $p < .05$; [b]$p < .01$
[c]Significantly different from ASD, $p < .05$

[4] A detailed account of the developmental profiles of the three groups is beyond the scope of this paper, and is the focus of another paper by Barbaro and Dissanayake (submitted).

Mothers were, on average, 34-years-old at their child's first assessment, and fathers were 37-years-old. Ethnicity of the sample was 60% Caucasian, 14% Asian/Middle-Eastern, and 4% African; 22% were unspecified. The primary language spoken at home was English (83%). The majority of children were first born (60%), 25% were second born and 15% were third to fifth born. Average annual family income was varied, with 26% of households earning AU$80,000+, 31% earning AU$50,000 to AU$80,000, and 24% earning ≤ AU$50,000; 19% were unspecified. Tertiary education was attained by 51% of the mothers, and 40% of the fathers. The Socio Economic Status of the 17 Local Government Areas (LGAs) the sample resided in was mostly high, with the mean Socio-Economic Indexes for Areas (SEIFA) score (M = 1066) being slightly higher than the mean SEIFA score of the whole of metropolitan Melbourne (M = 1033).

In addition to the referred sample from the SACS, an additional sample of typically developing children was also observed at their MCH consultation at 12-months (n = 13), 18-months (n = 12), and 24-months (n = 11), and the SACS behavioural items (see below) were completed on each child. These data were collected by the first author to determine reliability of the nurses' monitoring of the SACS items (see Barbaro & Dissanayake, 2010). These children were not assessed at the CDU.

Procedure

SACS behavioural items. Maternal and Child Health nurses were trained by the SACS team to identify infants and toddlers 'at risk' of an ASD by monitoring social attention and communication behaviours during their routine consultations. The nurses were trained to identify when a behaviour was atypical, such that it was either reduced or poorly developed, as opposed to simply present/absent. These behaviours were listed on a SACS 'Items' sheet and nurses were instructed on how each specific item was to be monitored at each age (see Appendix A for these items). Performance on 'KEY' items was used to refer infants and

toddlers 'at risk' for an ASD to the SACS team[5]. For the purposes of this paper, children's performance on all items, not just KEY items, was of interest.

The same SACS 'Items' sheets utilised by the nurses for referral were also completed by the first author to score the same behaviours during children's assessments at the CDU. All sessions were videotaped and used to assist in the coding of these sheets where necessary. The data used in the current study are based on these data collected at the CDU.

Inter-rater reliability. To determine reliability of the first author's scoring of the 'Items' sheets in the CDU, a second rater, blind to diagnostic status, was employed to re-code 15% of the items sheets for each of the 12-, 18-, and 24-month samples. Forty-three items were assessed across the three ages. Percentage agreement, calculated for items assessed at each age, was .96 or higher for all the items, and .80 or higher for each individual item, with the exception of two items[6].

Results

Frequencies of each of the social attention and communication behaviours for each group were compared using the Fisher's Exact Probability Test, which handles small expected cell frequencies (Howell, 2010). Fisher's tests were only conducted between the AD and DD/LD groups, and the ASD and DD/LD groups, to limit the number of comparisons and control for Type I error. At each age, correlations between the dependant variables were diverse, with most in the low to moderate range, and some in the high range (12-months: .000 to .800; 18-months -.006 to .700; 24-months: .009 - .700). Therefore, to further control for Type I error, a nominal *p* value of .01 was adopted for the 18- and 24-month data; however,

[5] See Barbaro and Dissanayake (2010) and Barbaro et al. (2010) for a more detailed description of the training method.

[6] *Attending to Sounds* (12-month item) = .50 inter-rater reliability. As only 2 participants were included in this reliability analysis (equal to ~15% of the sample), only one discrepancy led to .50 reliability. *Obeys Simple Instructions* (18-month item) = .71 inter-rater reliability.

due to the small sample sizes at 12-months, a *p* value of .05 was maintained. Effect size was evaluated using the Phi coefficient.

12-month Items

As 9 of the 10 12-month-olds assessed were later classified with an ASD, the DD/LD and autism groups could not be compared to ascertain which signs were specific to autism as opposed to developmental and/or language delay. Therefore, the autism groups (AD and ASD) were combined for the analyses (due to low *n*) and compared to a sample of 13 typically developing (TD) 12-month-olds (Mean age: 12.0 months; 7 male, 6 female).

As can be seen from Figure 1, a failure to engage in *Pointing, Waving, Imitation, Eye Contact*, and *Response to Name* significantly distinguished children with autism from the TD children at 12-months of age (all $p < .05$), and the effect sizes were moderate to high, with the Phi coefficient ranging between .6 and .8. While *Eye Contact* was recorded as absent for each of the 3 children with AD, it was recorded as present for 5 of the 6 of the children with ASD at 12-months. Similarly, *Response to Name* was absent amongst the children with AD, but present for 4 of the 6 children meeting criteria for ASD at this age.

Although fewer children in the autism groups engaged in *Follows Point* and *Social Smiles* relative to the TD group, these differences were not statistically significant (both $p > .05$). As with *Eye Contact* and *Response to Name, Social Smiles* was absent amongst each of the 3 children with AD but only absent in 2 of the 6 children with ASD.

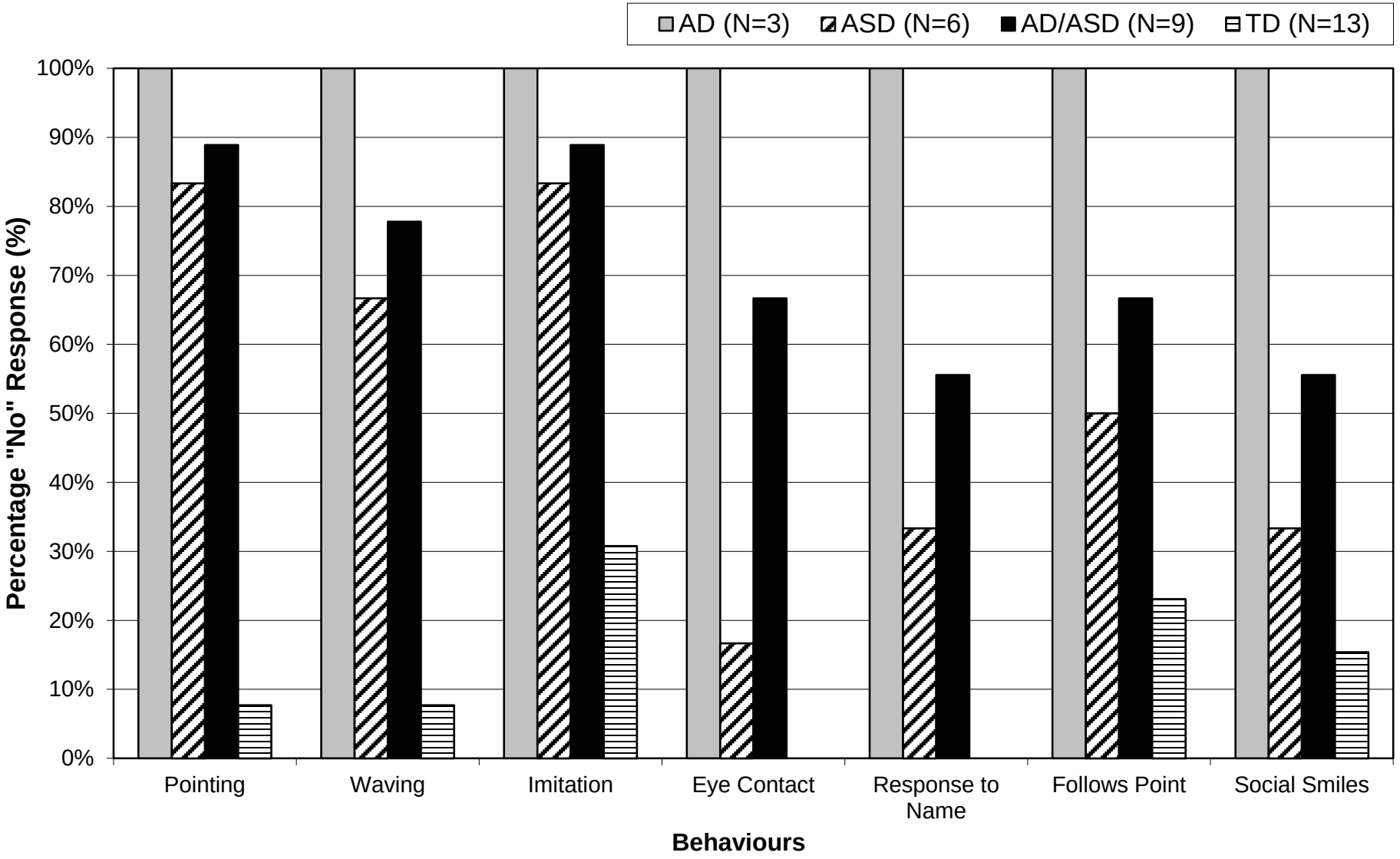

Figure 1. Behaviours that differentiate the autism (AD and ASD) groups from the TD group at 12-months. Pecentage of 'No' reponses.

Behaviours that were not as problematic for the autism groups at 12-months of age were *Conversational Babble, Speaks 1-3 Words, Cuddles,* and *Attending to Sounds* (see Figure 2). There were no significant differences between the autism and TD groups on these behaviours (all $p > .05$, Phi coefficient range: .09 - .48). Although over 50% of the children with autism had deficits in *Understands Simple Instructions*, 23% of the TD children also failed this item, resulting in a non-significant difference ($p = .19$; Phi = .33).

Summary of 12-month Data

Deficits in *Pointing, Waving, Imitation, Eye Contact,* and *Response to Name* distinguished children with autism from the TD children. *Follows Point, Social Smiles Conversational Babble, Speaks 1-3 Words, Cuddles, Attending to Sounds,* and *Understands Simple Instructions* did not significantly differentiate the groups.

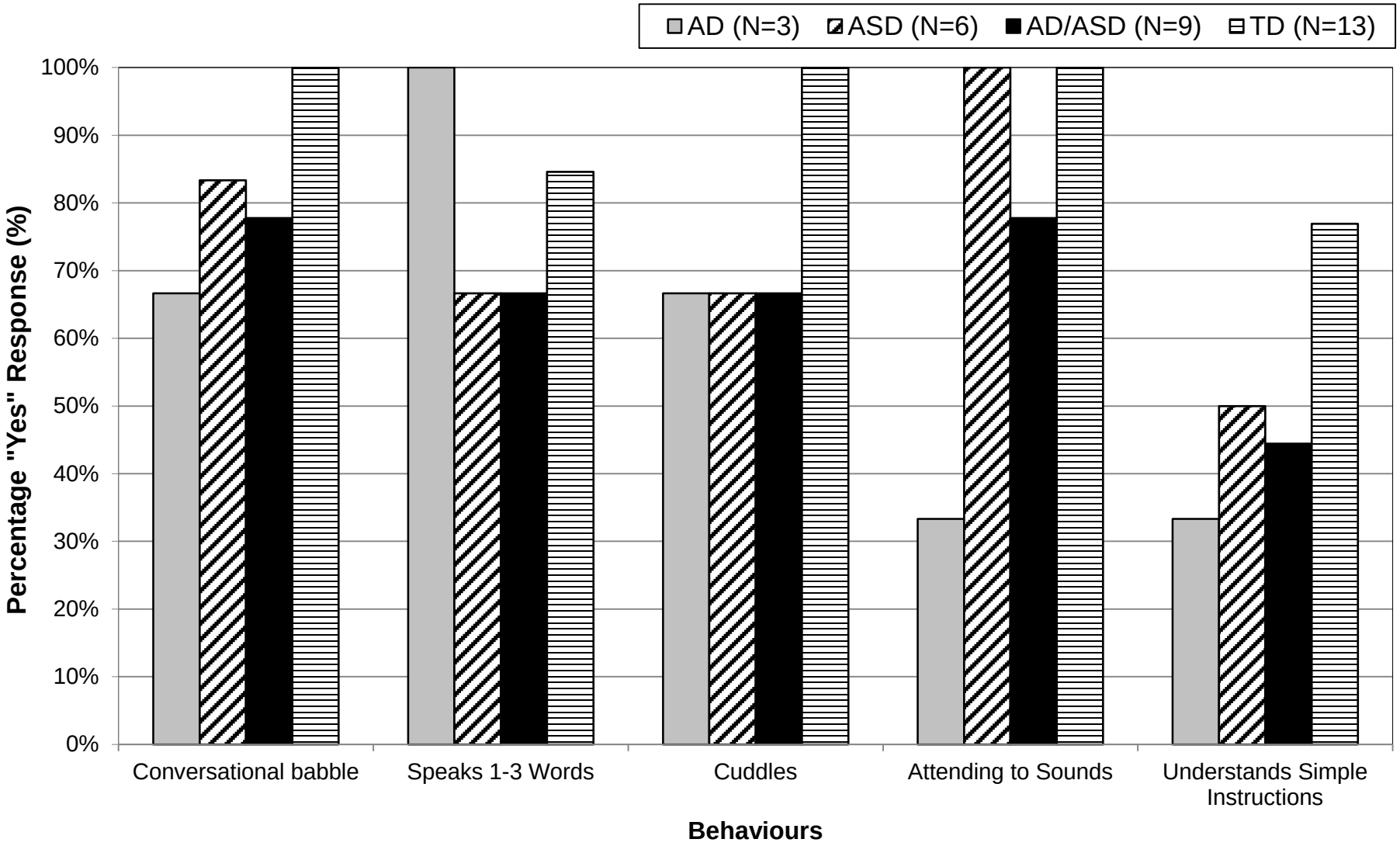

Figure 2. Behaviours that did not differentiate the autism (AD and ASD) groups from the TD group at 12-months. Pecentage of 'Yes' reponses.

18-month Items

As there were more children in the DD/LD group referred at 18-months, it was possible to compare the DD/LD group to the AD and ASD groups (separately) to indicate which behavioural items are more specific to autism as opposed to a developmental and/or language delay. Data from a sample of 12 TD children were included in the Figures for comparative purposes (Mean age: 18.0 months; 6 male, 6 female), but were not included in the analyses in an effort to limit the number of comparisons.

It is apparent from Figure 3 that deficits in *Pointing*, *Eye Contact*, and *Social Communication* (communicating socially with others by 'showing' objects to them) clearly differentiate both the AD and ASD groups from the DD/LD group, who passed each of these items at 18-months (all $p < .01$). Effect sizes were moderate to high, with Phi coefficients ranging from .6 to 1.0. Consistent with the findings from 12-months of age, all children with AD showed deficits in *Pointing* and *Eye Contact*, and they all showed deficits in *Social Communication*. Although the vast majority of the children with ASD did not engage in *Pointing*, over one-third of this group did engage in *Eye Contact* and *Social Communication*.

Behaviours that significantly differentiated the AD (but not ASD) group from the DD/LD group were *Social Smile, Response to Name, Follows Point, Uses 5-10 Words*, and *Understands Words* (all $p < .01$; Phi coefficient range = .6 to .8). The vast majority of the ASD group did engage in *Social Smile* (compared to only 15% of the AD group), and nearly 50% of the ASD group engaged in *Response to Name* (compared to none of the AD group). Over one-third of the ASD group also engaged in *Follows Point* (compared to only 8% of the AD group). However, although there were no significant differences between the ASD and DD/LD groups on *Uses 5-10 Words* and *Understand Words*, a high percentage of children in the ASD group did not show these behaviours (see Figure 3).

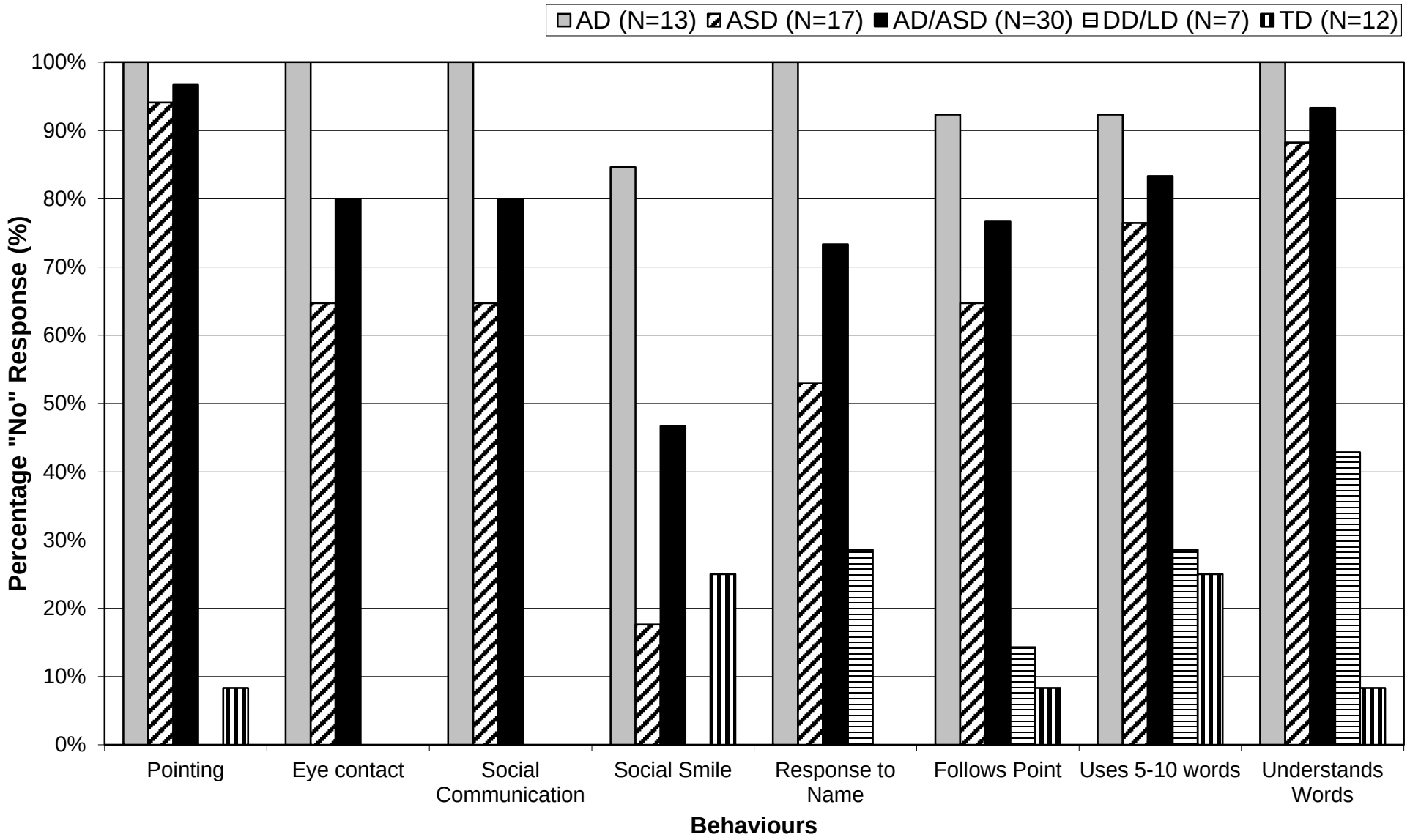

Figure 3. Behaviours that differentiate the ASD and/or AD groups from the DD/LD group at 18-months. Pecentage of 'No' reponses.

There were no significant differences between the AD and ASD groups and the DD/LD group in *Imitation, Pretend Play, Points to Facial Features, Obeys Simple Instructions, Waving, Cuddles, Affection/Comfort* and *Loss of Skills* (all $p > .01$). Only 17% and 13% of the AD and ASD groups showed deficits in *Cuddles* and A*ffection/Comfort*, respectively; none of the DD/LD (or TD) groups showed deficits in these areas (see Figure 4).

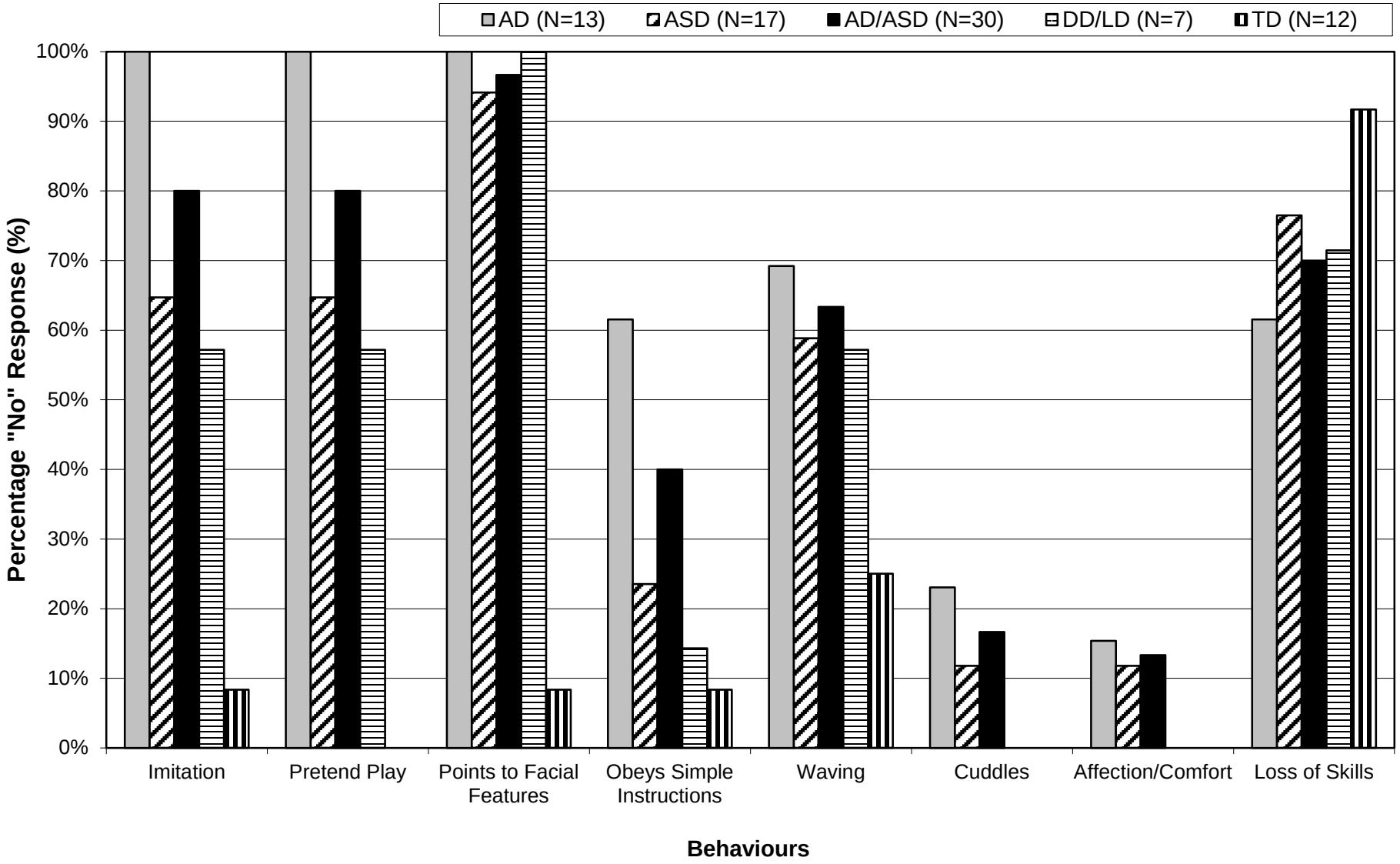

Figure 4. Behaviours that did not differentiate the AD and ASD groups from the DD/LD group at 18-months. Percentage of 'No' responses.

Summary of 18-month Data

Failure to show *Pointing, Eye Contact*, and *Social Communication* are key markers for the identification of autism (AD/ASD) in 18-month-olds. Behavioural markers of AD (but not ASD) are: *Social Smile, Response to Name, Follows Points, Uses 5-10 Words*, and *Understands Words.* The behaviours: *Imitation*, *Pretend Play*, *Points to Facial Features, Obeys Simple Instructions, Waving*, *Cuddles*, *Affection/Comfort* and *Loss of Skills* are not important markers of autism at 18-months.

24-month Items

In keeping with the 18-month analyses, percentage responses for each behaviour were analysed between the DD/LD group, and the AD and ASD groups. The data from a sample of 11 TD children were included in the Figures for comparative purposes, but were not analysed (Mean age: 24.0 months; 8 male, 3 female).

It is apparent from Figure 5 that deficits in *Pointing*, *Eye Contact*, *Social Communication, Pretend Play,* and *Waving* clearly differentiate both the AD and ASD groups from the DD/LD group (all $p < .01$; Phi coefficient range = .4 to .9). Consistent with the 12- and 18-month data, all the children with AD showed deficits in *Pointing*. Distinct from the AD group, nearly 50% of children in the ASD group did engage in *Pointing* and *Social Communication* at 24-months. It is also of note that over 50% of children in both the AD and ASD group engaged in *Waving*, and a large percentage of both the AD and ASD groups could engage in *Pretend Play* at 24-months (30% and 48%, respectively).

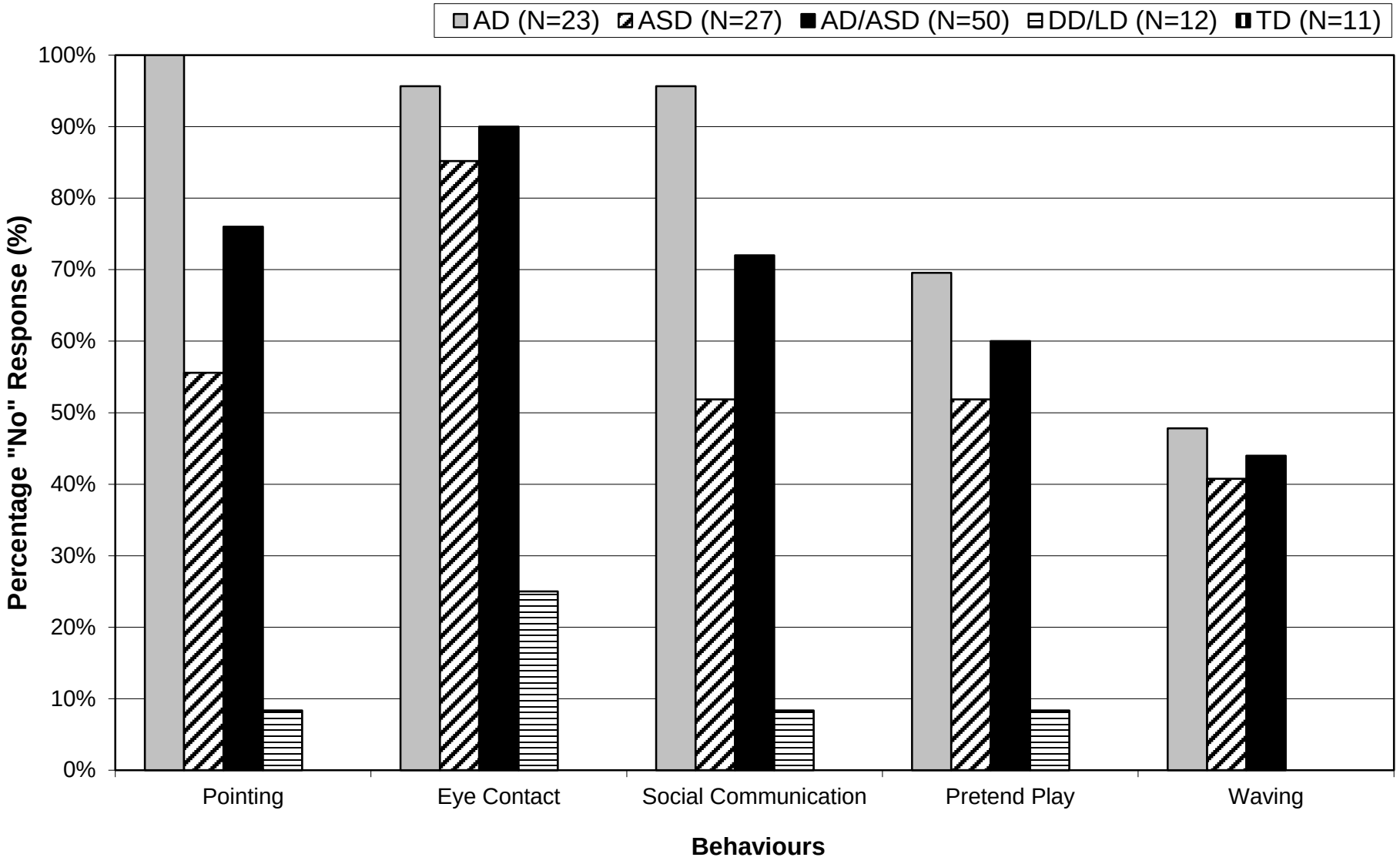

Figure 5. Behaviours that differentiated the AD and ASD groups from the DD/LD group at 24-months. Percentage of 'No' responses.

The behavioural items which differentiated the AD (but not ASD) group and the DD/LD group were: *Follows Simple Commands, Follows Point, Social Smile, Response to Name,* and *Loss of Skills* (all $p \leq .001$; Phi coefficient range = .6 to .7). Approximately one-half to three-quarters of the children in the ASD group engaged in *Follows Simple Commands, Follows Point, Social Smile,* and *Response to Name,* compared to approximately 20% of the AD group. It is worth noting that 33% of children in the DD/LD group, and 59% of children in the ASD group, also had *Loss of Skills* (See Figure 6).

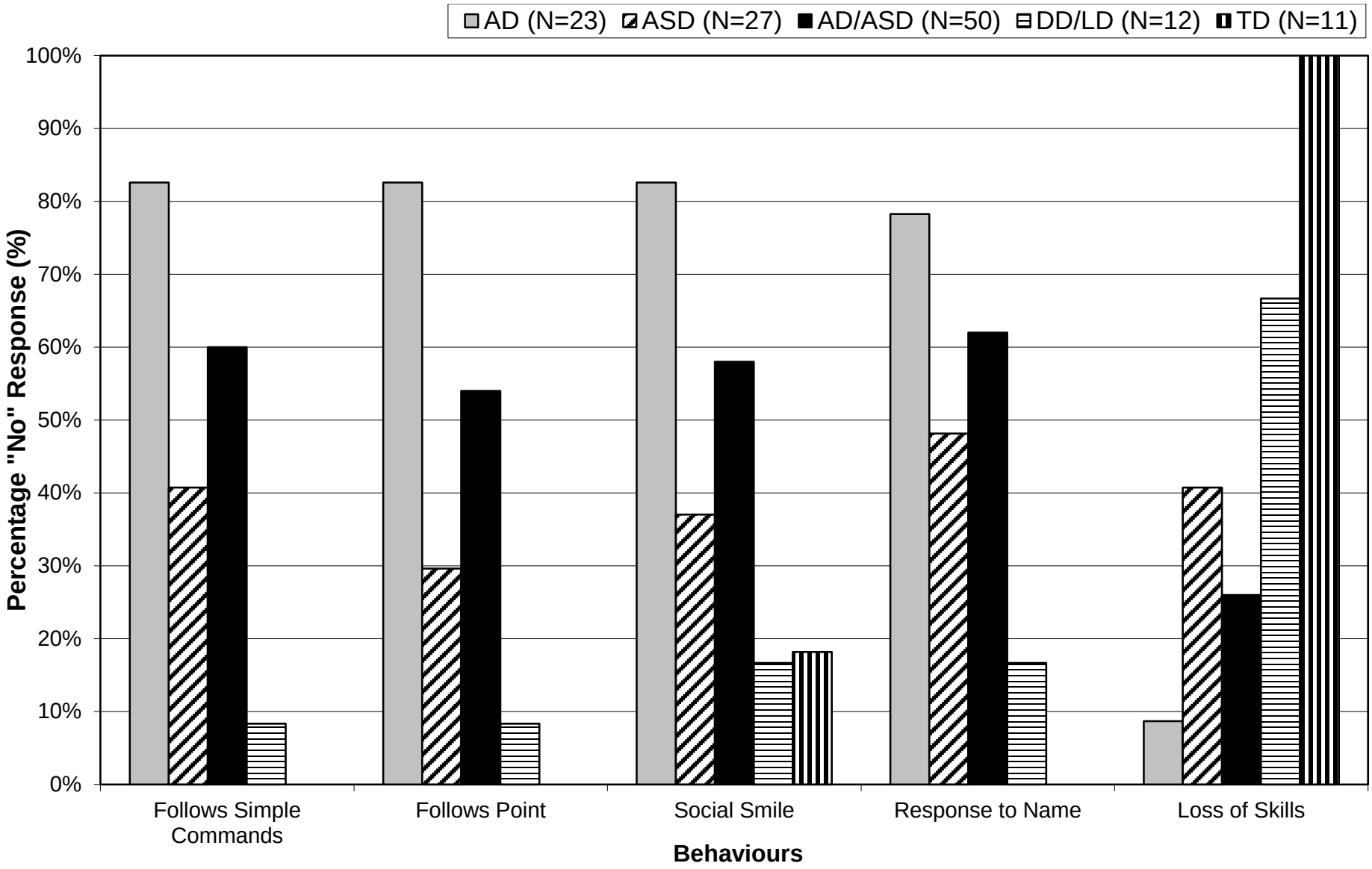

Figure 6. Behaviours that differentiated the AD group (only) from DD/LD group at 24-months. Percentage of 'No' responses.

There were no significant differences between both the AD and ASD groups and the DD/LD group in *Uses 20-50 Words, 2-Word Utterances, Parallel Play, Imitation,* and *Affection/Comfort* (all $p > .01$; see Figure 7). This is because, as with the autism groups, a large percentage of children in the DD/LD group failed to show *Uses 20-50 Words* (83%) and *2-Word Utterances* (92%). Furthermore, over 50% of children in the autism groups engaged in *Imitation* and *Parallel Play* by this age. Once again, it is apparent from Figure 7 that *Affection/Comfort* did not differentiate the children with autism from those with DD/LD (or the TD children).

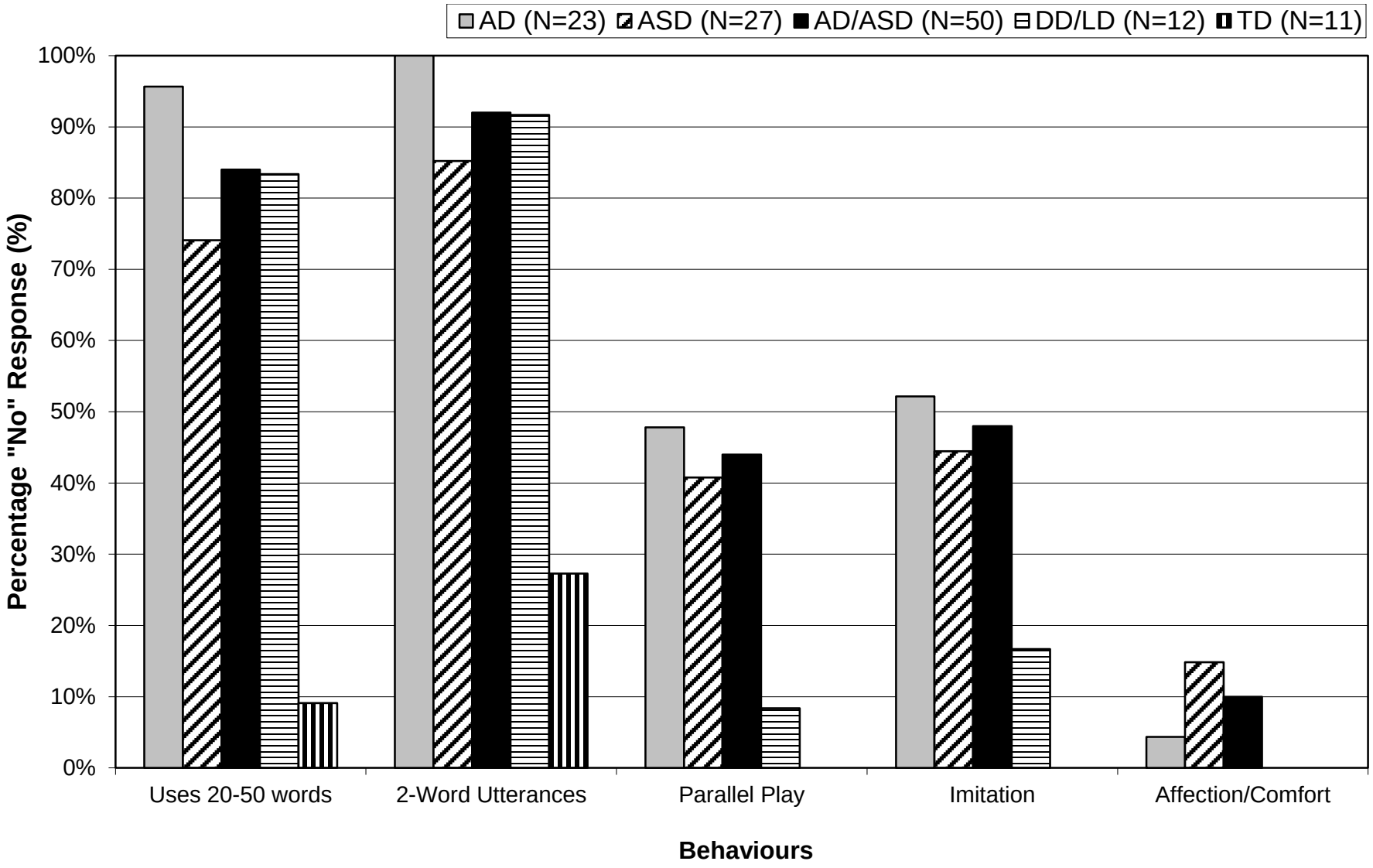

Figure 7. Behaviours that did not differentiate the AD and ASD groups from the DD/LD group at 24-months. Percentage of 'No' responses.

Group Predictors of an Autism (AD/ASD) vs. DD/LD Classification at 24-months

As there were a sufficient number of participants at 24-months, a logistic regression analysis was conducted to determine which group of behavioural items could best predict the probability of a diagnostic classification of autism versus DD/LD. The autism groups (AD and ASD) were combined, as it was of interest to ascertain the group of behaviours that could differentiate children with and without autism. The entire referred cross-sectional sample at 24-months was used in this analysis (N = 99; ASD: n = 42; AD: n = 37; DD/LD: n = 20).

A logistic regression analysis was utilised as it does not assume a normal distribution or equal variance among groups, and the results are independent of sample size (Howell, 2010). The resulting statistic, the odds ratio (OR), is a ratio between the means (with 95% confidence intervals – CIs), reflecting the increase in likelihood (odds) of being in the autism vs. DD/LD group as each variable increases by one (Howell, 2010).

Associations between the predictors were evaluated using cross-tabulations and Phi coefficients. Predictors with a significant bivariate association of .3 or higher with the dependent variable (diagnostic classification) were included simultaneously in the model predicting group membership. The following predictors were included*: Pointing, Pretend Play, Social Communication, Eye Contact, Follows Simple Commands, Follows Points,* and *Social Smile*.

To detect multicollinearity, bivariate correlations and Tolerance values were calculated for all predictors selected for the model. Bivariate correlations between each of the IVs must be < .70 (Tabachnick & Fidell, 2007). Tolerance is an indicator of how much of the variability of the specified IV is not explained by the other IVs in the model. Small values (i.e., < .10) indicates that correlations with other variables is high, suggesting a high possibility of multicollinearity. Each of the bivariate correlations between the predictors were less than .70, with the highest being .56, and all Tolerance values were .49 or higher,

suggesting that multicollinearity was not a serious problem. An alpha level of .05 was adopted for the analysis.

The results of the model predicting a diagnostic classification of AD/ASD are shown in Table 2. The final model was significant ($\chi 2$ (7, N=99) = 72.32, $p < .001$), and allowed prediction of 92.9% of cases: 80% of the DD/LD group, and 96.2% of the AD/ASD group. Significant predictors of a diagnostic classification of AD/ASD at 24-months of age included: *Pretend Play, Pointing, Eye Contact,* and *Social Communication.*

The OR was highest for *Pretend Play* (75.5), followed by *Pointing* (37.3), *Eye Contact* (28.5), and *Social Communication* (19.9). *Follows Simple Commands, Follows Point,* and *Social Smile* were also in the final model, with *Follows Simple Commands* and *Follows Points* containing high ORs. However, these predictors did not make significant unique contributions, and were thus not predictive of group membership at 24-months.

Table 2

Logistic Regression Analysis of Behavioural Items for a Diagnostic Classification of AD/ASD at 24-months of age (N = 99)

Behaviour	*B*	S.E.	Wald χ^2 test	df	*p*	Odds Ratio (OR)	95% C.I. for OR	
							Lower	Upper
Pretend Play*	4.32	1.64	6.95	1	.008	75.48	3.03	1878.44
Pointing*	3.62	1.66	4.77	1	.029	37.26	1.45	959.19
Eye Contact*	3.35	1.51	4.92	1	.027	28.54	1.48	552.09
Social Communication*	2.99	1.44	4.31	1	.038	19.93	1.18	335.67
Follows Point	3.00	2.06	2.12	1	.145	20.04	0.36	1130.52
Follows Simple Commands	2.79	2.85	0.96	1	.327	16.26	0.06	4296.88
Social Smile	1.09	1.51	0.52	1	.470	0.34	0.02	6.50

Note. S.E. = Standard Error; df = Degrees of Freedom; C.I. = Confidence Interval

*Key group predictors of a diagnostic classification of autism (AD/ASD) at 24-months

Summary of 24-month Data

Deficits in *Pointing, Eye Contact, Social Communication, Pretend Play,* and *Waving* are key markers for the identification of autism at 24-months. Markers of AD (only) were: *Follows Simple Commands, Follows Point, Social Smile, Response to Name,* and *Loss of Skills*. The behavioural items *Uses 20-50 Words, 2-Word Utterances, Parallel Play, Imitation,* and *Affection/Comfort* were not found to be discriminative markers of autism at 24-months. The key group markers, which could predict a diagnostic classification of autism (AD and ASD combined), included *Pretend Play, Pointing, Eye Contact,* and *Social Communication.*

Discussion

The aim of this study was to identify the most discriminating and predictive prospective markers used in the SACS at 12-, 18-, and 24-months of age so that these can be used to identify both low and high-functioning children with autism from 12- to 24-months. Each of the key individual markers and group predictors of autism (both AD and ASD) identified in this study has been flagged in Appendix A. In keeping with the study's hypotheses, it was found that the children in the AD group had pervasive deficits in the majority of the social attention and communication items monitored across the ages, with the children in the ASD group showing a less pervasive and severe presentation of deficits in these areas. However, with the exception of *Eye Contact, Response to Name,* and *Social Smile*, the majority of children in the ASD group were showing impairments in social attention and communication behaviours by 12-months of age, which is consistent with the literature showing deficits in children with autism by their first birthday (Baranek, 1999; Clifford & Dissanayake, 2008; Nadig, et al., 2007; Osterling & Dawson, 1994; Osterling, Dawson, & Munson, 2002; Watson, et al., 2007; Werner & Dawson, 2005; Werner, et al., 2000). Furthermore, the DD/LD group, although showing impairments in the language variables, did not show pervasive deficits in the social attention and communication variables monitored. Instead they showed a very similar pattern of response to the typically developing children on most variables.

Markers of Autism at 12-months of Age

Deficits in *Pointing, Waving, Imitation, Eye Contact*, and *Response to Name* are important markers for the identification of autism (both AD and ASD combined) at 12-months of age, which is consistent with both retrospective and prospective studies (Adrien, et al., 1993; Nadig, et al., 2007; Osterling & Dawson, 1994; Osterling, et al., 2002; Watson, et al., 2007; Werner, et al., 2000; Zwaigenbaum, et al., 2005). While *Response to Name* was

recorded as absent for all children with AD, it was recorded as present for the majority of children with ASD, resulting in 46% of the combined autism groups passing this item at 12-months. This finding is not surprising, given that Nadig et al. (2007) found that deficits in *Response to Name* is very specific at 12-months of age (.89), but not very sensitive (.50). Determining risk status for an ASD on this behaviour alone will therefore miss half of the children later diagnosed with an ASD, which is consistent with the data from the current study.

In comparison to typically developing 12-month olds, the children with autism also rarely engaged in *Follows Point* and *Social Smile*, but these differences did not reach significance, as the majority of children diagnosed with 'ASD' did pass these items. Therefore, deficits in *Eye Contact, Response to Name, Follows Points,* and *Social Smile* are important to investigate at 12-months to identify children at risk for autism. However, the presence of these behaviours does not rule out the possibility of 'broader' ASD, as the majority of children later diagnosed with 'ASD' at 24-months of age were not showing deficits in these areas at 12-months, particularly eye contact (only 17% were showing deficits at this age). Thus, as found by Landa et al. (2007), a subset of children later diagnosed with autism will not present with deficits in some social attention and communication behaviours around their 1st birthday. The items *Conversational Babble, Speaks 1-3 Words, Cuddles, Attending to Sounds,* and *Understands Simple Instructions* were not useful markers of autism at 12-months, and the presence of these behaviours should not be used to make a decision on a child's risk status for autism at this age.

Markers of Autism at 18-months of Age

Consistent with the findings from the 12-month data, deficits in *Pointing* and *Eye Contact* continue to be key markers for the identification of autism at 18-months, with both the AD and ASD groups showing deficits in these behaviours relative to the DD/LD group.

Social Communication ('showing' behaviours) becomes a very important marker for the identification of autism in 18-month-olds, as none of the children in the DD/LD and TD groups showed deficits in this area, compared to all of the AD group and 65% of the ASD group. These behaviours have consistently been found in the literature to be important markers for the identification of ASDs between 12- to 24-months of age (Adrien, et al., 1991, 1992, 1993; Baron-Cohen, et al., 1996; Landa, et al., 2007; Mars, Mauk, & Dowrick, 1998; Osterling & Dawson, 1994; Robins, et al., 2001; Vostanis, et al., 1998; Werner & Dawson, 2005; Young, et al., 2003).

Despite both the AD and ASD groups differing significantly to the DD/LD group in their *Eye Contact* and *Social Communication* skills, over one-third of the children with ASD did engage in these behaviours at 18-months of age. Thus, many children later diagnosed with 'broader' ASD will, in fact, pass these items at 18-months. Other behavioural markers that will identify children with classic autism (AD) but not broader ASD at 18-months included *Social Smile, Response to Name, Follows Point, Uses 5-10 Words,* and *Understands Words.* As the majority of children diagnosed with broader ASD at 24-months did engage in these behaviours at 18-months, tools utilising these behaviours as risk markers at this age will not have to capacity to identify these children.

Although *Imitation* and *Waving* were key markers at 12-months, they were no longer found to be key markers at 18-months. This may be because at 12-months, the autism groups were compared to a typically developing group, rather than a DD/LD group. It was found that nearly 60% of the DD/LD group was also showing deficits in *Imitation* and *Waving* at 18-months, and thus did not significantly differ to the autism groups. Similarly, the finding that *Pretend Play* was not a key marker for autism at 18-months was due to the DD/LD group also showing deficits in this area (57%). Thus, *Pretend Play* may be more indicative of general developmental/language delays at this age, rather than specific to autism. This

contrasts with tools such as the CHAT (Baron-Cohen, et al., 1996), which have found that *Pretend Play* is a key marker for the identification of autism in 18-month-olds.

While all of the children with AD in the current study displayed deficits in *Pretend Play* at 18-months, over a third of the children with ASD could engage in this behaviour. This finding, combined with the '*Follows Point*' finding, may explain the lack of sensitivity of the CHAT for broader ASD (Baird, et al., 2000), as it uses both of these behaviours as key items at 18-months of age.

Markers of Autism at 24-months of Age

Once again, consistent with the findings from the 12- and 18-month data, deficits in *Pointing*, *Eye Contact*, and *Social Communication* continue to be key markers for the identification of autism at 24-month of age, with both the AD and ASD groups showing deficits in these behaviours relative to the DD/LD group. Furthermore, the vast majority of the ASD group (86%) was showing deficits in *Eye Contact* at 24-months, in comparison to only 17% of this group at 12-months, and 65% at 18-months. Therefore, it seems that children with broader ASD may show some regression in this area across the second year of life. This is consistent with the pattern displayed in Landa et al.'s (2007) "later" diagnosis group.

Although children with both AD and ASD were significantly different from the DD/LD group in their *Pointing* and *Social Communication* skills at 24-months, nearly 50% of children in the ASD group did display these behaviours at 24-months. Therefore, many children on the spectrum will pass these items at 24-months of age, and so presence of these behaviours does not rule out the possibility of autism. However, an absence of these behaviours strongly suggests a child will be on the spectrum, given that none of the DD/LD (and TD) groups showed deficits in these skills. Other key markers of autism at 24-months

include *Pretend Play* and *Waving,* although some children with AD and ASD did engage in these behaviours at 24-months.

Similar to the 18-month results, there were also behavioural markers that were useful for identifying children with AD, but not broader ASD, and these included deficits in *Follows Simple Commands*, *Follows Point*, *Social Smile, Response to Name,* and *Loss of Skills.* Thus, tools designed for use at 24-months of age that utilise these behaviours as key items may not identify those children with 'broader' ASD.

Consistent with the findings from the 18-month data, *Imitation* was no longer a marker of autism at 24-months, as it was found that the number of children with AD presenting with deficits in this area dropped by almost half from 18- to 24-months. Not surprisingly, the DD/LD group displayed comparable deficits to the autism groups on the language variables, *Uses 20-50 Words* and *2-Word Utterances*. These language variables are therefore useful in indicating general language/developmental problems, and are not specific to autism at 24-months.

The pattern of results indicates the utility of individual key behavioural markers, which change with age, but also speak to the importance of relying on a group of markers rather than single behavioural items. The group of behaviours that were able to predict a diagnostic classification of autism (both AD and ASD combined) at 24-months included: *Pretend Play, Pointing, Eye Contact*, and *Social Communication.* Although a deficit in *Pretend Play* was not a useful marker of autism at 18-months, it became one of the most important predictors for a diagnostic classification of autism at 24-months. This is due to the percentage of children with a DD/LD displaying deficits in this area declining from 57% to 8% between 18- and 24-months. Thus, developmental surveillance of children at 24-months should include the investigation of deficits in each of these behaviours together to determine risk status for autism (both low and high-functioning).

'Loss of Skills' in Children with Autism and Developmental/Language Delay

The findings from the current study do not support the conclusion by Yirmiya and Charman (2010) that regression is relatively specific to AD. At 18-months, the combined autism group and the DD/LD group were displaying a similar rate of *Loss of Skills* (30% vs. 29%, respectively). Therefore, this item may be more indicative of general developmental/language delays, as opposed to being specific to autism at 18-months. In addition, despite only the AD group differing significantly to the DD/LD group on *Loss of Skills* at 24-months, quite a high percentage of both the ASD (59%) and DD/LD (33%) group also displayed *Loss of Skills* by 2 years of age. Evidently, definitions of 'regression' differ between studies, with some studies using ADI-R criteria for the definition of regression, which is quite stringent (Ozonoff, Heung, Byrd, Hansen, & Hertz-Picciotto, 2008). However, in the current study, <u>any</u> loss of <u>any</u> kind (noted by nurses or parents) was recorded, which is much less stringent than ADI-R criteria, and was therefore capable of identifying those children with broader ASD and DD/LD, as well as those with AD.

Strengths of Children on the Spectrum

Studies on the early markers of autism have focused on what behaviours are "lacking" in these children. However, the findings from the current study demonstrate not only the deficits seen in these children, but their relative <u>strengths</u>, especially amongst the children with broader ASD. This is perhaps why the prospective tools reviewed have low sensitivity, as they may have missed children displaying milder or atypical symptoms by using "lack of" terminology (Landa, 2008).

Raters in the current study, although using 'yes/no' criteria, assessed behaviours according to whether they were typical or atypical, and MCH nurses were trained by the SACS team to do the same. However, despite this, many children with broader ASD still passed some of these items. Thus, future research on tool development should 1) move away

from “lack of” and towards “typical/atypical” terminology, in order to identify children with more subtle or atypical presentation of symptoms, and 2) repeatedly monitor these behaviours, so that children who pass assessments at one age can still be identified at later examinations. This approach will facilitate the identification of not only those children with broader ASD, but also those children who show ‘regression’.

The results of the current study also demonstrate that an absence of even key behaviours, such as *Eye Contact* at 12-months, does not negate the possibility of a child being diagnosed with ‘broader’ ASD at 24-months, which is consistent with Landa et al.’s (2007) prospective study. Primary health care professionals thus need to be aware of this when determining risk status for autism, and be mindful that these children present with a pattern of deficits on various behaviours, which present differently across the second year of life.

Limitations

It is noted that many Fisher’s exact tests were used, which may have lead to inflated Type I error. However, this issue was addressed by using a strict *p* value of .01 for all Fisher’s tests (except at 12-months), and the percentage of ‘yes/no’ responses on the key markers of autism were clearly seen in the figures to be very different between the autism and non-autism groups.

It is unfortunate that there was quite a small sample size at 12-months, as well as the lack of a DD/LD comparison group to determine which behaviours were more specific to autism as opposed to DD/LD. Thus, the results from the 12-month analyses should be interpreted with caution. Furthermore, as a cross-sectional method was taken in this study to maximise sample numbers, it was not possible to examine change across time within individuals. In addition, while it is feasible that some of the children in this study will cross diagnostic boundaries as they age, it remains the case that children who move from a diagnosis of AD to ‘broader’ ASD nonetheless present with the ‘AD’ profile of symptoms

from 12- to 24-months, and can thus be identified on the basis of this profile. Secondly, the number of children, if any, who move off the spectrum are expected to be minimal on the basis of previous findings (Charman, et al., 2005; Lord, 1995; Paul, Chawarska, Cicchetti, & Volkmar, 2008; Stone, et al., 1999; Turner, et al., 2006). However, only a follow-up study can confirm this outcome, which is currently underway with this sample at ages 4 to 5.

Conclusions / Future Directions

Developmental surveillance of the early markers of ASDs at routine consultations undertaken at MCH centres in the SACS was successful in identifying children with an ASD, as well as some children with developmental and/or language delays (Barbaro & Dissanayake, 2010). These items were therefore identified as useful during Level 1 surveillance. However, the detailed analysis of each of these items in the current paper revealed the most discriminating markers at each age, and the predictive group of markers at 24-months, which can be used during Level 2 surveillance to more accurately identify children with autism. Across all ages, the recurring key markers of autism were *Eye Contact* and *Pointing*, and it was seen that *Social Communication* (showing) becomes an important marker at 18- and 24-months. Overall, the key markers consisted of social and joint attention behaviours, which is consistent with findings from both the retrospective and prospective studies reviewed. *Pretend Play*, although not identified as a key marker at 18-months, became an important marker at 24-months of age.

The key markers of autism also differed across the ages, and tools should therefore be tailored according to the age at which children are assessed. Future studies should also work towards identifying if sub-groups of children later diagnosed with autism emerge as showing a particular ‘pattern’ of deficits, with these sub-groups potentially showing similar deficits at similar ages. The results have also suggested that while an absence of key markers will identify the majority of children on the spectrum, the presence of any single behaviour should

not be used to negate or ‘rule out’ the possibility of an ASD, as many children later diagnosed with a ‘milder’ or ‘broader’ form of ASD will, in fact, pass some of the key items from 12- to 24-months. Due to deficit variability in children with ASDs, screening tools administered at only one age will continue to have problems with sensitivity. It is thus vital that the monitoring of the markers identified in this paper is done continually across the second year of life, which was found to be very effective in identifying young children across the spectrum of autism (Barbaro & Dissanayake, 2010).

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Appendix A

SACS 12-, 18-, and 24-month items

SACS ITEMS – 12-MONTH ASSESSMENT

1. Pointing **
Get a teddy bear, show it to the child and say "This is teddy". Then put the bear across the room (where the child can see it) and say, "Where's teddy?" Does the child point to the bear and look at your face? YES / NO

2. Waving 'bye-bye' **
Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child). Does s/he wave back? YES / NO

3. Imitation **
Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'. Does s/he imitate you? YES / NO

4. Eye contact **
Has the child spontaneously made eye contact with you during the session?
If not, interact with the child to elicit eye contact. Does s/he make eye contact with you? YES / NO

5. Response to name **
Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you) YES / NO

6. Follows point
Get the child's attention and then point to an object across the room and say 'WOW, look at that!' Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)? YES / NO

7. Social smiles
Has the child smiled while making eye contact with you? If not, smile at the child. Does s/he smile back? (Do not use physical contact to elicit a smile) YES / NO

8. Conversational babble
Does the child babble (e.g. saying agaga, adaba, mama, dada) in a conversational like manner? YES / NO

9. Speaks 1-3 words
Does the child speak 1-3 recognisable words? YES / NO

10. Cuddles
Does the child enjoy cuddles with the parent? YES / NO

11. Attending to sounds
Has the child been attending to / seem interested in sounds during the session? YES / NO

12. Understands simple instructions
Show the child a block and place it beside him/her. Then ask, "Give me the block". Does s/he give you the block? YES / NO

***** Key individual markers of autism (Autistic Disorder and Autism Spectrum Disorder) at 12-months***

SACS ITEMS – 18-MONTH ASSESSMENT

1. Pointing **
Get a teddy bear, show it to the child and say "This is teddy". Then put the bear across the room (where the child can see it) and say, "Where's teddy?" Does the child point to the bear and look at your face? YES / NO

2. Eye contact **
Has the child spontaneously made eye contact with you during the session?
If not, interact with the child to elicit eye contact. Does s/he make eye contact with you? YES / NO

3. Social communication (showing) **
Does the child try to communicate with the parent in a SOCIAL manner?
(i.e., not just to request food or an object – ask parent) YES / NO

4. Social smile *
Has the child smiled while making eye contact with you? If not, smile at the child.
Does s/he smile back? (Do not use physical contact to elicit a smile) YES / NO

5. Response to name *
Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you) YES / NO

6. Follows point *
Get the child's attention and then point to an object across the room and say 'WOW, look at that!'
Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)? YES / NO

7. Uses 5-10 words *
Does the child use 5-10 words? YES / NO

8. Understands words *
Does the child understand many more words? YES / NO

9. Imitation
Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'.
Does s/he imitate you? YES / NO

10. Pretend play
Give the child a toy cup and pot. Say "Can you pour a drink and drink it?"
Does the child pretend to pour a drink and/or drink it?
(Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy) YES / NO

11. Points to facial features
Get the child's attention. Say 'point to your eyes/nose/mouth'.
Does s/he point to his/her eyes/nose/mouth? YES / NO

12. Obeys simple instructions
Show the child a block and place it beside him/her. Then ask, "Give me the block".
Does s/he give you the block? YES / NO

13. Waving 'bye-bye'
Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child).
Does s/he wave back? YES / NO

14. Cuddles
Does the child enjoy cuddles with the parent? YES / NO

15. Affection/comfort
Does the child ever come to the parent for affection or comfort? (ask parent) YES / NO

16. Loss of skills
Ask the parent if the child has lost ANY language or social skills at ANY age.
Has the child lost any skills? YES / NO

***** Key individual markers of autism (Autistic Disorder and Autism Spectrum Disorder) at 18-months***
**** Key individual markers of Autistic Disorder <u>only</u> at 18-months***

SACS ITEMS – 24-MONTH ASSESSMENT

1. Pointing # **
Get a teddy bear, show it to the child and say "This is teddy". Then put the bear across the room (where the child can see it) and say, "Where's teddy?" Does the child point to the bear and look at your face? YES / NO

2. Eye contact # **
Has the child spontaneously made eye contact with you during the session?
If not, interact with the child to elicit eye contact. Does s/he make eye contact with you? YES / NO

3. Social communication (showing) # **
Does the child try to communicate with the parent in a SOCIAL manner?
(i.e., not just to request food or an object – ask parent) YES / NO

4. Pretend play # **
Give the child a toy cup and pot. Say "Can you pour a drink and drink it?"
Does the child pretend to pour a drink and/or drink it?
(Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy) YES / NO

5. Waving 'bye-bye' **
Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child).
Does s/he wave back? YES / NO

6. Follows simple commands *
Show child a teddy bear and place it beside him/her. Then ask, "Give me teddy".
Does s/he give you the teddy? YES / NO

7. Follows point *
Get the child's attention and then point to an object across the room and say 'WOW, look at that!'
Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)? YES / NO

8. Social smile *
Has the child smiled while making eye contact with you? If not, smile at the child.
Does s/he smile back? (Do not use physical contact to elicit a smile) YES / NO

9. Response to name *
Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you) YES / NO

10. Loss of skills *
Ask the parent if the child has lost ANY language or social skills at ANY age.
Has the child lost any skills? YES / NO

11. Uses 20 -50 words
Does the child use 20 – 50 words? YES / NO

12. 2-word utterances
Does the child use some two-word phrases (e.g., want drink)? YES / NO

13. Parallel play
Does the child play near (not necessarily with) other children? (ask parent) YES / NO

14. Imitation
Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'.
Does s/he imitate you? YES / NO

15. Affection/comfort
Does the child ever come to the parent for affection or comfort? (ask parent) YES / NO

 # Group predictors of a diagnosis of autism (Autistic Disorder and Autism Spectrum Disorder) at 24-months
***** Key individual markers of autism (Autistic Disorder and Autism Spectrum Disorder) at 24-months***
**** Key individual markers of Autistic Disorder only at 24-months***

PAPER 5

DEVELOPMENTAL PROFILES OF INFANTS AND TODDLERS WITH ASDs

Paper 5

Developmental profiles of infants and toddlers with Autism Spectrum Disorders prospectively identified in a community-based setting

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Abstract

The few studies conducted to date on the very early cognitive development of children with Autism Spectrum Disorders (ASDs) have used samples of siblings of children with ASDs or clinic-referred samples. It is therefore important to ascertain whether the findings from these studies are generalisable to children identified from community-based samples. The aim in the current prospective, longitudinal, study was to chart the developmental profiles of children with ASDs identified through routine developmental surveillance during the second year of life. A total of 110 children with Autistic Disorder (AD), 'broader' ASD, and developmental and/or language delays (DD/LD) were assessed using the Mullen Scales of Early Learning (MSEL; Mullen, 1995) at 12-, 18-, and 24-months of age. It was found that children with AD and broader ASD performed poorly on the language subscales of the MSEL in comparison to the nonverbal subscales, with a particular weakness in Receptive Language. The children with broader ASD displayed a similar developmental profile to children with DD/LD, with their profiles only differing in their Receptive Language abilities at 24-months of age. Thus, it was argued that Receptive Language was a core cognitive impairment that may determine whether a child will develop autism or DD/LD without autism. In addition, overall performance on the MSEL was seen to decline across time in the children with ASDs due to developmental stagnation. These findings highlight the urgency of identifying these children and intervening as early as possible to affect changes during this critical period of development.

Developmental profiles of infants and toddlers with Autism Spectrum Disorders prospectively identified in a community-based setting

Autism Spectrum Disorders (ASDs) are complex developmental disorders, with symptoms initially manifesting over the first 2 to 3 years of life (DSM-IV-TR; American Psychiatric Association, 2000). This period of development sees the most dynamic changes in symptoms of ASDs, given the rapid development of cognitive, social, and communication skills in children over the first 3 years of life (Chawarska, Klin, Paul, Macari, & Volkmar, 2009; Turner, Stone, Pozdol, & Coonrod, 2006). The combined ASDs (Autistic Disorder, [AD]; Asperger's Disorder, [AspD]; Pervasive Developmental Disorder-Not Otherwise Specified, [PDD-NOS]) affect approximately 1% of the population (Baird et al., 2006; Centers for Disease Control and Prevention (CDC), 2009; Kogan et al., 2009), with a wide range of functioning amongst affected individuals. Historically, co-morbid intellectual disability (ID) was reported to affect approximately 70% of individuals with autism (DSM-IV; American Psychiatric Association, 1994). However, given the broadening of diagnostic criteria and concomitant increase in diagnosis of ASDs in recent years, particularly amongst those with 'milder' symptoms (Bryson, Rogers, & Fombonne, 2003; Wing & Potter, 2002), this figure has decreased, with the latest CDC (2009) data indicating that approximately 41% to 44% of individuals on the entire spectrum have a co-morbid ID.

Early markers of ASDs have been investigated through various techniques, such as retrospective videotape and parent report studies, as well as prospective studies, including community-based, clinic-referred, and high-risk sibling studies. These markers have been used to undertake screening with, for example, the CHAT (Baron-Cohen et al., 1996), the ESAT (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006), and the M-CHAT (Robins, 2008), and during developmental surveillance (e.g., the SACS; Barbaro & Dissanayake, 2010). The ultimate goal of these studies was to identify children at the earliest

possible opportunity, given the importance of early intervention (Dawson, 2008; Rogers & Vismara, 2008). Accordingly, there has been much attention focused on identifying the earliest and most predictive early markers of ASDs, with considerably less attention on children's early cognitive profiles. It is important to chart the development of early verbal and nonverbal skills to not only ascertain overall developmental levels, but also to understand how the developmental profiles of children with ASDs change during their early years. This knowledge will provide necessary information about when intervention should begin and in which critical areas. It may also give an indication of what the developmental outcomes may be (Leekam, 2007). For example, Wetherby, Watt, Morgan, and Shumway (2007) found that in children with an ASD, language comprehension at 18- to 24-months of age was the strongest predictor of developmental outcome (both verbal and nonverbal) at 3 years. Furthermore, nonverbal ability in 2-year-old children with an ASD was found by Thurm, Lord, Lee, and Newschaffer (2007) to be the best predictor of developing functional language at age 5, indicating the close association between cognitive ability and language capacities.

It has long been reported that the cognitive and language skills of preschoolers and older children with an ASD are impaired, with those with 'AD' possessing the poorest verbal and nonverbal skills (Coolican, Bryson, & Zwaigenbaum, 2008; Wing, 1981). Furthermore, many of these children display "developmental dissociation", showing a substantial difference in the rate of development in various skill areas (Childers, 2006; Jordan, 2002). This uneven cognitive profile finds some children with skills in the normal or above normal range, with other skills in the severely impaired range. Generally, the standard cognitive profile is of disproportionate strengths in visual and nonverbal skills, relative to verbal skills (Akshoomoff, 2006; Charman, Drew, Baird, & Baird, 2003; Coolican et al., 2008; Joseph, Tager-Flusberg, & Lord, 2002; Lord & Paul, 1997; Tager-Flusberg & Joseph, 2003; Thurm et al., 2007). This is perhaps unsurprising, given that the earliest concerns of parents tend to be

deficits in speech and language (De Giacomo & Fombonne, 1998), as opposed to motor or visual reception skills.

Recently, Lennen, Lamb, Dunagan, and Hall (2010) did not find this verbal-nonverbal discrepancy amongst the majority of their sample with ASDs (mean age: 7 years), which is consistent with the findings from an older study by Siegel, Minshew, and Goldstein (1996). However, a subgroup (20%) did show the typically reported pattern, with increased strength in the nonverbal domain for the AD group. Furthermore, although Paul, Chawarska, Cicchetti, and Volkmar (2008) found the discrepant verbal-nonverbal profile in their sample of toddlers with ASD (mean age: 22 months), they did not find this disassociation when the children were re-assessed 2 years later. Thus, by age 4, their language skills seemed to "catch-up" to their nonverbal abilities. In light of these findings, it is important to prospectively investigate the cognitive profiles of children with ASDs from infancy to toddlerhood and beyond. Due to the relatively recent capability of identifying children on the spectrum from 12-months of age, there have been few studies that have investigated the cognitive profiles of very young children on the spectrum; these have mainly focused on high-risk siblings (ASD-sibs) or clinic-referred samples.

Landa and Garrett-Mayer (2006) conducted the first prospective, longitudinal, study of cognitive development in ASD-sibs from 6- to 24-months of age. They used the Mullen Scales of Early Learning (MSEL; Mullen, 1995) to measure Gross and Fine Motor abilities, Visual Reception, and Receptive and Expressive Language. No differences were found between the groups (unaffected, ASD, and language delayed [LD]) at 6-months. However, at both 14- and 24-months, children in the ASD group had lower scores than the unaffected children on all scales (except Visual Reception at 14-months). Moreover, at 24-months, children in the ASD group performed worse than children in the LD group on Gross Motor, Fine Motor, and Receptive Language abilities. Within the ASD group, the lowest

standardised scores at both 14- and 24-months were on Receptive Language, with significantly higher scores in the nonverbal domains. In contrast, children in the unaffected group had a more even cognitive profile. Landa and Garrett-Mayer (2006) also found a significant decrease in the ASD group on overall MSEL performance between 14- to 24-months of age. This "developmental worsening" has been found in a subsequent study of ASD-sibs by Landa, Holman, and Garrett-Mayer (2007), and was corroborated by Bryson et al. (2007).

Other studies that have used the MSEL with toddlers with ASDs all indicate a similar cognitive profile to that described above (Carter et al., 2007; Mitchell et al., 2006; Ventola et al., 2007). That is, overall cognitive skills in children with ASDs are lower than controls (developmentally/language delayed, non-ASD siblings, and low-risk controls), with the strongest performance on the nonverbal, over verbal, scales. Moreover, receptive language is characteristically more impaired than expressive language amongst the children with ASDs. This disjunction between comprehension and production contrasts with the language profile of typically developing children, where acquisition of spoken words lags behind comprehension (Fenson et al., 1994; Hudry et al., 2010).

The most recent study by Hudry et al. (2010), focusing specifically on receptive and expressive language in 152 preschoolers with ASD, found that receptive language was more impaired than expressive, although there was much individual variability across the sample. Therefore, children with ASDs typically understood fewer words than expected based on their expressive language skills, which is consistent with studies with older children (Charman et al., 2003; Eisenmajer et al., 1998; Kjelgaard & Tager-Flusberg, 2001; Luyster, Kadlec, Carter, & Tager-Flusberg, 2008).

Chawarska and colleagues also conducted prospective, longitudinal, studies investigating the cognitive profiles of toddlers on the spectrum, utilising samples of clinic-referred children. In their study of a small number of toddlers with PDD-NOS (n = 9) and ASD (n = 19), Chawarska, Klin, Paul, and Volkmar (2007) found that toddlers later diagnosed with an ASD have severely delayed verbal skills and moderately delayed nonverbal skills. In addition, although the two groups showed comparable verbal and nonverbal MSEL T scores at Time 1 (age range: 14- to 25-months), those with PDD-NOS had superior verbal and nonverbal skills compared to the ASD group at age 3, and an increased rate of verbal skill acquisition.

In a larger study (N = 89), Chawarska et al. (2009) included AD, PDD-NOS, and non-ASD groups. Children in the AD group were found to have the lowest verbal and nonverbal developmental quotient (DQ) scores. At Time 1 (mean age: 21.5-months), both the AD and PDD-NOS groups had lower verbal DQ than nonverbal DQ scores. At Time 2 (mean age: 47.9-months), verbal DQ continued to be lower than nonverbal DQ in the AD group only; verbal and nonverbal DQs were even in the non-ASD groups at Time 1 and 2. In the group with a stable AD diagnosis from Time 1 to 2, receptive language was more impaired than expressive language skills. Thus, Chawarska et al. (2009) also detected the verbal-nonverbal discrepancy in their sample of toddlers with ASDs, with receptive language the most severely impaired skill.

To date, no study has focused on the cognitive profiles of young children identified prospectively in a community-based sample. The findings from high-risk sibling studies and studies using clinic-referred children may not be applicable to those children identified via developmental surveillance or primary level screening. Therefore, the aim in the current longitudinal study was to investigate the developmental profiles of children with ASDs from 12- to 24-months, who had been prospectively identified through developmental surveillance

in a large community-based sample (Barbaro & Dissanayake, 2010; Barbaro, Ridgway, & Dissanayake, 2010). It was hypothesised that children with autism (both AD and 'broader' ASD) would perform below age-appropriate norms on the MSEL, and lower than a developmentally and/or language delayed comparison group on their overall performance. It was also expected that the children with autism will have an uneven cognitive profile, performing more poorly on verbal (Receptive and Expressive) relative to nonverbal (Visual Reception and Fine Motor) skills. Furthermore, it was predicted that these children will have poorer Receptive than Expressive Language skills. Following Landa et al.'s (2007) and Bryson et al.'s (2007) findings, it was also hypothesised that the children with AD and 'broader' ASD will show a decline in their cognitive abilities from 12- to 24-months of age.

Method

Participants

Participants in the current study were drawn from a cohort of 20,770 community-based participants monitored in metropolitan Melbourne, Victoria, as part of the Social Attention and Communication Study (SACS; Barbaro & Dissanayake, 2010; Barbaro et al., 2010). A total of 110 children were assessed at the Child Development Unit at La Trobe University. These children were referred by their Maternal and Child Health nurse after being identified by a SACS checklist as 'at risk' for an ASD (see Barbaro & Dissanayake, 2010, for further details).

Children were referred from 12-months onward, and assessed at 6-monthly intervals until 24-months of age, when a diagnostic assessment was conducted. Eight children were assessed at all three times points (12-, 18-, and 24-months), 30 children were assessed at two time points (at 18- and 24-months), and 72 children were assessed at only one time point (2 at 12-months, 8 at 18-months, 62 at 24-months); thus, a total of 156 assessments were conducted. The average time between referral and assessment was just over 3 weeks.

Children's diagnostic status was determined at 24-months using a combination of Module 1 (pre-verbal) of the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000; Lord, Rutter, DiLavore, & Risi, 1999), and the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), as well as clinical judgment by both authors. The first author (JB) was trained to research reliability on both instruments. Diagnoses of ASDs at 24-months have been found to be both accurate and stable over time using the ADI-R and the ADOS together, and in combination with clinical judgment (Barbaro & Dissanayake, 2009; Charman et al., 2005; Chawarska et al., 2009; de Bildt et al., 2004; Le Couteur, Haden, Hammal, & McConachie, 2008; Lord, 1995; Stone et al., 1999; Turner et al., 2006). Children were classified as AD (Autistic Disorder), ASD (Autism Spectrum Disorder; children showing signs of 'broader' ASD, but not meeting criteria for AD)[1], DD/LD (developmental and/or language delay), or TD (typically developing)[2].

Table 1 presents the sample characteristics at each assessment, including the verbal and nonverbal T scores from the MSEL (Mullen, 1995). The AD group had the lowest verbal T scores at 18- and 24-months, and poorer nonverbal T scores than the ASD group 24-months. There were no significant differences in chronological age between the groups. The Socio Economic Status of the 17 Local Government Areas (LGAs) the sample resided in was mostly high, with the mean Socio-Economic Indexes for Areas (SEIFA) score (M = 1066) being slightly higher than the mean SEIFA score of the whole of metropolitan Melbourne (M = 1033).

[1] The term "autism" will be used throughout to refer to both children with AD and ASD.
[2] Only one typically developing child was referred and assessed at 18- and 24-months; however, this child was excluded from all tables, figures, and analyses.

Table 1

*Sample Characteristics (Mean, SD, 95% CIs) at the 12-, 18-, and 24-month Assessments (N = 154)**

	Group		
	AD (*n* = 56)	ASD (*n* = 69)	DD/LD (*n* = 29)
12m assessment	*n* = 3	*n* = 6	*n* = 1
Chronological age (months)	13.7 (1.2)	12.7 (0.5)	15.0 (-)
Mental age (months)	10.6 (3.6) ± 4.1	10.3 (2.2) ± 1.8	12.3 (-)
T score – Verbal	29.7 (4.0) ± 4.5	34.5 (8.3) ± 6.6	24.0 (-)
T score – Nonverbal	36.7 (12.5) ± 14.1	40.8 (8.8) ± 7.0	50.0 (-)
18m assessment	*n* = 16	*n* = 21	*n* = 8
Chronological age (months)	19.2 (1.0)	19.1 (1.2)	19.9 (1.6)
Mental age (months)	13.2 (1.9) ± 0.9	14.8[a] (1.8) ± 0.8	15.4[a] (1.5) ± 1.0
T score – Verbal	23.5 (2.8) ± 1.3	27.9[b] (3.5) ± 1.5	30.2[b] (2.9) ± 2.0
T score – Nonverbal	40.8 (9.0) ± 4.4	41.9 (10.0) ± 4.3	39.5 (6.2) ± 4.3
24m assessment	*n* = 37	*n* = 42	*n* = 20
Chronological age (months)	25.2 (1.6)	25.6 (2.2)	25.8 (2.7)
Mental age (months)	15.1 (2.5) ± 0.8	18.6[b] (2.9) ± 0.9	19.5[b] (3.3) ± 1.4
T score – Verbal	22.1 (2.5) ± 0.8	29.0[b] (7.3) ± 2.2	32.4[b] (7.2) ± 3.2
T score – Nonverbal	33.4 (8.2) ± 2.6	38.3[a] (7.9) ± 2.4	37.2 (9.6) ± 4.2
Gender (Male – Female)	41 – 15	59 – 10	20 – 9

Note. SD = Standard Deviation; CIs = Confidence Intervals; AD = Autistic Disorder; ASD = Autism Spectrum Disorder; DD/LD = Developmental and/or Language Delay

* One typically developing child, referred and assessed at 18- and 24-months, has been excluded

[a] Significantly different from AD, $p < .05$; [b] $p < .01$

Procedure

Developmental status was assessed at 12-, 18-, and 24-months of age using the MSEL (Mullen, 1995). The MSEL measures early development, yielding T Scores and Age Equivalent (AE) scores on five subscales: *Gross Motor* (not measured in this study), *Visual Reception (VR), Fine Motor (FM), Receptive Language (RL),* and *Expressive Language (EL).* The T scores from the *VR* and *FM* subscales, and the *RL* and *EL* subscales, were averaged to form the nonverbal and verbal T scores, respectively, which were presented in Table 1.

Developmental quotient (DQ) scores were also calculated for each separate subscale, and further combined into an *Overall DQ* score, to determine levels of functioning. The DQ scores are based on the AE scores and calculated from the formula: (AE/Chronological Age)*100). The MSEL was administered in a standardised format, with all assessments conducted in the same laboratory playroom. Children were seated at a child-sized table, with the examiner seated opposite the child. A parent/caregiver was seated behind the child during all assessments.

Results

Developmental Profiles

Analyses were not conducted on the measures taken at 12-months due to low participant numbers. Thus, only interpretations of the mean scores between the AD and ASD groups are presented below. Profile analysis (Tabachnick & Fidell, 2007) was used to compare the cognitive profiles of the three groups at both 18-months and 24-months using 3 x 4 mixed-model repeated measures ANOVAs. Group membership (AD, ASD, DD/LD) was the between-subjects variable, and MSEL subscale DQ (VR, FM, RL, EL) was the within-subjects variable.

The test of “parallelism” is the primary question addressed by profile analysis, and investigates whether the different groups have parallel profiles. The interaction effect of the repeated measures ANOVA represents a test of parallelism of the DQ profiles. The “levels” test investigates the overall difference between groups, regardless of whether the profiles are parallel or not. The group effect of the repeated measures ANOVA represents a test of equality of the levels of the DQ profiles. The test of “flatness” addresses the similarity of response to all DVs, independent of groups; however, this effect is only relevant if profiles are parallel, and was thus not reported if there were no interaction effects. When significant differences were found in level, parallelism, or flatness, follow-up simple main effects

analysis of (a) group differences for each subscale DQ, and (b) subscale DQ differences within each group, were conducted.

Where simple main effects were significant, post-hoc Tukey HSD pairwise comparisons were conducted. Effect size was judged based on Cohen's (1988) criteria: η^2 of .01 as a small effect; η^2 of .09 as a medium effect, and η^2 of .25 as a large effect. An alpha level of .05 was used. The assumptions for repeated measures ANOVA were met: tests of normality were within acceptable limits, the sphericity assumption was not violated, and trimmed means, outliers, histograms and boxplots were inspected and also deemed to be within normal limits.

12-months. It is apparent from Figure 1 that the small number of children with AD and ASD assessed had very similar developmental profiles. Overall, children with AD and ASD showed stronger performance on nonverbal skills than on verbal skills. In particular, *Fine Motor* was an area of strength in each group, with DQ scores around population norms (100), while both groups had the lowest mean scores on *Receptive Language*.

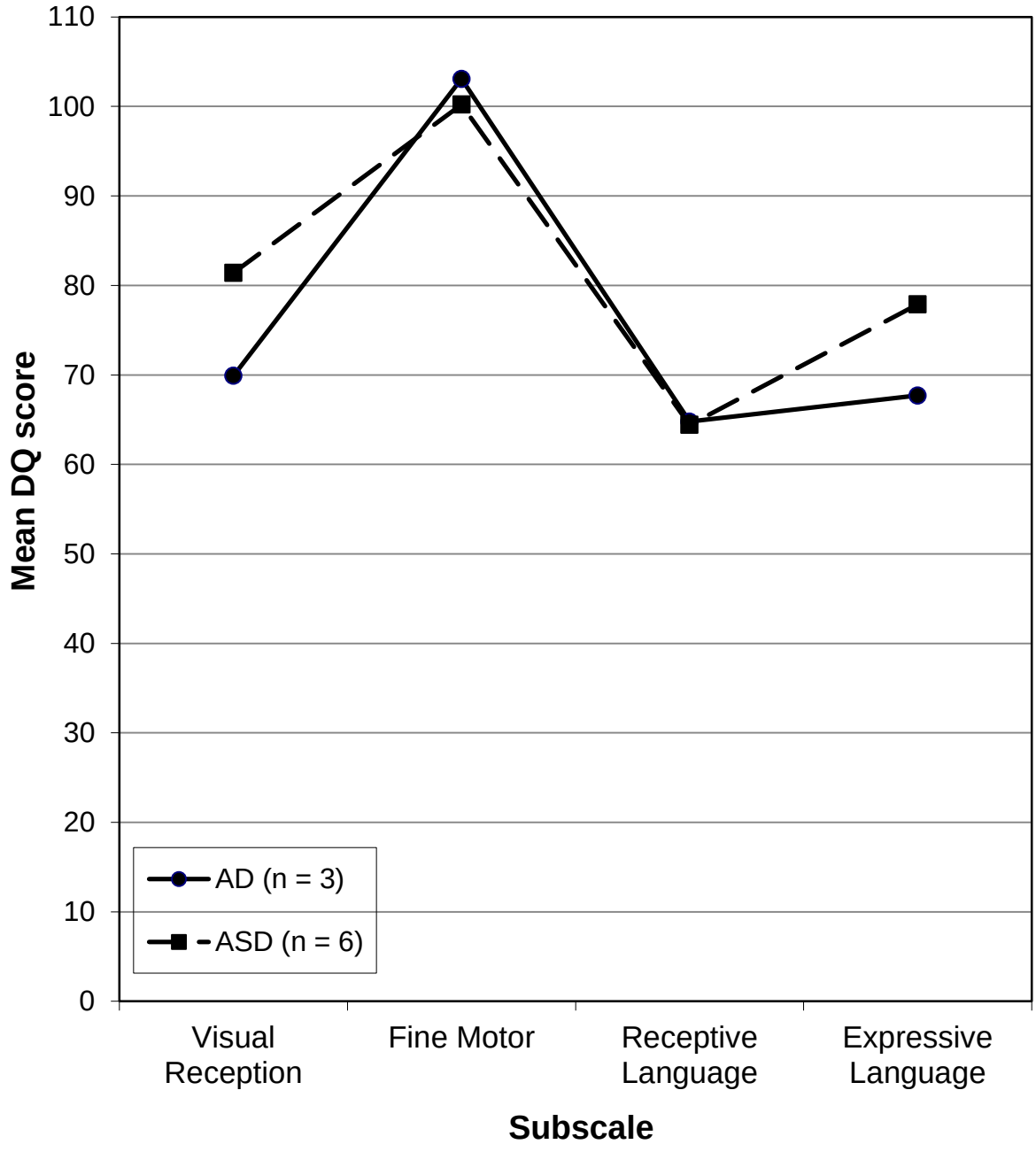

Figure 1. Developmental profiles at 12-months for the AD and ASD groups. Mean DQ scores presented.

18-months. Mean DQs ± standard error of the mean (SEM) for each of the MSEL subscales at 18-months are presented in Figure 2. The profile analysis revealed significant differences between the groups for the levels test, $F(3, 40) = 4.47$, $p = .017$, $\eta^2 = .18$. Furthermore, there was a significant interaction between group and subscale DQ, $F(6, 80) = 2.39$, $p = .035$, $\eta^2 = .15$, indicating that the profiles of the three groups were not parallel.

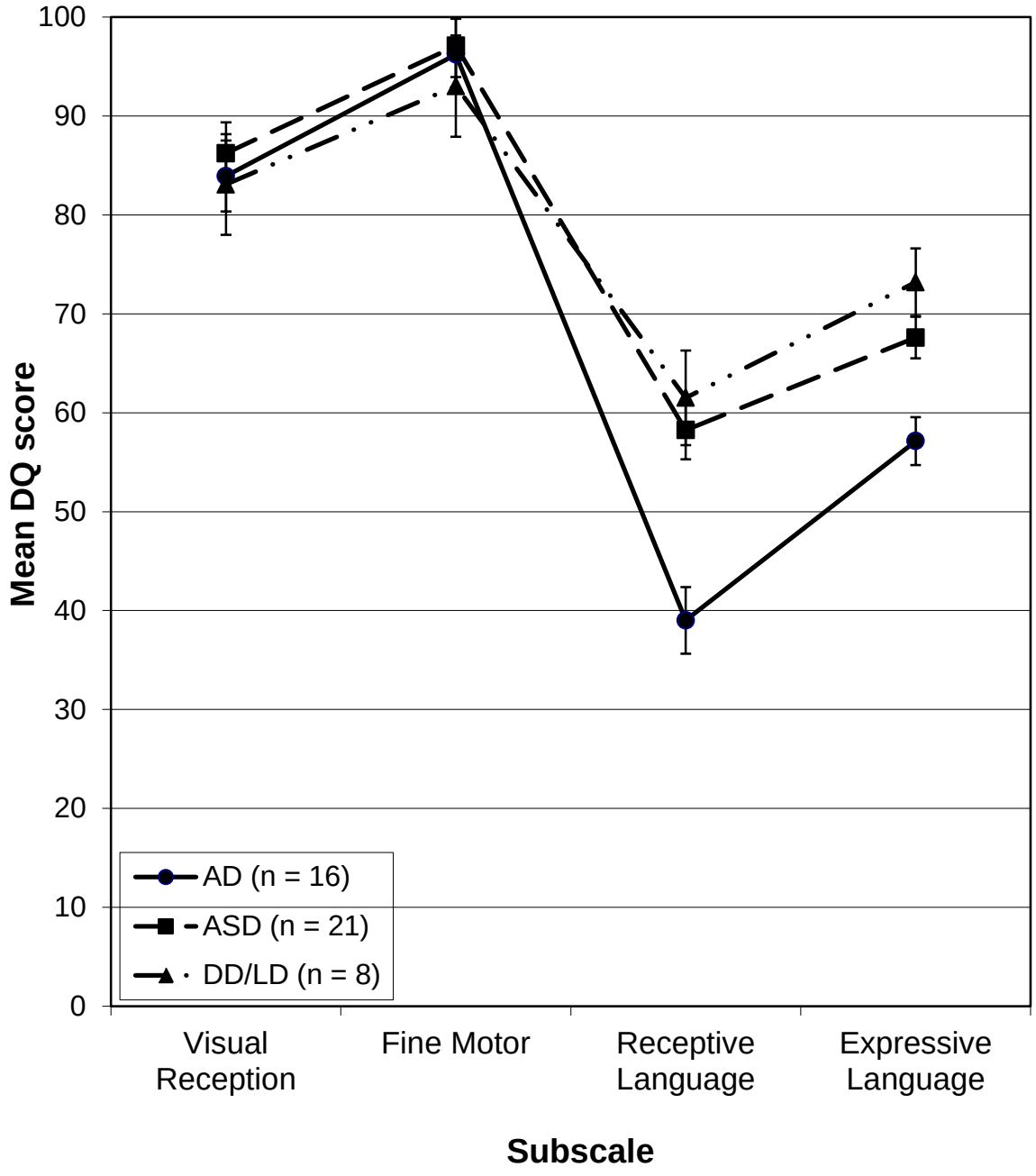

Figure 2. Developmental profiles at 18-months for each group. Mean DQ scores ± SEM presented.

Simple main effects analyses were conducted to examine group differences for each subscale DQ. There were no significant group differences for *Visual Reception*, $F(3, 40) = .189$, $p = .829$, $\eta^2 = .01$, and *Fine Motor*, $F(3, 40) = .229$, $p = .796$, $\eta^2 = .01$. However, groups significantly differed on *Receptive Language*, $F(3, 40) = 11.61$, $p < .001$, $\eta^2 = .36$, and *Expressive Language*, $F(3, 40) = 8.93$, $p < .010$, $\eta^2 = .30$ at 18-months.

Post hoc analyses revealed significant differences between the AD and ASD groups ($p < .001$) and the AD and DD/LD groups ($p < .010$) on *Receptive Language*, with the AD group performing most poorly on this subscale in comparison to the other two groups. There were also significant differences between the AD and ASD groups ($p = .006$) and the AD and DD/LD groups ($p < .010$) on their *Expressive Language* skills, with the AD group again showing the lowest scores, followed by the ASD and DD/LD groups. No significant differences were found at 18-months between the ASD and DD/LD groups on *Receptive Language* ($p = .830$) or *Expressive Language* ($p = .352$).

Simple main effects analyses also revealed significant within group differences across the four subscale DQs for each of the groups (AD: $F(3, 40) = 54.72$, $p < .001$, $\eta^2 = .80$; ASD: $F(3, 40) = 35.29$, $p < .001$, $\eta^2 = .73$; DD/LD: $F(3, 40) = 8.82$, $p < .001$, $\eta^2 = .40$). Posthoc analyses revealed differences between all subscales for all groups (all $p < .050$); the only exception was between *Visual Reception* and *Expressive Language* for the DD/LD group ($p = .072$). Consistent with the 12-month results, the autism groups had the lowest scores on the verbal subscales, particularly on *Receptive Language*, and all groups showed the highest performance in *Fine Motor* skills (see Figure 2).

24-months. Mean DQs ± SEM on each of the MSEL subscales at 24-months are presented in Figure 3. The profile analysis revealed significant differences between the groups for the levels test, $F(3, 94) = 20.65$, $p < .001$, $\eta^2 = .30$. Furthermore, there was a significant interaction between group and subscale DQ, $F(6, 188) = 5.69$, $p < .001$, $\eta^2 = .15$, indicating that the profiles of the three groups were not parallel.

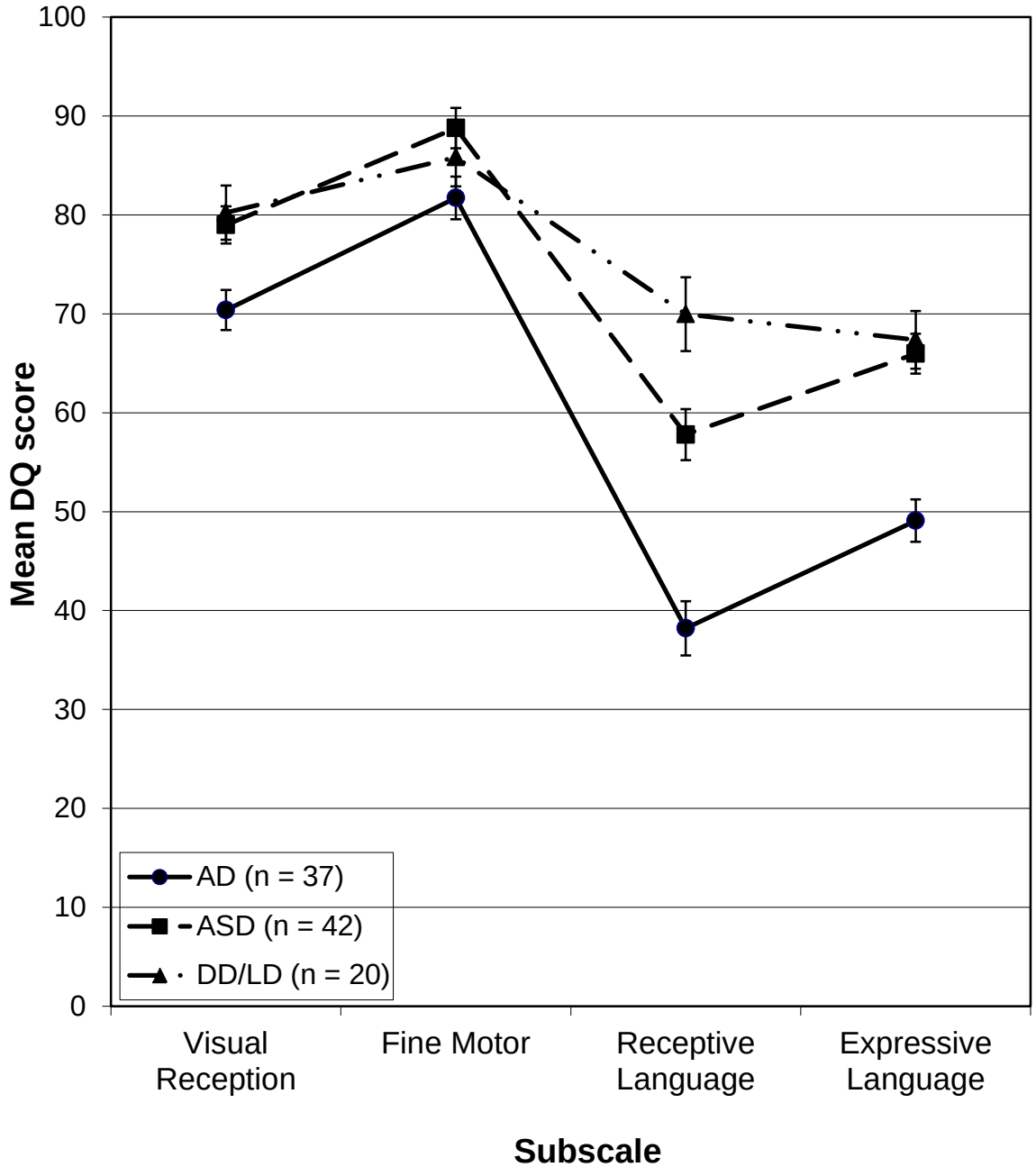

Figure 3. Developmental profiles at 24-months for each group. Mean DQ scores ± SEM presented.

Simple main effects analyses were conducted to examine group differences for each subscale DQ. The groups were significantly different on *Visual Reception, F*(3, 94) = 6.32, $p = .003$, $\eta^2 = .12$, *Receptive Language, F*(3, 94) = 26.61, $p < .001$, $\eta^2 = .36$, and *Expressive Language*, *F*(3, 94) = 20.51, $p < .001$, $\eta^2 = .30$. Once again, there were no significant group differences on the *Fine Motor* subscale, *F*(3, 94) = 2.82, $p = .064$, $\eta^2 = .06$.

Post hoc analyses revealed significant differences between the AD and ASD groups ($p = .007$) and the AD and DD/LD groups ($p = .013$) on their *Visual Reception* skills; however, no significant differences were found between the ASD and DD/LD groups ($p = .926$). All groups differed significantly from each other on their *Receptive Language* skills (AD v ASD, $p < .001$; AD v DD/LD, $p < .001$; ASD v DD/LD, $p = .023$), where children with DD/LD had the highest mean scores and those with AD had the lowest scores. The AD group again performed poorly on *Expressive Language* compared to the ASD and DD/LD groups (both $p < .001$), who were not differentiated on this subscale ($p = .920$). Once again, it is evident that the children with AD performed most poorly overall on the MSEL.

Simple main effects analyses also revealed significant within group differences across the four subscale DQs for each of the groups (AD: *F*(3, 94) = 81.55, $p < .001$, $\eta^2 = .72$; ASD: *F*(3, 94) = 44.44, $p < .001$, $\eta^2 = .59$; DD/LD: *F*(3, 94) = 9.54, $p < .001$, $\eta^2 = .23$). Consistent with the 18-month data, posthoc analyses revealed these differences were between all subscales for all groups (all $p < .05$); the only exception was between *Receptive Language* and *Expressive Language* for the DD/LD group ($p = .434$). Consistent with the results from 18-months, the highest performance was seen in *Fine Motor*, with poorest performance on the *Receptive Language* subscale in the autism groups (see Figure 3).

Developmental Change Across Time

Overall DQ. A group (3) x time (2) repeated measures ANOVA was undertaken to investigate developmental change in *Overall DQ*, from 18- to 24-months. Group differences were also investigated at both 18- and 24-months. Again, due to the small numbers, the 12-month data are added to Figure 4 for reference, but were not analysed. As only the data on those children who were seen at both 18- and 24-months were included in the analyses, the sample sizes for each group are reduced.

Analysis of the *Overall DQ* scores revealed a significant main effect for group, $F(2, 34) = 9.00$, $p < .010$, $\eta^2 = .35$, and a significant interaction, $F(2, 34) = 4.22$, $p = .023$, $\eta^2 = .20$. Simple main effects analyses indicated that the groups significantly differed on *Overall DQ* at both 18-months, $F(2, 34) = 3.81$, $p = .032$, $\eta^2 = .18$, and 24-months $F(2, 34) = 11.67$, $p < .001$, $\eta^2 = .41$. Pairwise comparisons revealed a significant difference between the AD and ASD groups at 18-months ($p = .036$) and 24-months ($p = .003$), and between the AD and DD/LD group at 24-months ($p < .001$); no difference was found between the AD and DD/LD groups at 18-months ($p = .134$). Furthermore, there were no differences between the ASD and DD/LD groups at 18- or 24-months ($p = .978$ and .313, respectively). As is evident in Figure 4, the children with AD had the lowest *Overall DQ* scores at both 18- and 24-months.

Simple main effects analyses also revealed that the AD group showed a significant decrease in their *Overall DQ* from 18- to 24-months, $F(1, 34) = 9.83$, $p = .004$, $\eta^2 = .22$. However, the *Overall DQ* for children in the ASD group, $F(1, 34) = 1.99$, $p = .167$, $\eta^2 = .06$, and DD/LD group, $F(1, 34) = 1.61$, $p = .213$, $\eta^2 = .05$, did not change significantly across time.

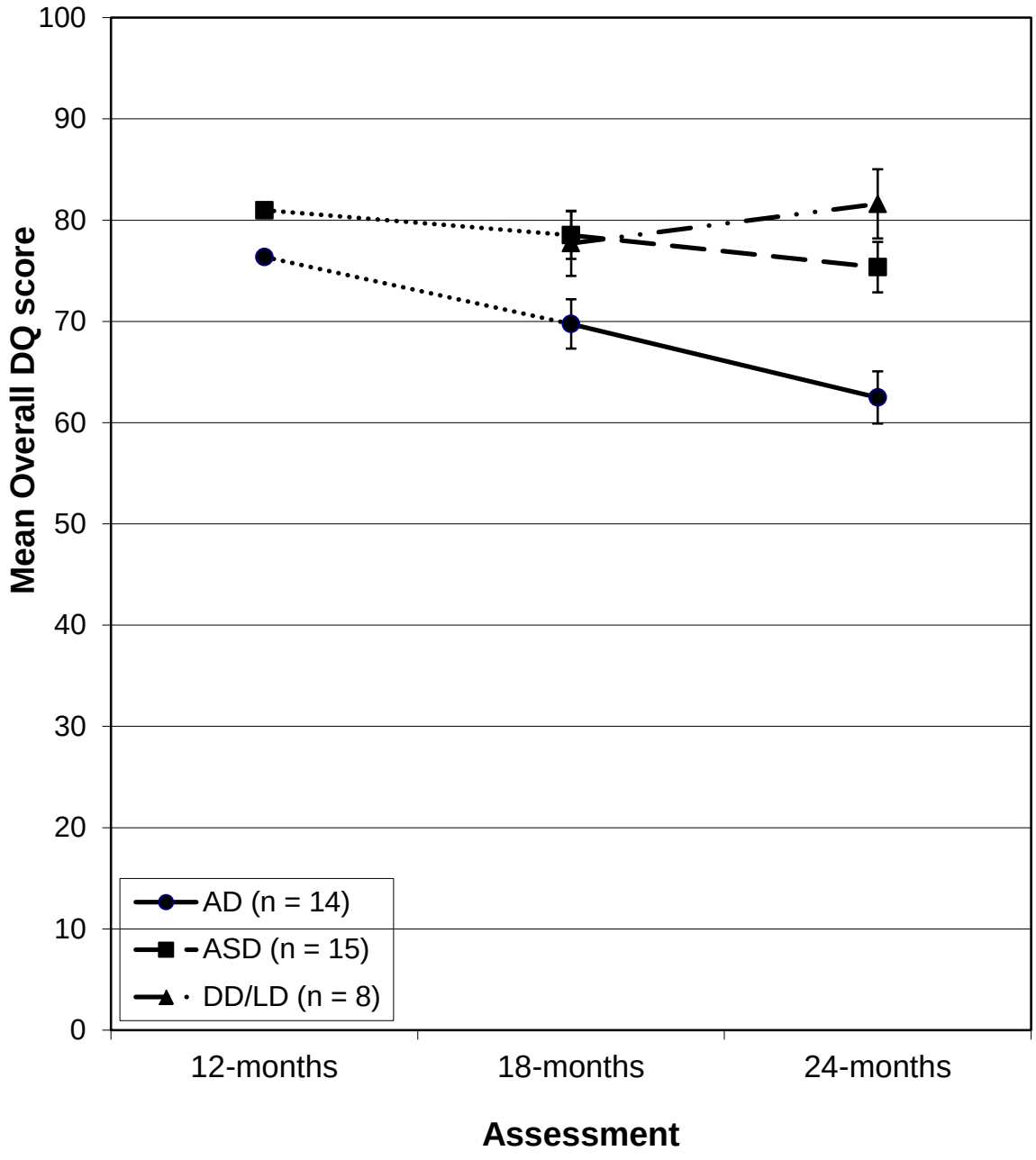

Figure 4. Mean changes (± SEM) in *Overall DQ* scores from 12- to 24-months for each group.

It is also apparent from Figure 4 that at 12-months, the children in each of the autism groups have *Overall DQs* above 70, and they are thus not showing an overall developmental delay at this age[3]. However, at 18-months, the mean DQ of the AD group has decreased to 70, while the ASD group maintains their overall DQ of approximately 80, which is similar to the DD/LD group. Thus, neither of these latter groups demonstrate overall developmental delay at 18-months. At 24-months, the AD group shows an additional decrease in their *Overall DQ*, moving even further away from the other groups, descending toward an *Overall DQ* of 60. The ASD and DD/LD groups, although on the lower end of average, are not performing below the threshold of 70 to be considered as having overall developmental delay.

In view of the findings from the analysis of *Overall DQ*, it was of interest to examine the separate subscales of the MSEL to determine which specific subscales were driving the changes across time. Hence, four group (3) x time (2) repeated measures ANOVAs were used to investigate developmental change on each of the MSEL subscales, from 18- to 24-months. The effects of group are not reported here as they mirrored those in the preceding profile analyses. Given the number of separate ANOVAs conducted, a Bonferroni correction was considered to control for Type I error; however, as the sample sizes were small, a *p* value of .05 was maintained, and effect sizes were emphasised.

[3] An *Overall DQ* of 70 or below is considered an overall developmental delay, with performance significantly below average (Jordan, 2002).

Visual Reception. The repeated measures ANOVA revealed a significant main effect for time for *Visual Reception* abilities, $F(1, 34) = 4.95$, $p = .033$, which contained a medium effect size ($\eta^2 = .13$). The interaction effect was not significant, $F(2, 34) = 1.45$, $p = .249$, $\eta^2 = .08$; however, it is apparent from Figure 5 that both of the autism groups displayed a decrease in their DQ scores from 18- to 24-months, while the DD/LD group maintained their DQ during this time.

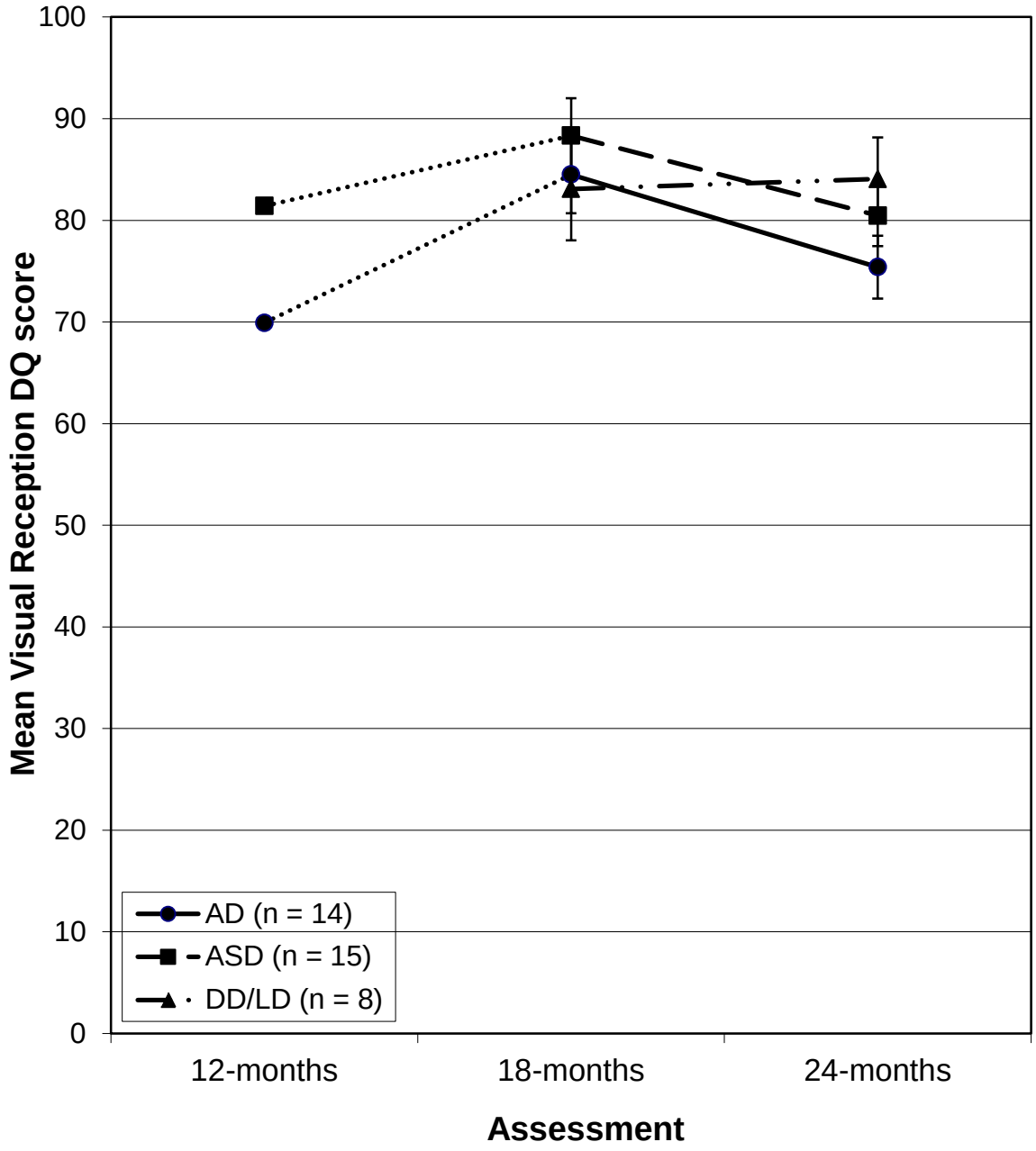

Figure 5. Mean changes (± SEM) in *Visual Reception* DQ scores from 12- to 24-months for each group.

Fine Motor. A significant main effect for time was found for *Fine Motor* skills, $F(1, 34) = 9.73$, $p = .004$, with a large effect size ($\eta^2 = .22$). However, the interaction effect was not significant, $F(2, 34) = 1.38$, $p = .267$, $\eta^2 = .08$. Figure 5 shows that the two autism groups performed at around population norms for this skill at 18-months, with DQs around 100; however, a decrease in skills is evident amongst these two groups towards 24-months, particularly amongst children with AD.

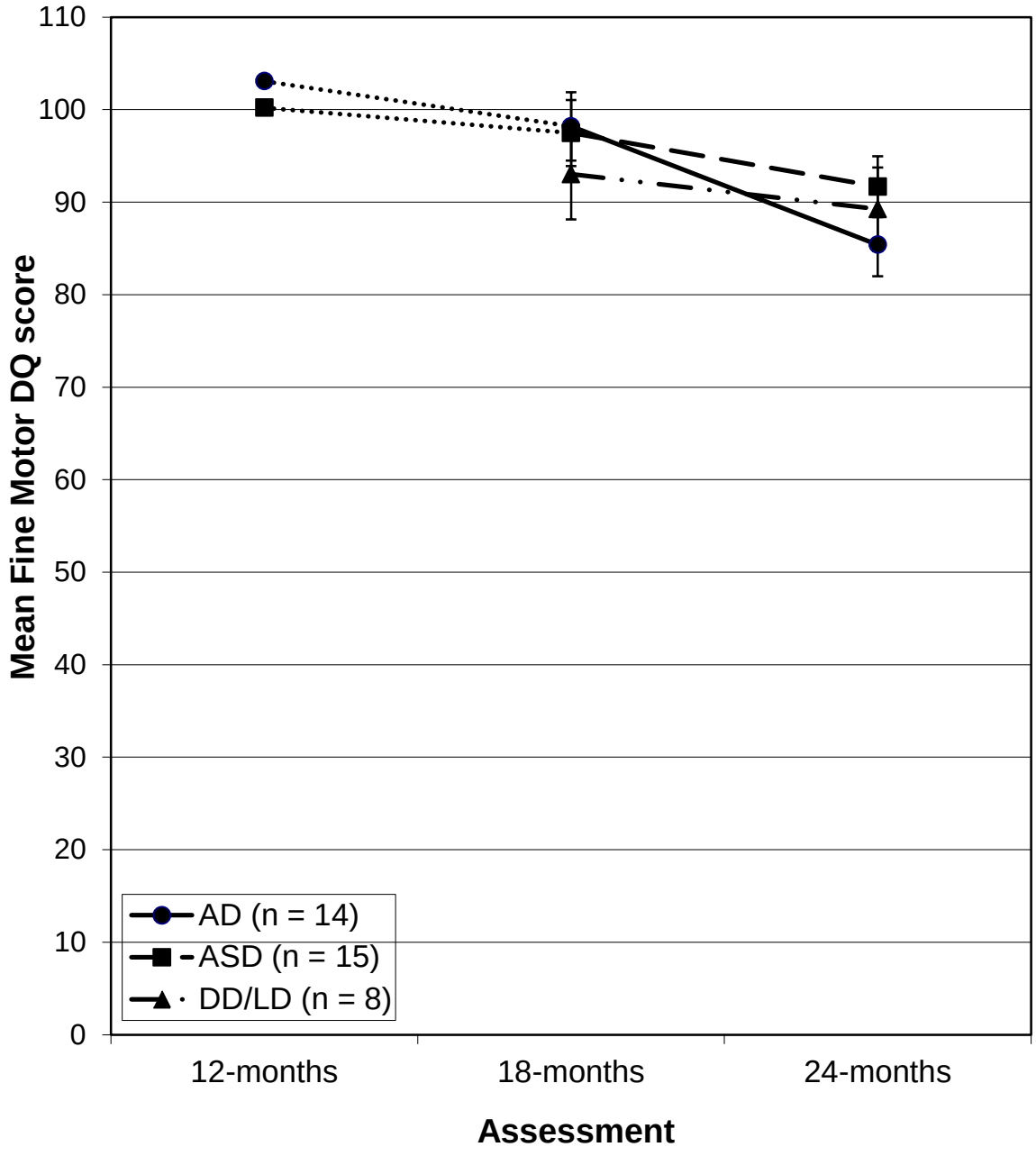

Figure 6. Mean changes (± SEM) in *Fine Motor* DQ scores from 12- to 24-months for each group.

Receptive Language. Analysis of children's *Receptive Language* scores again revealed a significant main effect for time, $F(1, 34) = 5.55$, $p = .024$, $\eta^2 = .14$, and a significant interaction effect, $F(2, 34) = 3.25$, $p = .050$, $\eta^2 = .16$, with medium effect sizes. Simple main effects analyses show a significant improvement from 18- to 24-months for the DD/LD group, $F(1, 34) = 9.32$, $p = .004$, $\eta^2 = .22$, but not for the AD, $F(1, 34) = .004$, $p = .950$, $\eta^2 = .00$ and ASD groups, $F(1, 34) = .192$, $p = .664$, $\eta^2 = .01$. Thus, the autism groups continue to perform at the same level for *Receptive Language* from 18- to 24-months.

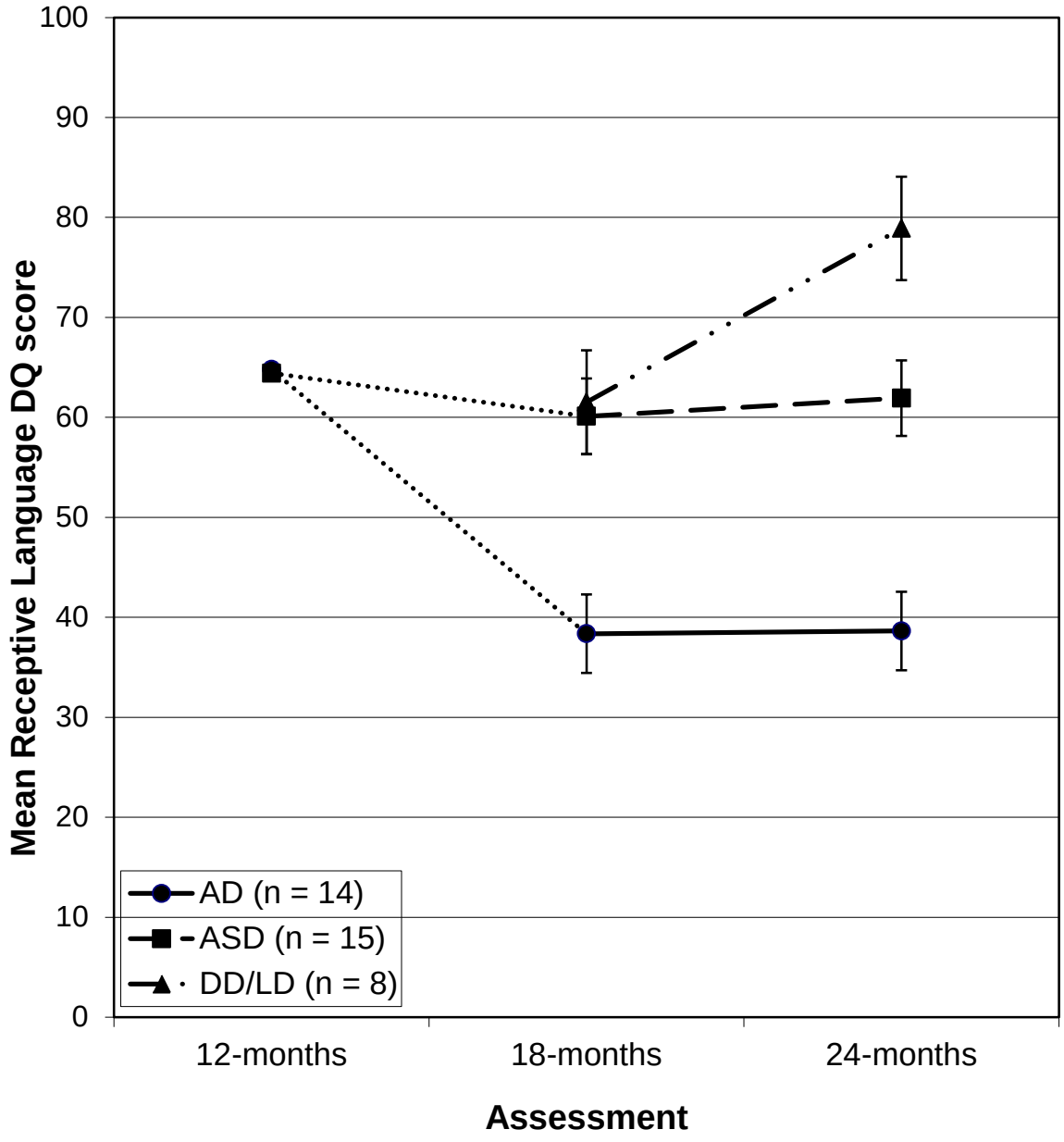

Figure 7. Mean changes (± SEM) in *Receptive Language* DQ scores from 12- to 24-months for each group.

Expressive Language. Although there was an apparent decrease in mean *Expressive Language* DQ scores amongst children with AD, demonstrated in Figure 8, there was no significant main effect of time, $F(1, 34) = 1.33$, $p = .257$, $\eta^2 = .04$, or an interaction effect, $F(2, 34) = 1.60$, $p = .216$, $\eta^2 = .09$.

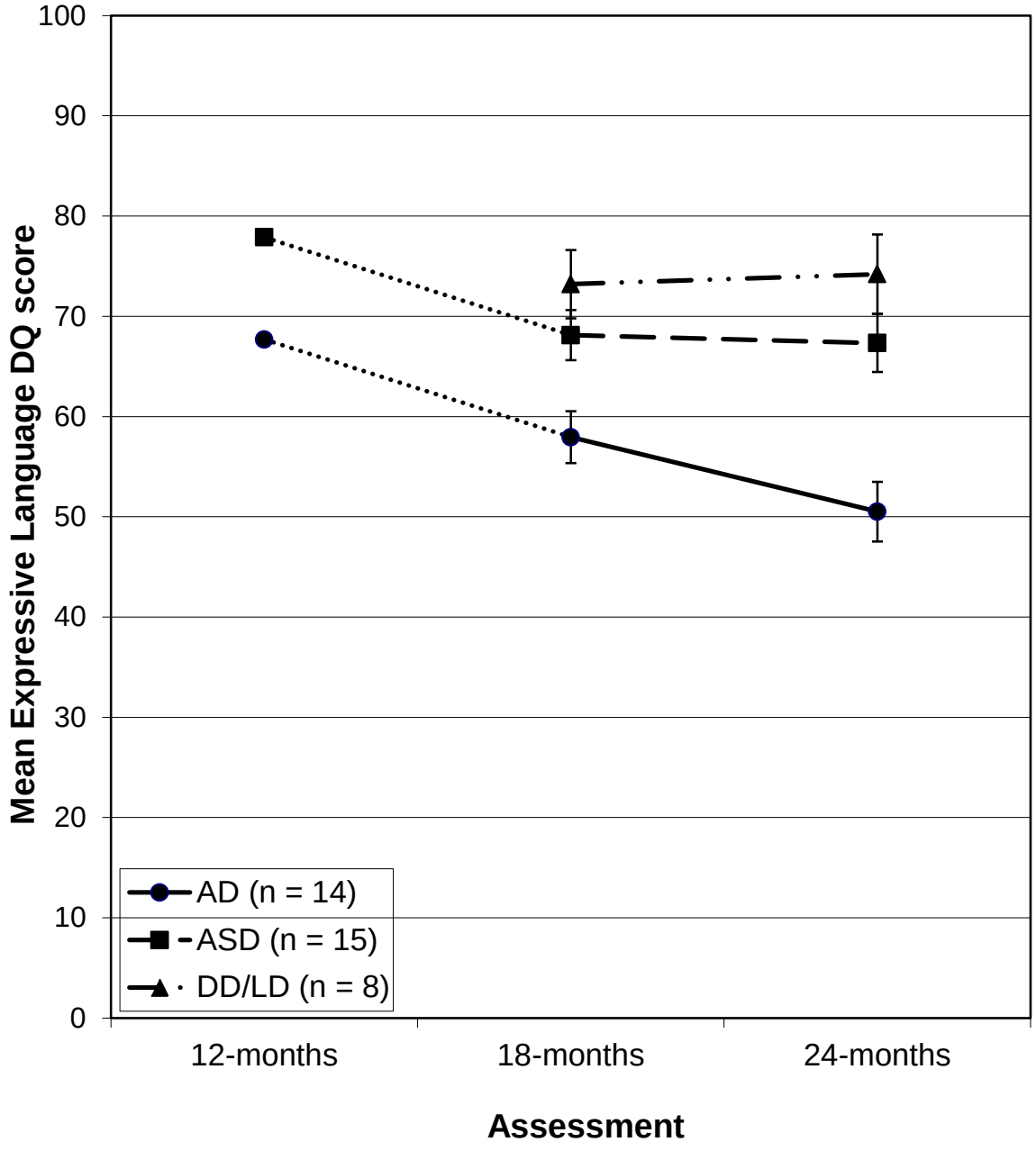

Figure 8. Mean changes (± SEM) in *Expressive Language* DQ scores from 12- to 24-months for each group.

Discussion

This is the first prospective, longitudinal study of the developmental profiles of children with autism from a community-based sample. Consistent with the study's hypotheses, children with autism (both AD and ASD) performed below age-appropriate norms on the MSEL, with the exception of *Fine Motor* skills at 12- and 18-months of age, which was an area of strength. Furthermore, those in the AD group performed more poorly, overall, than the ASD and DD/LD groups on the MSEL.

Also supporting our predictions, the children with autism displayed an uneven cognitive profile, with poorer performance on verbal skills (particularly *Receptive Language*) relative to nonverbal skills. *Fine Motor* was the strongest skill amongst children in the autism groups from 12- to 24-months, and *Receptive Language* was the most severely affected skill across all the ages. These results corroborate those from previous prospective studies using high-risk or clinic-referred infants and toddlers (Chawarska et al., 2009; Landa & Garrett-Mayer, 2006; Landa et al., 2007), as well as from studies on older children (Akshoomoff, 2006; Coolican et al., 2008; Joseph et al., 2002; Thurm et al., 2007), which found that nonverbal outweighs verbal performance. Similar to the autism groups, the children with DD/LD also displayed this uneven developmental profile. In particular, *Receptive Language* was more impaired than *Expressive Language* at 18-months. However, due to their significant improvement in *Receptive Language* from 18- to 24-months, the disassociation between *Receptive* and *Expressive Language* was no longer apparent amongst the children in the DD/LD group at 24-months. Consequently, their cognitive profile was 'flatter' relative to the autism groups by 24-months of age.

Lastly, our hypothesis of a decrease in cognitive abilities from 12- to 24-months for the autism groups was also supported, with the "developmental worsening" seen in previous

prospective studies of toddlers with autism (Bryson et al., 2007; Landa et al., 2007) also found in the current study, particularly for children in the AD group.

Changes in Developmental Profiles across the Second Year

Overall DQ. At both 18- and 24-months, the AD group displayed the lowest mean *Overall DQ* scores, with no differences found between the ASD and DD/LD groups at this time. Furthermore, the children with AD showed a significant decrease in their *Overall DQ* scores from 18- to 24-months. This was in contrast to the children with ASD and DD/LD, who did not display this significant decrease, instead maintaining their *Overall DQ* from 18- to 24-months. This decrease in *Overall DQ* for the children with AD resulted in this group showing overall developmental delays at 24-months. However, the ASD and DD/LD groups were not showing overall developmental delays at 24-months, although they were still delayed relative to population norms. Thus, it can be seen that the AD group is progressively falling further behind children with DD/LD as well as children with broader ASD across the second year of life, which is consistent with previous prospective studies (Bryson et al., 2007; Landa & Garrett-Mayer, 2006; Landa et al., 2007).

Language profile. It is apparent from our results that infants and toddlers with autism have better *Expressive* than *Receptive Language*, which is evident from as early as 12-months and persists until at least 24-months. This finding is consistent with the findings from Hudry et al.'s (2010) study on a sample of preschoolers with AD. The data from the current study demonstrates that this atypical language profile characterises children with broader ASD, as well as those who meet the stricter criteria for AD.

Despite children in the DD/LD group displaying this unconventional language profile at 18-months, they markedly improved their *Receptive Language* from 18- to 24-months of age, with similar or even slightly higher (albeit non-significant) scores on *Receptive* than *Expressive Language* at 24-months. Chawarska et al. (2009) also reported that their non-ASD

toddlers (with DD or LD**)** showed a different language profile from their toddlers with ASD, which was characterised by better understanding and responsivity to language than by the production of language. Unlike the DD/LD group, the *Receptive Language* skills amongst the children with autism in the current study did not 'catch up' to their *Expressive Language* skills by 24-months; hence, they continued to show the atypical language profile.

The development of *Receptive Language* abilities in this sample of children may shed some light on Leekam's (2007) query of why one child with developmental delay goes on to develop autistic impairments, while another does not. Increases in *Receptive Language* between 18- to 24-months may place children on a developmental trajectory away from the autism spectrum, whereas those who do not develop these skills during this period may traverse the trajectory toward autism. A critical element in this development may be joint attention skills. With age, children in the DD/LD group may increasingly attend to the social world through more advanced joint attention skills, which, in turn, leads to better responsiveness to language, drawing them closer toward the path of typical development. This hypothesis seems plausible, as it is well known that joint attention deficits are related to impairments in language (Mundy, Sigman, & Kasari, 1990; Tomasello, Carpenter, Call, Behne, & Moll, 2005). Furthermore, the young children with AD and ASD reported here were characterised by marked deficits in social and joint attention skills, as outlined in Barbaro and Dissanayake (submitted)[4].

Nonverbal profile. Children in each of the three groups did not differ in their nonverbal skills (*Visual Reception* and *Fine Motor*) at 18-months. However, although the interaction was not significant, it was apparent from Figures 5 and 6 that there was a slight decrease in nonverbal skills in the AD group from 18- to 24-months of age. In particular, although *Fine Motor* ability was a relative strength in the children with AD, their DQs in this

[4] Paper 4

area declined from around 100 at 12- and 18-months, to approximately 85 at 24-months. The ASD group also showed a slight decrease in their nonverbal DQs, dropping nearly 10 DQ points from 18- to 24-months in *Visual Reception* and *Fine Motor*. These findings highlight the importance of early intervention to facilitate the maintenance of nonverbal skills between 18- to 24-months, which would serve to not only increase children's *Overall DQ* scores, but also their language outcomes at age 5 (Thurm et al., 2007).

On the basis of the current findings, it appears that children with autism, especially those with AD, are not maintaining nor acquiring the necessary skills to ensure adequate cognitive development between 18- to 24-months. The DD/LD group, although maintaining their *DQs*, are still delayed relative to age-appropriate norms (i.e., DQs around 100). These results are consistent with the findings by Landa and colleagues (Landa & Garrett-Mayer, 2006; Landa et al., 2007) and Bryson et al. (2007) that indicate that the period between the first and second birthday is one of particular vulnerability, whereby developmental slowing, stagnation or regression occurs amongst the children with autism.

Bryson et al. (2007), who found this "developmental worsening" between 12- to 24-months in their sample of high-risk siblings, noted that it was unclear whether there was an actual loss of skills or an arrest in cognitive development. It was also unclear if this was a gradual process or a more abrupt one. The results of the current study suggest that, rather than loss of skills, per se, there appears to be stagnation in development amongst children in the autism groups, particularly amongst those children meeting criteria for AD. Although inspection of the *Overall DQ* and nonverbal DQ graphs show a general decline across time in each of the autism groups, these are standardised scores. Inspection of Table 1 reveals that Mental Ages (MA) do not decline from 12- to 24-months for either the AD or ASD groups. Rather, there is a very slight increase in MA over time in the AD group, instead of a decrease which would suggest a loss of skills. The MAs of the ASD and DD/LD groups, although still

delayed relative to their chronological age, are seen to increase at a faster rate than the AD group. In terms of momentum, it can be seen from Figures 4 to 8 that there is a gradual decrease of DQ scores from 12- to 24-months for the autism groups, rather than an abrupt shift in developmental momentum. These data stress the importance of early intervention at 18-months and earlier, to facilitate the acquisition of appropriate cognitive and communication skills, which may, in turn, alter the developmental course of autism (Dawson, 2008; Dawson et al., 2010; Landa et al., 2007).

Differences in Developmental Profiles between Children with AD and ASD

Analysis of the developmental profiles in the current study reveal that, overall, the children meeting criteria for broader ASD had higher levels of verbal and nonverbal abilities relative to the children with AD, which is consistent with the findings from Chawarska et al.'s (2009) sample of toddlers with PDD-NOS and autism (AD). Indeed, it is most likely these differences in cognition that determine behavioural presentations and their diagnoses of AD versus PDD-NOS (or broader ASD). Furthermore, the cognitive and communicative advantages seen in Chawarska et al.'s PDD-NOS group by the 3rd year of life is seen to begin in our sample even earlier, from the 2nd year of life, with the ASD group showing higher verbal, nonverbal, and consequently higher *Overall DQ* scores at 18- to 24-months. This is despite the children in the AD and ASD groups displaying similar developmental profiles at 12-months. However, replication of this finding is clearly needed given the small sample sizes at 12-months.

Notwithstanding the group differences in the severity of cognitive deficits amongst the AD and ASD groups, with differences being greatest on *Receptive* and *Expressive Language* at 18- and 24-months, their relative strengths and weaknesses were similar. Children in both groups showed higher nonverbal than verbal skills, with *Fine Motor* their relative strength, and *Receptive Language* their weakest ability.

Limitations

Although there was a relatively large number of participants in the cross sectional analyses, the samples sizes available for the analyses of developmental change across time were small, particularly for the DD/LD group. Furthermore, the number of analyses conducted investigating this developmental change across time may have inflated Type I error, requiring some caution in interpreting these results. Future studies should therefore attempt to replicate these results with children prospectively identified from a community-based sample. In addition, the results of the differences between the children with AD and ASD should be treated with caution, as it is known that there is some shift between diagnostic boundaries of AD and broader ASD as children age (Charman et al., 2005; Eaves & Ho, 2004; Kleinman et al., 2008). We are therefore following-up this cohort at 4 to 5 years of age to establish diagnostic stability across time.

It is also important to consider the issue of regression to the mean when conducting experiments with repeated measurements, particularly when coupled with issues of reliability of standardised assessments in very young children. The changes across time from 12- to 24-months reported in this study were gradual, rather than showing extreme (unusually large or small) values at one age followed by values that were closer to the population mean of the samples assessed (Barnett, van der Pols, & Dobson, 2005; Ostermann, Willich, & Ludtke, 2008). Furthermore, there were skills that did not change over time for each group, particularly language skills (except *Receptive Language* for the DD/LD group). Thus, it may be argued that regression to the mean was not an issue in this study. However, replication is needed to verify the findings reported here. Despite these limitations, the findings of the current study are largely consistent with those from previous studies using high-risk samples, as well as those conducted with preschoolers and older children with autism, which offer some confidence in these effects.

Implications and Future Directions

The stagnation and decline of DQ scores seen amongst the children with autism in the current study emphasises the tremendous importance of early identification and intervention. Given that nonverbal skills are relative strengths amongst these children, it is important that these are maintained or even improved with appropriate intervention to promote better developmental outcomes. Furthermore, improving communication and language abilities will serve to increase *Overall DQs* in children with autism, as it is performance on the verbal subscales that result in *Overall DQs* well below age-appropriate norms. If intervention can begin before the decreases in DQ scores in the latter part of the second year of life, prevention of these declines may be possible (Dawson, 2008; Dawson et al., 2010).

The finding that *Receptive Language* was a key impairment amongst children with autism, coupled with Wetherby et al.'s (2007) findings that understanding of words at 18- to 24-months was the best predictor of developmental outcomes at 3 years, demonstrate the importance of targeted *Receptive Language* intervention early in development. Clinicians delivering language intervention to these children should focus heavily on developing attention to language and responsivity to speech in others, as well as focusing on increasing and shaping expressive speech (Paul et al., 2008). Furthermore, additional longitudinal studies are needed to further investigate the development of *Receptive Language* in young children with autism as well as in those developing typically, by taking frequent and detailed measures of *Receptive Language* during the important 18- to 24-month developmental period. Understanding this development has treatment implications, since the development of specific skills, such as joint attention, may be the critical factor that leads children in the DD/LD group, but not in the autism groups, to dramatically improve their *Receptive Language* skills from 12- to 24-months.

As the children in the DD/LD group showed a similar cognitive profile to the ASD group (with the exception of *Receptive Language* at 24-months), children with 'milder' or 'broader' ASD may be mistaken as having a DD/LD at 18- to 24-months, due to their very similar cognitive development. However, poor *Receptive Language* skills, along with social attention and communication deficits, may serve as a red flag for ASD in children who are showing developmental and/or language delays at 24-months of age. *Receptive Language* should therefore be stringently monitored in any developmental surveillance program, to identify young children developing an ASD.

Summary and Conclusions

The findings from this study contributes to the small but growing body of literature on the developmental profiles of very young children on the autism spectrum, by highlighting the relative strengths in nonverbal skills and weaknesses in verbal skills at an early age, particularly in *Receptive Language*. The children with autism showed the typically uneven cognitive profile, with nonverbal skills exceeding verbal skills, and an atypical language profile, with impairments in receptive skills being far more severe than expressive skills. The children with broader ASD were seen to display a very similar developmental profile to children in the DD/LD group, and their profile was only distinguishable on the basis of *Receptive Language* deficits at 24-months of age. *Receptive Language* may therefore be the core cognitive impairment that determines whether a child will develop autism or continue to show developmental or language problems without autism. The findings from this study highlight the urgency of identifying children with autism and intervening as early as possible. Timely intervention may affect crucial changes during the critical period of development between 12- to 24-months, where developmental stagnation is all but too apparent in young children with autism.

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GENERAL DISCUSSION

The utility of early markers of Autism Spectrum Disorders (ASDs) for the identification of 'at risk' infants and toddlers in a community-based setting was investigated in this thesis. The primary goal was to identify children with ASDs at the earliest possible opportunity with a high level of accuracy, so that early intervention can begin during their early and most critical years. This was achieved by implementing developmental surveillance in the Maternal and Child Health (MCH) system, with the aim of prospectively identifying young children with ASDs from 8- to 24-months of age. The results of this implementation confirmed that primary health care professionals have a central role to play in the early identification of these children. A further objective was to identify which of the early behaviours surveyed were the most successful in discriminating children with autism (both Autistic Disorder – AD, and broader ASD) versus children with developmental and/or language delays (DD/LD), and which were the most predictive of a diagnosis of autism at 24-months. Furthermore, given the paucity of information on the very early cognitive development of these children, the final aim was to chart the early developmental profiles of young children developing with an ASD from 12- to 24-months of age.

This chapter will begin with a summary of each of the papers presented in this thesis, followed by a discussion of the key findings, drawing particular attention to how these findings have contributed to understanding and identifying ASDs in early life. The limitations of the research presented in this thesis will be considered next, followed by a discussion of future directions, prior to drawing conclusions.

Paper 1: Literature Review of ASDs in Infancy and Toddlerhood

Paper 1 provided a comprehensive overview of the early signs of ASDs, and the tools used to identify and diagnose these disorders. It was concluded that social attention and communication behaviours are the key markers of ASDs in infants and toddlers, which are evident from the first year of life. Stereotyped and repetitive behaviours, although present in

some young children, were deemed not to be useful markers, as they were not found to be predictive of an ASD diagnosis. It was also found that there were no Level 1 screening instruments available for universal use due to their poor psychometric properties. The few large-scale, prospective, community-based studies undertaken to date had utilised screening tools at a single age, leading to inadequate sensitivity. It was proposed that the repeated monitoring of infant development may serve to increase the chances of identifying early manifestations of ASDs, consequently increasing the sensitivity of the screening tool or surveillance method utilised. In addition, repeated sampling was suggested as useful in tracking the subtle changes in symptoms and cognitive skills that occur in infants with an ASD overtime (Yirmiya & Ozonoff, 2007). It was concluded that a brief and highly predictive observational tool or method able to detect infants and toddlers with ASDs, who were not already identified as being at a higher risk of developing an ASD, was needed.

The recommendation from *Paper 1* was the platform for the development of the Social Attention and Communication Study (SACS), implemented in the Maternal and Child Health (MCH) system in metropolitan Melbourne, Victoria. Its successful implementation and evaluation is outlined in *Paper 2.*

Paper 2: Developmental Surveillance of ASDs in Infants and Toddlers by Maternal and Child Health (MCH) Nurses

Paper 2 detailed the implementation of the SACS in a cohort of 22,168 children monitored at 184 MCH centers in metropolitan Melbourne, Victoria. This didactic paper was largely methodological, and provided details of the MCH training undertaken, including how the social attention and communication behaviours were monitored by the nurses, and the criteria required to identify a child as ‘at risk’ for an ASD. A main focus in this paper was provision of a detailed account of each of the early signs used to identify children with ASDs, to assist primary health care professionals in monitoring the development of these

behaviours. These details were written on the basis of the candidates direct observational experience while assessing the 110 children that were referred to the Child Development Unit (CDU), totaling 156 assessments from 12- to 24-months age, and 100 parental interviews using the ADI-R (Lord, Rutter, & Le Couteur, 1994).

The early manifestations of stereotyped, repetitive and sensory behaviours were also outlined in *Paper 2* to inform health care professionals of the aberrant behaviours seen in many of these children. It was emphasised that these behaviours could not be used in isolation to determine a child's risk status given the heterogeneity of these behaviours, and their absence in many children with ASDs prior to 3 years of age. Based on the early signs of ASDs, checklists were developed for use by primary health care professionals to assist in the identification of children 'at risk' of an ASD.

Data from the evaluations given to the MCH nurses at the beginning, middle, and end of the study were also provided in *Paper 2.* The overwhelming response from the nurses was positive, reporting that they felt confident to monitor and refer 'at risk' children. They reported that the SACS was easy to implement as part of their regular checks, without taking much additional time. The nurses reported that the study helped them understand the presentation of ASDs in infancy and toddlerhood, and that it had a positive impact on their current practice. The results from the SACS (outlined in *Paper 3*) and the nurses evaluations strongly indicated that MCH nurses have a key role to play in the early identification of ASDs. It was argued that developmental surveillance of social attention and communication behaviours should be undertaken universally and within children's regular health checks during their second year of life.

Paper 3. Prospective Identification of ASDs in Infancy and Toddlerhood Using Developmental Surveillance

Paper 3 detailed the main outcome from the SACS. It is the first large-scale study to demonstrate that it is possible to prospectively identify infants at risk of ASDs in a community-based sample from 12- to 24-months of age. A total of 216 children identified as 'at risk' for an ASD were referred to the CDU, with 110 children assessed at 12-, 18-, and/or 24-months of age. The social attention and communication behaviours, previously found to be key markers of ASDs in infants and toddlers (Barbaro & Dissanayake, 2009), served to prospectively identify these children via their routine MCH assessments from 12-months of age, with a Positive Predictive Value (PPV) of 81%. True sensitivity and specificity rates could not be determined; however, they were estimated to be 83.8% and 99.8%, respectively. The rate of ASDs estimated in the SACS was 1 in 119, which is consistent with the 1% prevalence rates currently being cited (Baird et al., 2006; CDC, 2009; Kogan et al., 2009).

The repeated monitoring of children from 8-to 24-months, unlike previous studies that have screened children at only one time point (using CHAT, M-CHAT, ESAT), resulted in a high ascertainment rate with few false positives. Thus, very early identification is not limited to those already 'at risk' of an ASD, such as siblings of affected children, but is possible at a universal level with adequate education of health care professionals on the early signs. On the basis of the results presented in *Paper 3*, a developmental surveillance approach was advocated, where developmentally appropriate social attention and communication behaviours are routinely monitored throughout the first 2 years of life.

Paper 4: Early Markers of ASDs in Infants and Toddlers Prospectively Identified by the SACS

Although developmental surveillance of the early markers of ASDs outlined in *Paper 3* was successful in identifying, with high accuracy, children with ASDs from a community-based sample, a small percentage of children with DD/LD were also identified. Thus, a detailed analysis of each of the behaviours monitored in the SACS was required to determine the most discriminating and predictive markers of ASDs from 12- to 24-months. Therefore, the aim in *Paper 4* was to identify the most predictive prospective markers between 12- and 24-months of age, so that these could be used to identify children across the spectrum of autism with greater accuracy.

It was found that the children in the AD group had pervasive deficits in the majority of the SACS items monitored across the ages, whereas the children meeting criteria for 'broader' ASD showed a much less pervasive and severe presentation of deficits. Furthermore, children in the DD/LD group, although showing impairments on the language variables, did not have pervasive deficits on the social attention and communication items that were monitored. Instead they showed a very similar pattern of response to typically developing children on most of these variables.

Across all ages, the recurring key markers of autism (both AD and ASD) were *Eye Contact* and *Pointing*, and from 18-months of age, *Social Communication* (showing) became an important marker of autism. *Pretend Play*, although not identified as a key marker at 18-months, also became an important marker at 24-months of age. These behaviours, in combination, were found to be the best predictors for a diagnostic classification of autism (both AD and ASD) at 24-months. As the key markers of autism were found to differ across the ages, and many children later diagnosed with 'broader' ASD passed some of the key items between 12- and 24-months, it was argued that the monitoring of the markers identified

in *Paper 4* be done continually across the second year of life. These results reinforce the argument that screening tools administered at only one age will result in problems with sensitivity, particularly for children with 'milder' or broader ASD.

Paper 5: Developmental Profiles of Infants and Toddlers with ASDs Prospectively Identified in a Community-Based Setting

Previous literature had identified a critical period between the first and second birthdays, where a subset of children with an ASD progressively lose cognitive skills, while another subset of children maintain their cognitive abilities (Bryson et al., 2007; Landa & Garrett-Mayer, 2006; Landa, Holman, & Garrett-Mayer, 2007). As these studies have focused on high-risk samples, it was deemed important to ascertain whether these findings are generalisable to a community-based sample of children. *Paper 5* reports on the first prospective, longitudinal study charting the developmental profiles of children with an ASD from a community-based sample. Using the Mullen Scales of Early Learning (MSEL; Mullen, 1995) from 12- to 24-months of age, it was found that children with autism (both AD and ASD) performed below age-appropriate norms on the MSEL, with the exception of *Fine Motor* abilities at 12- and 18-months, which was an area of strength. Furthermore, children in the AD group performed more poorly, overall, than those with an ASD or DD/LD on each of the separate subscales of the MSEL, as well as on *Overall DQ*.

The children with autism also displayed an uneven cognitive profile, with poorer performance on verbal skills relative to nonverbal skills. *Receptive Language,* in particular, was the most severely affected skill amongst these children from 12- to 24-months. These results corroborate those from previous prospective studies using high-risk or clinic-referred infants and toddlers (Chawarska, Klin, Paul, Macari, & Volkmar, 2009; Landa & Garrett-Mayer, 2006; Landa et al., 2007), as well as those from studies on older children

(Akshoomoff, 2006; Coolican, Bryson, & Zwaigenbaum, 2008; Joseph, Tager-Flusberg, & Lord, 2002; Thurm, Lord, Lee, & Newschaffer, 2007).

The children with broader ASD displayed a very similar developmental profile to children with DD/LD; their cognitive profile was only distinguishable on the basis of *Receptive Language* deficits at 24-months of age. *Receptive Language* was, therefore, argued to be a core cognitive impairment that may determine whether a child will develop autism or developmental/language delays without autism. Furthermore, the children with AD and ASD mainly differed in the severity of their cognitive symptoms, rather than showing qualitatively different developmental profiles.

The "developmental worsening" evident in previous prospective studies of high risk toddlers who developed autism (Bryson et al., 2007; Landa & Garrett-Mayer, 2006; Landa et al., 2007) was also apparent in *Paper 5*, particularly for children meeting criteria for AD. These findings highlight the urgency of identifying children with autism and intervening as early as possible, in order to effect crucial changes during this critical period of early development.

Key Findings

Screening versus Developmental Surveillance

The study detailed in this thesis was the first large-scale prospective study using a community-based sample, which identified children 'at risk' of ASDs as young as 12-months of age. Previous large-scale studies conducted in the community have identified children at 14/15-months and 18-months using the ESAT and CHAT (Baron-Cohen et al., 1996; Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006), but these tools had poor psychometric properties as a result of screening children for ASDs at a single age. In contrast, the developmental surveillance approach used here was successful in identifying children across the autism spectrum with a high level of accuracy in the second year of life. It is

therefore recommended that more emphasis be placed on the developmental surveillance of autism specific symptoms that include social attention and communication behaviours.

Developmental surveillance has been previously advocated by researchers such as Dworkin (1989), and is utilised in health care systems such as the MCH system for the identification of developmental anomalies and maternal health problems alike (DEECD; 2007). Furthermore, both the American Academy of Neurology (Filipek et al., 1999, 2000) and the American Academy of Pediatrics (AAP; 2007; Johnson & Myers, 2007) have recommended that developmental surveillance be conducted at every well-child visit. However, they each recommend general developmental surveillance, to identify children with any developmental anomalies, which is then followed-up with an autism specific screening instrument. In contract, the objective of the SACS was to prospectively and accurately identify children with ASDs in the first instance, via developmental surveillance.

The autism screening tools recommend by Filipek at el. (1999, 2000) following developmental surveillance (appropriate for use in infants and toddlers) were the CHAT (Baron-Cohen et al., 1996), M-CHAT (Robins, Fein, Barton, & Green, 2001), and PDDST-II (Siegel, 1996, 1998; Siegel & Hayer, 1999). The CHAT and M-CHAT have been reviewed in this thesis and deemed to have insufficient sensitivity and specificity to be used during in community-based populations, and the usefulness of the PDDST-II as a Level 2 screening tool has not yet been published (Coonrod & Stone, 2005). Furthermore, the recommendation by the AAP (2007; Johnson & Myers, 2007) of the use of screening tools at 9-, 18-, and 24/30-months is problematic given the lack of universally recommended screening tools for detecting ASDs.

The heterogeneity of the autism spectrum, and the differing ages at which symptoms become apparent, has meant that developing a screening tool to be administered at a given age with good psychometric properties has proven to be difficult. In contrast, the results of

the SACS, outlined in *Papers 2* and *3*, have provided a means by which developmental surveillance of autism specific symptoms is both possible and accurate. The repeated assessment of social attention and communication behaviours across the second year of life clearly facilitated the identification of children who may otherwise go undetected with current screening tools. If a child with an ASD is missed, or is not showing symptoms at a particular age, s/he is likely to be identified at a subsequent consultation.

Developmental surveillance for the purpose of identifying children with ASDs should not just be limited to one system or service but, rather, be conducted each time children come into contact with a health care professional, be they a MCH nurse, general medical practitioner, paediatrician, etc. This ensures that there is every possible opportunity to identify developmental anomalies and raise concerns with parents where necessary (Dworkin, 1989). As reported in *Paper 3*, approximately half of the children referred by their MCH nurse were not assessed by the SACS team due to parents/caregivers declining consent for further developmental assessments. If these same parents, when visiting their general practitioner or paediatrician, were repeatedly confronted with similar concerns about their child's development, they may be more likely to address these concerns resulting in earlier diagnoses and intervention for affected children.

Skilled Observations

The findings from the SACS reinforce the need for all primary health care professionals to conduct skilled observations of children's behaviour, rather than relying solely on parental report. The limitations with parental report, raised in *Paper 1,* include incorrect memory recall, recall biases, distortion of events, and alertness in recognising behaviour (Gillberg, 1989; Zwaigenbaum et al., 2005). Moreover, as mentioned, approximately 50% of parents/caregivers did not accept their nurse's referral for further assessments. Consequently, there may be reluctance by a group of parents/caregivers to

accept that there are concerns regarding their child's development. However, even if the concerns raised via health care professionals are not accepted in the first instance, the marking of these concerns may assist in subsequently leading the child to an earlier diagnosis[1].

The Dynamic Nature of Symptom Presentation

Primary health care professionals must be educated about the ever dynamic nature of the symptoms of autism, particularly from 12- to 24-months of age, and informed that if a child is not 'at risk' of an ASD at one age, this does not negate the possibility of a subsequent diagnosis. Certainly, the results from *Paper 4* demonstrate this, as some children with milder manifestations of ASD did not show concerns on many of the behaviours considered 'red flags' for an ASD in the second year of life. For example, deficits in *Eye Contact, Response to Name, Follows Points,* and *Social Smiles* were found to be important markers of 'classic autism' (AD) at 12-months. However, the majority of children classified with broader ASD at 24-months of age did not show deficits on these behaviours at 12-months, particularly *Eye Contact* (with only 17% showing deficits at this age). Thus, consistent with Landa et al.'s (2007) findings, a subset of children later diagnosed with an ASD will not present with deficits in some social attention and communication behaviours around their 1st birthday. Furthermore, despite both the AD and ASD groups differing significantly to the DD/LD group in their *Eye Contact* and *Social Communication* skills at 18-months of age, and their *Pointing* and *Social Communication* skills at 24-months, many children later diagnosed with broader ASD passed these items at both 18- and 24-months of age. Thus, it is evident that some children with ASDs will not present with an absence of even 'key' behaviours.

[1] Anecdotally, we were informed that many of the parents who did not consent to participate in the SACS opted to speak to their general practitioner, paediatrician, or other health care professional, and thus may still have been on the right path to an early diagnosis.

It is also important to highlight that the key markers of ASDs change over time, as illustrated in the findings reported in *Paper 4.* For example, a deficit in *Pretend Play* was more indicative of general developmental/language delays at 18-months of age, rather than being specific to autism. However, by 24-months, it was one of the most important predictors for a classification of autism, largely due to the percentage of children with DD/LD displaying deficits in this area declining from 57% to 8% between 18- and 24-months. Conversely, at 18-months, an *Imitation* deficit was found to be a key maker of autism; however, by 24-months, the number of children with AD presenting with deficits in this area declined by almost half from 18- to 24-months; thus, *Imitation* was no longer a key marker of autism by 2 years of age.

The findings reported in *Paper 4* highlight that children with ASDs present with a pattern of deficits on various behaviours that manifest differently across the second year of life, which emphasises the developmental nature of these related disorders. It also reinforces the importance of repeatedly monitoring behaviours indicative of autism from 12- to 24-months of age, enabling children with ASDs who pass autism surveillance at one age to be identified at later examinations.

Autistic Disorder versus Broader Autism Spectrum Disorder

The findings from *Papers 4* and *5* suggest that children with AD could be distinguished from those meeting criteria for broader ASD on the basis of the severity of their social and communication deficits (*Paper 4*), and their language and cognitive impairments (*Paper 5*). As apparent from *Paper 4*, although fewer children in the ASD group showed deficits in areas such as *Response to Name* and *Follows Point* at 18- and 24-months, both the children with AD and ASD were showing deficits in ‘key’ social attention and communication behaviours. Conversely, the children in the DD/LD and TD group were much more similar to one another in their social attention and communication behaviours.

The children with AD and ASD also showed similar cognitive profiles to one another from 12- to 24-months of age. As evident from the findings reported in *Paper 5*, these groups differed mainly in the severity of their cognitive impairments, rather than showing qualitatively different profiles. These findings support the approach being taken in the drafting of DSM-V, which includes these children in a single diagnostic spectrum ('Autism Spectrum Disorder'), rather than assigning them to the distinctive diagnostic categories advocated in DSM-IV-TR (APA, 2000).

Receptive Language as a Key Marker

An important cognitive ability that appears to lie at the heart of deficits in ASDs is poor *Receptive Language*. As apparent from *Paper 5*, this deficit was clearly evident from 12-months of age in the sample of children with both AD and ASD. Importantly, although the children with DD/LD showed similar deficits in *Receptive Language* to those meeting criteria for broader ASD until 18 months of age, they began to traverse away from both of the autism groups by 24-months of age. Thus, on the basis of this finding, it is vital that deficits in *Receptive Language* are monitored alongside deficits in social attention and communication behaviours, as a deficit in *Receptive Language* may be used as an additional risk marker for the identification of AD and ASD at 24-months of age.

Loss of Skills and Developmental Stagnation

Consistent with the finding from previous prospective studies of toddlers with autism (Bryson et al., 2007; Landa & Garrett-Mayer, 2006; Landa et al., 2007), it was found in *Paper 5* that children meeting diagnostic criteria for autism, particularly those with AD, showed developmental worsening across the second year of life. Although they did not lose particular skills in each of the subscales of the MSEL (Mullen, 1995), their DQs were seen to decrease across time as their abilities were not developing in accordance with their chronological age. Furthermore, as illustrated in *Paper 4*, only 17% of children meeting

criteria for broader ASD showed deficits in *Eye Contact* at 12-months. By 18-months, this figure increased nearly four fold to 65%, and increased yet again to 86% by 24-months. Therefore, it seems that children with broader ASD show some regression in social attention during the second year of life. These findings are consistent with the pattern of development seen in Landa et al.'s (2007) "later" diagnosis group, where some children did not show symptoms of autism at 14-months of age.

In addition, it was also found in *Paper 4* that by 24-months of age, 91% of the children in the AD group and 59% of the children in the ASD group were reported by their parents/caregivers to have had "Loss of Skills" (language or social skills). A small percentage (33%) of children in the DD/LD group was also reported to have lost skills. The combined findings from *Papers 4* and *5* on developmental stagnation and loss of skills highlights the urgency of identifying children with autism, as well as those with DD/LD, and intervening as early as possible. Effective early intervention provides the best chance of affecting crucial changes during the critical period of early development, as it can minimise or even prevent worsening of social attention, communication and cognitive abilities apparent in the second year of life (Dawson, 2008).

Limitations and Future Directions

Despite the successful implementation of the SACS in a community-based sample, the findings reported here are not without limitations, which are necessarily a part of community-based research. Further research is therefore recommended on the basis of the limitations outlined here.

One of the main limitations of the SACS was the failure to incorporate control regions, where referral rates of ASDs were recorded in Local Government Areas (LGAs) where the study was not implemented. Inclusion of control regions would have enabled comparison of referrals rates within the SACS regions to that of control regions, allowing

absolute confirmation of the success of the SACS training provided to nurses. The scope of the research outlined in this thesis did not allow for the inclusion of this comparison, which is planned in future research. A study is currently being designed whereby a small number of LGAs (not part of the SACS) will be selected, and referral rates of ASDs within these LGAs recorded and compared to those obtained within the SACS. This comparison will also seek to establish the ages of children at referral within the control regions. We also plan to monitor children with an ASD at school entry in a subset of LGAs included in the SACS, in order to establish the amount of children not identified by the SACS. These new data will enable more accurate estimates of sensitivity and specificity, as well assisting in further establishing the prevalence rates within the SACS cohort.

Another limitation in the research reported here is the size of the comparison sample (the DD/LD group), which comprised children with developmental and/or language delays. This was due to the small number of children referred to the study that did not meet criteria for AD or ASD at 24-months (false positives), which speaks to the success of the SACS. However, as a consequence, it was not possible to have separate control groups of both children with language delays and developmental delays. Future studies should therefore aim to recruit children from the community with language and developmental delays, alongside children ‘at risk’ of ASDs, as this would lead to a study with greater power to detect group differences between children with autism, developmental delays, and language delays only.

Similarly, the size of the 12-month sample was also small due to a low referral rate at this age. More extensive training and reassurance of the MCH nurses about their skilled observations and accurate referrals (PPV = 90% at 12-months) may lead to higher identification rates at 12-months. This finding emphasises the importance of repeated monitoring of behaviours at 18- and 24-months, as reliance on very early signs alone will fail

to identify those children who subsequently regress, as well as those with few, mild or subtle symptoms at 12-months.

A further possible limitation is that the findings reported in *Papers 2* to *5* of this thesis are based on diagnostic classifications determined at 24-months of age. While some children may cross diagnostic boundaries with age, it is unlikely, on the basis of previous studies, that many will move off the spectrum (Charman et al., 2005; Lord, 1995; Paul, Chawarska, Cicchetti, & Volkmar, 2008; Stone et al., 1999; Turner, Stone, Pozdol, & Coonrod, 2006). However, these studies indicate that there is greater shift within the spectrum, that is, between AD and broader ASD. We are thus currently following-up the cohort of children assessed during the SACS at 4 to 5 years of age to further establish the stability of the AD and ASD classifications made at 24-months, using the ADOS and ADI-R. We also aim to investigate changes in symptoms and symptom severity over time, and the relationship, if any, with the type and amount of intervention received following early identification.

Throughout this thesis, the importance of education of all primary health care professionals on the early signs of autism to facilitate early identification has been emphasised. Thus, an important outcome of the work undertaken here is the delivery of continuing education seminars within the MCH system and related services, as well as within other primary health care sectors. The feedback received by the MCH nurses who participated in the SACS strongly endorsed the efficacy of the training they received: “I wish we had this type of training regularly throughout our practice”. Furthermore, since the commencement of the study, many requests have been received for presentations to relevant professionals (MCH nurses, general practitioners, paediatricians, teachers, early childhood educators and intervention workers, psychiatrists, psychologists, and other allied health professionals), not only in Victoria, but across Australia. Thus, the positive outcomes from the SACS are being realised within the community. There has also been much interest from

abroad on the delivery and implementation of the SACS model. It is anticipated that a ‘train the trainer’ approach will help facilitate the timely dissemination of the information both locally and internationally.

Conclusions

The SACS is the first large-scale community-based study to demonstrate that prospective identification of ASDs is possible in children from as young as 12-months of age, and with great accuracy across of the second year of life. The main objective in this thesis was therefore realised. The training of MCH nurses on the early signs of ASDs allowed them to prospectively identify infants and toddlers ‘at risk’ within a community-based setting from 12- to 24-months of age, thereby facilitating early diagnosis and an earlier access to intervention for these children.

The developmental surveillance approach adopted in the SACS allowed the repeated monitoring of different, developmentally appropriate, social attention and communication behaviours from 8- to 24-months of age. Due to the variability in symptom presentation in children with ASDs, screening tools administered at only one age will continue to miss many children later diagnosed with an ASD. It is thus vital that repeated monitoring of social attention and communication behaviours be undertaken universally and preferably within children’s regular health-checks throughout their second year of life.

Developmental surveillance of social attention and communication behaviours at children’s routine check-ups, with particular attention to the key markers of ASDs identified in *Paper 4*, will help identify the majority of children with an ASD as opposed to other developmental disorders. The period of development between 12- to 24-months, where skill loss and developmental stagnation was evident, highlights the importance of early intervention to effect developmental changes during this critical period of development.

The developmental approach to the identification of ASDs taken in the SACS is strongly recommended in all primary health care settings, as it recognises the dynamic nature of children's early social, cognitive, and communication skills during the first two years of life. This approach has clearly facilitated the very early identification of children with ASDs, enabling earlier diagnoses and subsequent intervention, which will serve to minimise the impact of ASDs in young developing children and their families.

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THESIS – Appendix A

LA TROBE UNIVERSITY

HIGHER DEGREES COMMITTEE (RESEARCH)

THESIS BY PUBLISHED AND UNPUBLISHED PAPERS

(ALTERNATIVE THESIS FORMAT GUIDELINES)

Higher Degrees Committee (Research)
Thesis by Published and Unpublished Papers

1 As an alternative to the traditional format for a higher degree thesis, it is permissible for candidates to submit a thesis in the form of a series of articles arising from the candidate's higher degree research. These must be along a central theme and may or may not be already published. The presentation of the articles should take into account current regulations for PhDs (see R21.2.9), for Professional Doctorates (see R21.3.9) and for Masters by Research (see R21.5.9). Where the thesis includes work of joint authorship the candidate shall include in the thesis a signed declaration for each article, stating the extent and nature of his or her contribution and justifying the inclusion of the material. A signed declaration from at least one of the co-authors should also be included, verifying the extent and nature of the candidate's contribution.

2 The presentation of a thesis as a collection of articles must include at least one substantial integrating article, or preferably a separate introduction, general discussion and conclusion that in combination provide an integration of the material presented. In addition, a clear statement must be included in the thesis indicating which chapters are based on published articles and providing full publication details of these articles.

3 The number of articles to be included will depend on the content and length of each and should take full account of the University's requirements for the degree as well as the amount of research expected for the degree in that discipline. Each disciple area may have specific requirements, in addition to those described in these guidelines and in the university regulations.

4 With respect to the regulation governing the completion of work undertaken during candidature, (see point 1), it is expected that unless written approval is given to include work undertaken prior to candidature at La Trobe University, e.g., a small proportion of data collected during the Honours degree to be re-analysed, all work will have been completed during the period of candidature. Work published prior to commencement of candidature must **not** be included in the thesis, although reference to such material is permitted.

5 With respect to the regulation governing joint authorship (see point 1) the candidate is expected to have made a significant and leading contribution to the work reported, equivalent to that expected for a traditional thesis.

6 A published book can also be submitted as a thesis for a Masters, PhD or professional doctorate, provided that it fulfills the requirements set out in the above five clauses of these guidelines.

7 The thesis will be examined in the normal way and according to the normal requirements set out for the degree (see Appendix A and Appendix D of the *Handbook for Candidates and Supervisors for Masters Degrees by Research and Doctoral Degrees).* Examiners of a thesis by published and unpublished papers will be given a copy of these guidelines.

8 The decision to submit a thesis in the form of a series of published and unpublished articles should be given careful consideration. Candidates should note that this is not an accepted practice in all disciplines. Moreover, it is likely, especially with a series of articles along one theme, that there will be considerable repetition across the articles which may detract from the presentation of the thesis. For these reasons, it may be more appropriate to prepare the thesis in the traditional format, including reprints of any published articles arising from the thesis as an appendix.

AB Amended 26.11.07
Thesis by Publication.doc (modified from GuidAltThesisFormatREV2.doc)

THESIS – Appendix B

PAPER 1 PUBLISHED MANUSCRIPT

Barbaro, J. & Dissanayake, C. (2009). Autism Spectrum Disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification tools, and early diagnosis. *Journal of Developmental and Behavioral Pediatrics, 30,* 447-459

Autism Spectrum Disorders in Infancy and Toddlerhood: A Review of the Evidence on Early Signs, Early Identification Tools, and Early Diagnosis

Josephine Barbaro, BBSc (Hons), Cheryl Dissanayake, PhD

ABSTRACT: To date, the biological basis of autism spectrum disorders (ASDs) remains unknown. Thus, identification and diagnosis are reliant on behavioral presentation and developmental history. There have been significant advances in our knowledge of the early signs of ASD through the use of retrospective videotape analysis, parental report, screening studies, and more recently, studies on high-risk infant siblings. Despite behavioral markers being identified within the first year of life, the current average age of diagnosis for ASD remains at approximately 3 years or older. Consequently, these children are not receiving intervention in their early years, which is increasingly recognized as an important time to begin intervention. There remains little research on the prospective identification of these children in a community-based sample before 18 months. It is recommended that future prospective studies monitor behavior repeatedly over time, thereby increasing the opportunity to identify early manifestations of ASD and facilitating the charting of subtle behavioral changes that occur in the development of infants and toddlers with ASD.

*(J Dev Behav Pediatr 30:*447–459, 2009) **Index terms:** autism spectrum disorder, autistic disorder, infancy, early identification, early diagnosis, screening tools.

The last decade has seen significant advances in our knowledge of the very early manifestations of autism spectrum disorders (ASDs), beginning with the use of retrospective home videotapes for the purpose of examining behavioral features in infants who later received a diagnosis of an ASD (Unless otherwise stated, ASD will be used throughout the review to refer to autistic disorder, Asperger's disorder, and pervasive developmental disorder-not otherwise specified). This increasing knowledge of the early ASD phenotype has led to attempts to prospectively identify ASDs in infancy and toddlerhood. Importantly, prospective studies allow the researcher to elicit behaviors at a specific age, rather than relying on spontaneous presentation on videotape or retrospective parental report. More recently, prospective studies of infant siblings of children with an ASD have also contributed to increased knowledge of the early phenotype.

Despite the unquestioned neurobiological basis of ASDs, limited knowledge regarding the underlying neuropathology for these related conditions has meant that diagnosis is reliant on behavioral presentation and developmental history. Although there is now increasing empirical information on the very early developmental histories and behavioral presentation of children with ASDs, scientific knowledge about the early signs vastly precedes standard practice, with the average age of diagnosis still at approximately 3 years. Thus, the purpose of this article is to bring together recent advances in the field, including recent research involving "high-risk" infants, to inform practitioners about the very early signs of ASDs, as well as the instruments used to identify these signs, consequently informing their current practice.

Together, this body of work will be reviewed with the ultimate aim of reducing the age at which ASDs are diagnosed. Early identification and diagnosis provide the best opportunity for early intervention, which can prevent ASDs from becoming fully manifest in the developing child, thereby serving to maximize developmental outcomes.[1,2]

Age of Onset/Recognition of Symptoms

Although the DSM-IV-TR[3] and the International Classification of Diseases-10[4] state that the onset of impairment in autistic disorder must be before 36 months, a large proportion of children manifest developmental problems between 12 and 24 months,[5–7] with some showing abnormalities before 12 months.[8–15]

Neither the DSM-IV-TR[3] nor the International Classification of Diseases-10[4] specify an age of onset criterion for Asperger's disorder. However, onset in Asperger's disorder is usually reported to be later than in autistic disorder because these children develop language at an appropriate age and display less severe symptoms. As there are fewer symptoms to alert parents and professionals that development is impaired, Asperger's disorder

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is typically not identified before children becoming part of a preschool or school setting (i.e., usually after 4 years[16,17]). Nonetheless, it is possible to identify some (albeit a very small percentage) children with Asperger's disorder before 36 months.[18,19] Thus, it is the recognition of impairments in Asperger's disorder, and not onset, which occurs later than 36 months.

Individuals with pervasive developmental disorder-not otherwise specified, by definition, do not need to have an onset of impairment before 36 months.[3,4] However, this is not typical of most individuals with pervasive developmental disorder-not otherwise specified.[20]

INFANT SIGNS OF AUTISM SPECTRUM DISORDERS: REVIEW OF THE RETROSPECTIVE LITERATURE

Retrospective Videotape Analyses

Adrien et al[8–10] were the first researchers to use home videotapes to assess the behaviors of children with and without an autism spectrum disorder (ASD) before and after their first birthday. Using the Infant Behavioral Summarized Evaluation Scale, the key behaviors that differentiated the groups were in the areas of socialization (ignores people, prefers aloneness, poor social interaction, and no eye contact) and communication (lack of vocal communication, lack of appropriate facial expressions, no social smile, lack of gestures, no or poor imitation of others).

In their study of first birthday videotapes, Osterling and Dawson[12] found that 4 behaviors correctly differentiated 90% of their sample of children later diagnosed with an ASD from those without an ASD. These were a low frequency of looking at others (including eye contact) and orienting to name call, an absence of showing objects, and a lack of pointing. These findings were later replicated.[13,21] A deficit in orientating to name call has consistently been found to differentiate children with and without an ASD as early as 8 months, in both retrospective and prospective studies.[11,15,22] Interestingly, Osterling et al[115] found that while 12-month-old children with an ASD and associated intellectual disability oriented to their names and looked at others less frequently than infants with only an intellectual disability, both groups engaged in repetitive motor actions more frequently when compared with typically developing (TD) infants. Thus, repetitive and stereotyped behaviors may not be specific to ASDs, but associated with intellectual disability; the findings suggest that social attention and communication behaviors are better early indicators of ASDs.[23]

Observations of home videotapes by Clifford and Dissanayake[24] revealed that infants later diagnosed with an ASD showed deficits in social smiling and eye contact as early as 6 months compared with infants without an ASD. In toddlerhood, affected children showed deficits in initiating and responding to joint attention behaviors. They found that requesting behaviors were less problematic, indicating that it is the sharing quality of joint attention behaviors that is deficient in these children and not the act of requesting attention. Clifford et al[25] also found a lack of protodeclarative showing in children with autistic disorder compared with TD and developmentally delayed infants.

Although the use of retrospective home videotapes is an effective means of charting the very early development of children with an ASD, there are limitations to this methodology. First, the behaviors observed are constrained to selective and less naturalistic representations of the child's behavior because the videotapes are usually of the child's birthday party or a family event and not of undesirable or unpredictable situations. Furthermore, it is not possible to elicit a desired behavior, such as response to a social smile, thus limiting observations to behaviors spontaneously demonstrated in the situation.[11]

Retrospective Parental Reports

Retrospective parental reports have long been used as a source of information about the development of ASDs in infancy. Vostanis et al[26] requested the parents of children with an ASD, learning disabilities, and language disorders to complete a questionnaire about their child's development between 12 and 18 months. The children with an ASD were rated significantly lower on items involving social attention and communication, including imitation, pointing at objects, playing peek-a-boo, seeking and enjoying cuddles, checking for their parents, interest in other children, and waving bye-bye without being asked.

Young et al[27] asked 153 parents of children with an ASD to complete a questionnaire concerning their child's very early development and the age of onset of problematic behaviors. Parents were primarily concerned about their child's difficulties in social awareness and understanding, lack of shared enjoyment in interaction, and poor eye contact. Little interest in other children and lack of social referencing (joint attention behaviors) were also reported, with 95% of parents indicating that these behaviors occurred before the age of 2 years.

The Early Development Interview was recently developed to chart the development of children with an ASD from birth to 2 years.[23,28] The parents of young children with an ASD, developmental delay, and TD children were interviewed with the Early Development Interview regarding various behaviors including social attention and communication behaviors. The children with an ASD were reported to have more social deficits than TD children from as early as 3 to 6 months, and more deficits than children with developmental delay at 13 to 15 months. Consistent with the retrospective videotape studies, these deficits included poor eye contact, failure to orient to their name, deficits in the use of joint attention, and little engagement in social interaction. Werner and Dawson[23] concluded that social behaviors were the best indicators of diagnostic differences between children with an ASD and TD children, as well as between children with an ASD and developmental delay, albeit at a later age.

Baranek and coworkers[29,30,31] developed a parental questionnaire that focuses on the behavior of children at risk for ASDs before 12 months, called the First Year Inventory. To examine the construct validity of the First Year Inventory, Watson et al[31] developed a retrospective version and gave this to parents of preschoolers with an ASD, developmental disability, and TD children. The items that were most useful in distinguishing between ASDs and developmental disability were orienting to name call, following a point, social orienting, interest in their age, social smiling, facial expression, playing peek-a-boo, and demanding attention of the caregiver. Items on imitation, expressive communication, sensory processing, regulatory patterns, reactivity, and repetitive behaviors generally differentiated children with an ASD and developmental disability from TD children but were not good at distinguishing the former groups. Thus, once again, the items that best distinguish children with and without an ASD are located in the realm of social attention and communication.

A limitation of parental report studies is that parents' responses are vulnerable to incorrect memory recall, recall biases, and distortion of events.[32] Furthermore, various factors, including parental alertness in recognizing behavior, socioeconomic status, personality, intelligence, and parental mental health can influence their responses, reducing reliability of the data.[33] However, it is worth noting that the findings from the parent report studies do largely concur with the findings from the videotape studies.[24]

In addition to the behavioral signs identified by retrospective studies, more recently, biological markers, namely enlarged head circumference, have been investigated as possible signs of ASDs. Although head circumference size is normal or near normal at birth, subsequent accelerated head growth during the first 2 years of life leads to approximately 20% of children with an ASD having a head circumference above the 97th percentile.[34–36] Used together with social attention and communication behaviors, head circumference data may be a useful accompaniment when determining the diagnostic status of a child. However, this information must be used with caution as no prospective data have yet been collected to show whether atypical head growth in very early infancy can predict a diagnosis of an ASD.[36]

AGE OF DIAGNOSIS

Despite the accumulating evidence that signs of autism spectrum disorders (ASDs) are present in early infancy, the interval between many parents' first concerns and a definitive diagnosis is approximately 3 to 4 years.[37] This interval increases to as high as 9 years for those diagnosed with Asperger's disorder (AspD).[27,38–41] Recent developments in the early identification field have facilitated lowering the average age of diagnosis for the ASDs, with the average age of diagnosis in the United States being 3.1 years for autistic disorder (AD), 3.9 years for pervasive developmental disorder-not otherwise specified, and 7.2 years for AspD.[37] However, given that the literature is showing that signs of ASDs are present in the first year of life, the mean ages for diagnosis are still very high, especially for ASDs other than AD. There are a number of reasons for the late diagnosis of ASDs despite their early behavioral manifestations.

Current Diagnostic Criteria

A significant limitation to an early diagnosis is the fact that many of the characteristic behaviors currently used in diagnosis of ASDs, based on the DSM-IV-TR[3] and the International Classification of Diseases-10[4] criteria, are not apparent before 36 months. These criteria are based on symptoms that are rarely seen in infants and toddlers with ASDs but are common in older children and adults.[42,43] For example, difficulties socializing with peers and deficits in language skills are symptoms that develop later in childhood and are thus not easily observed in infancy.[14] Some of the behaviors may also be secondary, developing to compensate for the primary "core" deficits of ASDs, which are those that are seen early in the development of the disorder.[44,45]

In addition, the DSM-IV-TR[3] and International Classification of Diseases-10[4] require a presence of repetitive behaviors, interests, stereotypies, or rituals to diagnose an ASD. This is problematic when attempting to diagnose very young children because these behaviors present in only a minority of children before 18 months and tend to develop, or become more apparent, at approximately 3 to 4 years.[42,45–47] Therefore, the absence of these behaviors in infants and toddlers with social and communication impairments does not exclude the possibility of an ASD.[42] However, more recently, data suggest that repetitive and stereotyped movements can distinguish between children with an ASD and those with delayed or typical development late in the second year of life.[48] The focus on behaviors evident later in development inevitably means that the diagnosis of infants and toddlers is delayed. To promote early diagnosis, the criteria in current diagnostic manuals require modification to reflect those behaviors that are present in the infancy period.[49]

Late Onset/Regression

Although most children with an ASD show problems before 12 months, there is a cohort of children who appear to develop typically in the first 15 to 21 months of life. These infants reach appropriate language and social skill milestones, but then progressively "lose" these skills, with the majority losing skills between the ages of 13 and 18 months.[23,50–54] This "regression" occurs in approximately 20% of children with an ASD, although this figure has been reported to be as high as 49%.[51,55–58] The differing percentages may be an outcome of the diagnostic status of the child, with a recent report[54] charting the incidence of regression to be highest in those with a diagnosis of AD (as opposed to AspD and pervasive developmental disorder-not otherwise specified).

The most frequently reported skill loss is language, followed by social skills.[50,55,58] However, it should be

noted that most cases of regression do not involve completely normal development before regression,[23,59,60] with some children having lower language abilities than their typically developing peers before regression.[58,61] Nonetheless, the existence of regression in a subset of children with ASDs means that professionals must remain cognizant of this group of children. If this period of regression remains unrecognized, diagnoses may be unnecessarily delayed.

Language Development

It is usually the absence of typically developing language, which becomes evident at about 2 years, that leads to children being referred and diagnosed with an ASD.[62] Delay in language development is one of the first and most frequently expressed concerns of parents of children later diagnosed with an ASD.[5,27,40] It is thus not surprising that delays in referral are seen when a child is verbal and are exacerbated when the child does not have associated intellectual disability. These children usually receive a diagnosis of AspD, which, as previously mentioned, is diagnosed much later than AD.[16,17] Indeed, Mandell et al[37] found that children with severe language deficits received a diagnosis of an ASD 1.2 years earlier than children with less severe language deficits.

Knowledge of Infant Symptoms

Most general practitioners and pediatricians do not have specialized skills or training regarding ASDs in infancy.[38] Consequently, they do not possess sufficient clinical expertise to identify the subtle symptoms of ASDs in infancy and often attribute any abnormalities to general developmental problems.[5] Too often, parents are reassured by their physician and told "not to worry," and that "they'll grow out of it." Howlin and Asgharian,[40] studying more than 770 families in the United Kingdom, found that over a quarter of parents of children with AD and a third of parents of children with AspD were reassured that their child was developing normally. The average age of the children with AD when parents first sought help was 2 years, and with AspD, 3.5 years; however, on average, a diagnosis was given at 5.5 years for the children with AD and 11 years of age for the children with AspD.

What is most concerning is the lack of familiarity among practitioners with the tools to identify ASDs. Wiggins et al[63] found that 70% of practitioners do not use a diagnostic instrument when assessing for an ASD. Furthermore, Dosreis et al[64] found that 82% of the pediatricians sampled screened for general developmental delays but only 8% screened for ASDs. The main reason cited was lack of familiarity with specific tools for ASDs (62% of respondents).

Even in toddlerhood, many physicians are not recognizing the signs of ASDs and are unnecessarily delaying diagnosis. As a consequence, children with an ASD are not receiving intervention in their critical early years.[1,39,65–68]

IMPORTANCE OF EARLY DETECTION AND DIAGNOSIS

Early identification of the signs of autism spectrum disorders (ASDs) is the first step to facilitating early referral and diagnosis. Early diagnosis provides the best opportunity for early intervention, which serves to maximize developmental outcomes for affected children and their families. It is widely recognized that the earlier intervention begins in child's development, the better the opportunities to move the young child toward a more typical developmental trajectory because of the plasticity of the young brain.[1,69] However, few studies have investigated the efficacy of intervention before 2 years, and there continues to be a need for more randomized controlled trial studies in this area.[1,70,71] Despite this, the results from these few studies, including those that use case reports and single-subject designs, are promising.[1,71–78]

Importantly, the onset of secondary (compensatory) behaviors may be prevented, or at least minimized, with early intervention.[27,45] Furthermore, if a child is referred before a "drop off" in language and social skills, the impact of early intervention is even greater, as it may prevent some of these losses.[1] Mundy and Crowson[79] proposed a "cybernetic model" of ASDs, whereby an initial pathological process (i.e., a decrease in attending to and processing social stimuli) feeds back on itself during the first 2 years of life, resulting in a secondary neurological disturbance (i.e., resulting in secondary deficits of ASDs). They argue that without early intervention, the effects of secondary neurological disturbance push the child with an ASD further away from the path of typical development, as the initial pathological process and secondary neurological disturbance continue to feedback on the child's developing nervous system. Thus, early detection leading to early intervention reduces the cumulative effects of secondary neurological disturbance, consequently keeping the child closer to the path of typical development, in comparison with those who do not receive such intervention (Fig. 1).

Early detection and diagnosis also means that the delays and the resulting distress that families often face when trying to obtain a diagnosis for their child are avoided or minimized.[58] Indeed, the main factor associated with parental satisfaction in the diagnostic process is early diagnosis.[41] Thus, it is no surprise that parents want to be told at the earliest possible opportunity if there is any concern about their child's development or well-being.[80]

SCREENING STUDIES

The increasing knowledge of the early signs of autism spectrum disorders (ASDs) coupled with the benefits of early intervention has led researchers to develop screening tools to identify ASDs in infancy and toddlerhood. Although the majority of these studies are based on Level 2 screening (i.e., screening for ASDs in populations with developmental anomalies), some studies have attempted to identify children with an ASD who have not previously

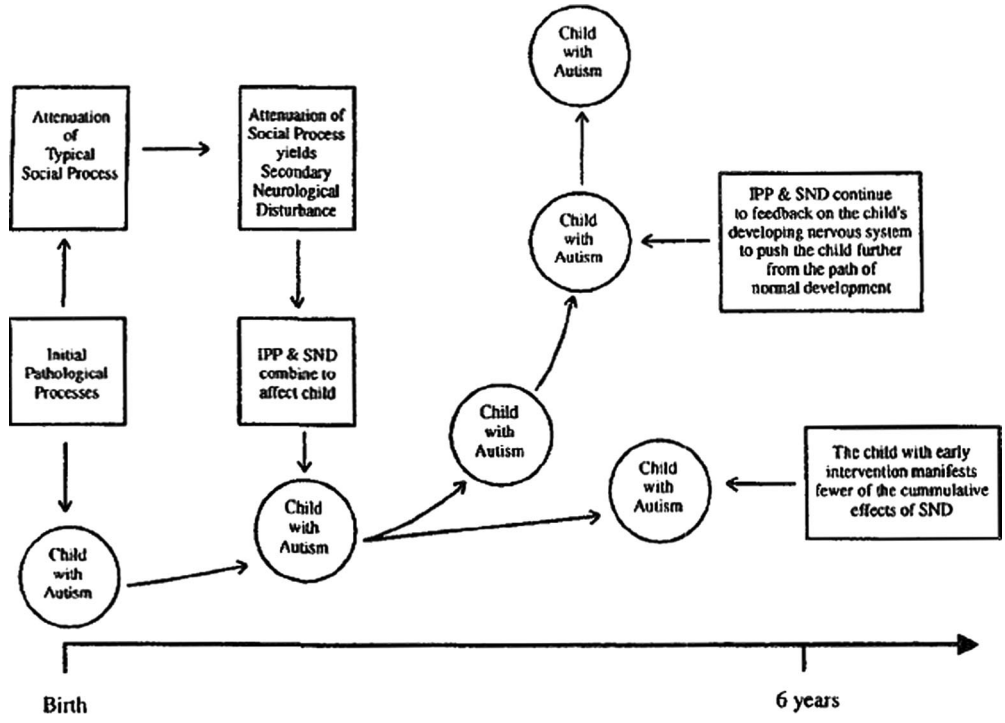

Figure 1. Path of typical development. Mundy and Crowson's cybernetic model of ASDs.

been identified with developmental problems. Prospective screening studies conducted in the general population are known as Level 1 screening studies.[81,82] Prospective studies have also been conducted with siblings of children with an ASD (ASD-sibs), as they are at increased (genetic) risk of developing an ASD.[83–85]

Delayed Population (Level 2) Screening Studies

Level 2 screens focus specifically on differentiating children at risk for an ASD from other developmental difficulties, such as general developmental or language delays, and are more detailed than Level 1 (or general population based) screens. They are usually administered in specialized settings, take more time to administer,[81,82] and have thus provided substantial information about ASDs in infancy and toddlerhood.

The Screening Tool for Autism in Two-Years-Olds (STAT) (Stone WL, Ousley OY, unpublished manuscript, 1997) was designed to differentiate 2-year-old children at risk of autistic disorder (AD) from those at risk of other developmental disabilities. It is an interaction-based measure of 12 items assessing play, motor imitation, communication, and joint attention skills. To develop a scoring algorithm that would maximize identification of AD, and also to examine the validity of the STAT, Stone et al[86] used this tool with 19 children with AD and 54 children with non-AD developmental disorders. The development analyses resulted in a sensitivity of 1.00, and a specificity of 0.91, and the validity analyses resulted in a sensitivity of 0.83 and a specificity of 0.86.

To develop cutoff scores for the STAT, Stone et al[87] used signal detection procedures with developmentally matched groups of 26 children with AD and 26 children with non-ASD disorders. The specificity, sensitivity, and positive (PPV) and negative predictive values (NPV) were all very high, and the inter-rater agreements and test-retest reliability were also high. However, despite the excellent psychometric properties of the STAT, it is designed for use with children aged 2 to 3 years and is only aimed at differentiating AD (rather than all ASDs) from other developmental disorders.[88]

To determine the utility of the STAT with children younger than 24 months, and its ability to distinguish between the milder forms of ASDs and other developmental problems, Stone et al[89] administered it to 71 high-risk children (59 ASD-sibs and 12 referred due to developmental concerns) aged 12 to 23 months. Using an increased cutoff score to reflect less developed social and communication skills in younger children, the screening properties for identifying children with an ASD at 14 months and older were good (sensitivity: 0.93; specificity: 0.83; PPV: 0.68; NPV: 0.97) but inadequate for 12- to 13-month-old children. As the sample size of the children who went on to receive a diagnosis of an ASD was small (n = 19), these results should be interpreted with caution until they are replicated in larger samples.

A new tool, the Autism Detection in Early Childhood (ADEC) (Young R, Brewer N, Williamson P, unpublished manual, 2007), has recently been developed in Australia. Previously known as the Flinders Observational Schedule of Preverbal Autistic Characteristics (Young R, Brewer N, Pattison C, unpublished manuscript, 2001), it is a semistructured observational scale for identifying the primary core deficits seen in preverbal infants with AD. It has been developed as a screening tool for nonclini-

cians as well as professionals, and can be used with children as young as 12 months. The behaviors targeted are early social and communication behaviors.

The psychometric properties of the ADEC were assessed in a sample of 149 children with AD, 60 typically developing (TD) children, and 60 children with language or other developmental disorders (Young R, Brewer N, Williamson P, unpublished data, 2007). It was shown to have good internal consistency (Cronbach's $\alpha = 0.85$), good test-retest reliability ($r = .82$), and very high inter-rater reliability ($r = .97$). The specificity of the ADEC was 0.80, and the sensitivity was 0.70, with these figures increasing to 0.90 and 0.88, respectively, when only children younger than 30 months were considered. However, despite the promising psychometric properties of the ADEC, these data are preliminary and are yet to be published in a peer-reviewed journal. Furthermore, these data are based on children with AD, many of whom were older than the targeted age. Thus, the properties of the ADEC for use with young children with all forms of ASD are yet to be established. Moreover, the study needs to be replicated with a younger, community-based sample.

Prospective Studies

Prospective studies of ASDs, conducted in community-based samples, are highly desirable for a number of reasons. First, the researcher can attempt to elicit the behaviors of interest at a particular age and under standardized conditions, allowing comparison between different groups and at different time points in the child's life. Furthermore, behaviors can be studied longitudinally, so that the relationship between early deficits and later behavioral manifestations can be examined. In addition, prospective studies have the added benefit of not only informing us of the signs of ASDs in infancy (as do Level 2 screens) but also of being able to identify previously unrecognized cases of ASDs. Prospective studies have been conducted on both high-risk populations (ASD-sibs) and in the general population.

Sibling Studies

Twin studies indicate that there is 60 to 92% concordance rate for ASDs in monozygotic twins and 0 to 10% concordance rate in dizygotic twins and siblings of affected individuals.[83–85] Consequently, studies of ASD-sibs have been an invaluable source of information on the very early development of ASDs. The Autism Observation Scale for Infants[90] was developed to investigate the behavioral manifestations of ASDs between 6 and 18 months in a sample of ASD-sibs. It includes 18-specific risk markers for ASDs, and uses a standardized procedure for detecting each of these markers through a semistructured, play-based assessment. Using the Autism Observation Scale for Infants, Zwaigenbaum et al[32] conducted a longitudinal study of 150 ASD-sibs ("high-risk" for ASDs) and 75 "low-risk" infants matched on sex, birth order, and age. Observations at 6 months did not predict classification of an ASD at 24 months. However, by 12 months, the presence of 7 risk markers prospectively identified 6 of the 7 children diagnosed with an ASD at 24 months, compared with 2 of the 58 non-ASD siblings, and none of the 23 low-risk controls. Thus, the sensitivity and specificity of the Autism Observation Scale for Infants were 0.84 and 0.98, respectively.

The individual markers on the Autism Observation Scale for Infants that predicted a diagnosis of an ASD at 24 months were abnormal eye contact, visual tracking, disengagement of visual attention, orienting to name, imitation, social smiling, reactivity, social interest, and sensory-orienting behaviors (all $p < .003$, adjusting for multiple comparisons). These preliminary data now need to be replicated in the full sample. Unfortunately, as there was no non-ASD developmentally delayed comparison group, we cannot be sure whether these behavioral markers are specific to ASDs or whether they share these markers with other developmentally disabled groups of infants.[32]

Bryson et al[91] prospectively followed 9 of the ASD-sibs from the Zwaigenbaum et al study[32] who received an ASD diagnosis (at 24 months) at 6 monthly intervals until 24 months, and then again at 36 months. All of these children showed, in varying degrees, a combination of impaired social-communicative development. Furthermore, there was evidence for the emergence of 2 subgroups, with the first subgroup defined by a major drop in cognitive development from 12 to 24 months; the second subgroup maintained their cognitive profile of average or near-average intelligence. The cognitive profiles of these 2 groups were indistinguishable at 12 months (8 of the 9 infants had average or close to average intelligence quotients) however, 6 of these children had severe cognitive impairments by 24 and/or 36 months.

Landa and Garrett-Mayer[92] compared a group of ASD-sibs (n = 60) and TD infants (n = 27) at 6, 14, and 24 months, on their performance on each of the subscales of the Mullen Scales of Early Learning[93] (fine and gross motor, visual reception, and receptive and expressive language). As with Zwaigenbaum et al[32] and Bryson et al,[91] there were no statistical differences in the behavioral presentations of ASD and non-ASD groups at age 6 months, and there was "developmental worsening" between 14 and 24 months for the ASD group. This period of slowed development between 14 and 24 months emphasizes the importance of early intervention, as this increase in developmental delay may be minimized if intervention begins before this stage.

Sullivan et al[94] conducted a prospective study on response to joint attention (RJA) with 51 ASD-sibs at 14 and 24 months and again at 30 to 36 months. Three groups were established: ASD (n = 16), "broader autism phenotype" (BAP; n = 8), which comprised children who displayed language and/or social delays but were not given a classification of an ASD at 3 years, and non-BAP (n = 27), which included children who did not meet classification of BAP or an ASD at 3 years. Deficits

in RJA were present by 14 months in the children later diagnosed with an ASD and BAP. However, although there were large improvements in RJA for the BAP and non-BAP groups at 24 months, there was minimal improvement for the ASD group. Moreover, as performance on RJA at 14 months predicted later language and ASD outcome, Sullivan et al concluded that RJA is an important behavior for the early screening of ASDs and subsequent intervention.

Another prospective study investigating the BAP was conducted by Cassel et al.[95] In comparison with non-ASD siblings (n = 19), ASD-sibs (n = 12) were found to engage in lower rates of higher level behavioral requests (i.e., pointing at, or giving the examiner a desired toy, with or without eye contact) at 12 months, lower rates of initiating JA (i.e., pointing at an object or event out of interest, with or without eye contact; holding up a toy to show it to the examiner) at 15 months, and lower rates of RJA (i.e., following the examiner's gaze or point) at 18 months. Although the diagnostic status of these infants has not yet been determined, the results demonstrate the BAP in both ASD-sibs who do not go on to receive a diagnosis of an ASD and those who do.

Mitchell et al,[96] in their prospective study of 97 ASD-sibs and 49 low-risk controls, found that the children who received a diagnosis of an ASD at 24 months (n = 18) showed deficits in language and communication as early as 12 months. These infants understood fewer phrases and produced fewer gestures by 12 months (e.g., giving, pointing, showing, shaking and nodding head, holding arms up to be lifted, and knowledge of appropriate use of real and toy objects); at 18 months, they showed delays in their understanding of phrases and single words, use of gestures, and production of single words. As production and comprehension of words did not differ significantly between children with and without an ASD until 18 months, the authors argue that use of gestures may be more important in prospectively identifying ASDs in children younger than 18 months.

In addition to the social and communication impairments that are consistently reported in infants with ASDs, behavioral reactivity, difficulties with transitions, and impaired motor control have also been found to account for unique variance in ASD risk in a sample of 115 18-month-old ASD-sibs.[97] Furthermore, Ozonoff et al[98] found that 12-month-old ASD-sibs engaged in significantly more spinning, rotating, and unusual visual exploration of objects than the non–ASD-sibs. Thus, although social and communication impairments have been found to be the best predictors of ASDs in infancy, future research should focus on the subtle and very early behavioral manifestations alongside social and communication impairments.

Despite the recent surge of research with ASD-sibs and the invaluable insights gained into their early development, some caution needs to be exercised when interpreting the results from these studies. First, many are designed to compare groups based on risk status and not on eventual diagnosis. If the ultimate aim in these prospective studies is to improve knowledge of the early signs of ASDs in infancy, and to use these signs to prospectively identify young children, then eventual diagnostic status of these ASD-sibs becomes critical.[99] Second, high-risk samples are unique and are not representative of a "true" prospective sample. Children who have grown up in an environment already affected by an ASD may have different symptomatology in comparison with those children with an ASD who were not reared in that environment. Moreover, it has been found that children with an ASD from multiplex families are higher functioning in adaptive skills and cognitive development than those from singleton families.[100]

Thus, numerous factors need to be considered as possible influences contributing to differences in development, including alteration in parent–child interaction, early recognition of symptoms and subsequent intervention, affected parenting styles because of exposure to early intervention techniques, and parental stress.[99] In addition, genetic expression of ASDs may differ in multiplex compared with singleton families, although there is little research to date investigating this possibility.

General Population (Level 1) Screening Studies

Level 1 ASD screens are used to identify children for general developmental disability, with specific emphasis on the signs of ASDs. These screens are used in the general population and are usually applied in community health services, such as in infant and child health centers or in general medical practice settings.[81,82] There are currently very few screening studies for ASDs that have been conducted in community-based settings, and many of these have used tools that screen for ASDs at only one specific age.

Baron-Cohen et al conducted the first prospective study of ASDs. They developed the Checklist for Autism in Toddlers (CHAT),[38] designed to be administered in a primary health care setting to identify 18-month-old children at risk for an ASD. This brief observational tool was initially administered to 41 ASD-sibs and 50 TD children, all aged 18 months. Three key items (protodeclarative pointing, gaze monitoring, and pretend play) were successful in identifying children who later received an ASD diagnosis at 36 months. Baron-Cohen et al[101] subsequently used the CHAT on 16,235 18-month-old children during their routine developmental checkup. Twelve children were identified as "at risk," with 10 of these children receiving a diagnosis of an ASD and 2 receiving a diagnosis of developmental delay; these diagnoses remained stable at 3.5 years, giving a false-positive rate of 16.6%. In a long-term follow-up study of this same population, Baird et al[102] found that although the CHAT had excellent specificity (0.98), it lacked sensitivity (0.38), as 50 additional children were identified at the age of 7 years as having an ASD, none of whom had been identified as at risk at 18 months. The low sensitivity of the CHAT reduces its use as a screening instrument, as a large per-

centage of children with an ASD (approximately 60%) will not be identified by the CHAT at 18 months.

A modified version of the CHAT was developed in an attempt to increase the sensitivity of the tool. The M-CHAT[103] relies entirely on parental report and is designed for use with 24-month-old children; unlike the CHAT, it has a lower threshold for identifying ASDs. A nonselected population of 1,122 18- to 25-month-old children and a high-risk sample (referred from early intervention services) of 171 18- to 30-month-old children were screened using the M-CHAT. Six items in the areas of social relatedness and communication were found to best discriminate between children diagnosed with and without an ASD (protodeclarative pointing, response to name, interest in peers, bringing things to show parents, following a point, and imitation). Using various cutoff scores on the checklist, sensitivity ranged from 0.87 to 0.97, specificity ranged from 0.95 to 0.99, and PPV ranged from 0.36 to 0.80, depending on which cutoff scores were used, and whether the M-CHAT was followed-up with a scripted telephone interview. These preliminary data suggest that the M-CHAT is able to discriminate between ASDs and other DDs by 24 months and has a higher sensitivity for detecting ASDs than the CHAT.

In a study by Ventola et al,[104] 195 children (mean age: 24 months) who failed the M-CHAT were grouped into developmental delay (n = 15), developmental and language disorder (n = 30), and ASD (n = 150) to investigate differences in symptom presentation. Once overall language level was controlled for, only 4 items significantly differed between the DD/developmental and language disorder and ASD groups. These were all joint attention and social responsiveness items (response to name, pointing for interest and to request, ability to follow a point) reinforcing past literature that social responsiveness and joint attention behaviors are core, and particularly unique, deficits in ASDs.

To address the usefulness of the M-CHAT as a screen for ASDs in a community-based sample, as well as to establish absolute sensitivity and specificity, Kleinman et al[105] screened 3309 low-risk children (new cases) as part of their well-child care visits, and a further 484 high-risk children referred for early intervention. All children were screened at 16 to 30 months (Time 1) and followed-up at 42 to 54 months (Time 2). For the total sample, PPV at Time 1 was close to that of the original study (0.36–0.74), again depending on whether a follow-up phone interview was used; PPV for the total sample at Time 2 was similar (.59–.74). However, for the low-risk sample, PPV at Time 1 was extremely low (0.11 ± 0.05) when the M-CHAT was used alone. When used in conjunction with a follow-up phone interview, it increased to 0.65 ± 0.17. Thus, the PPV increases to an acceptable level, but only in conjunction with a follow-up phone interview, which is consistent with the findings of both Pandey et al[106] and Robins.[107] These data suggest that the use of the M-CHAT alone as a screen for ASDs in a community-based sample is problematic. The M-CHAT may be useful in identifying children in need of further assessments but should not be used as a screen to exclude the possibility of an ASD.[108]

The Q-CHAT,[109] a quantitative version of the CHAT, marks a major revision of the instrument. Like the M-CHAT, it relies solely on parental report and contains 25-items rated on a 5-point Likert scale. Its test properties and clinical validity have not yet been established, although preliminary data on a sample of 779 children (unselected group: mean age 21 months; ASD group: mean age 44 months) have resulted in a range of scores that approximate a normal distribution. Thus, the Q-CHAT may be a useful instrument to measure trait differences in the general population and not just in the ASD population. However, its revision into a parental report only measure lends itself to the problems associated with these types of measures, as discussed previously.

An ongoing longitudinal, prospective study, called the FIRST WORDS® project, uses the Communication and Symbolic Behaviors Scales[110] as a screen with children in the general population, recruited from health and child care clinics.[111] The Communication and Symbolic Behaviors Scales comprises an Infant-Toddler Checklist that parents complete when their child is younger than 24 months, and a behavior sample, which is a direct evaluation of the child after 18 months by a clinician, which is videotaped for later analysis. Wetherby et al.[112] examined the social and communication behaviors of 123 children (50 with an ASD, 23 with developmental delay, and 50 TD children) aged 18 to 26 months using the Communication and Symbolic Behaviors Scales who were recruited from the FIRST WORDS® project. Compared with children with developmental delay, who were matched on age and developmental level, the children with an ASD were found to display 5 core social and communication deficits. These included deficits in gaze shifts, following of gaze/points, rate of communicating, acts for joint attention, and inventory of conventional gestures.

To determine the efficacy of the Infant-Toddler Checklist as a general population screening tool, 5385 children from the general population were administered this checklist between 6 and 24 months.[113] Of the 60 children who went on to receive an ASD diagnosis, 56 (93%) screened positive between 9 and 24 months. However, although the sensitivity of the Infant-Toddler Checklist between 9 and 24 months is excellent, it is unable to distinguish between children with an ASD and those with communication delays, as 813 children were identified on the Infant-Toddler Checklist as needing further developmental surveillance.

Only one other community-based ASD screening study has been conducted to date. Swinkels et al[114] developed an instrument known as the Early Screening of Autistic Traits Questionnaire. A population of 31,724 children aged 14 to 15 months were first prescreened at well-baby clinics using a 4-item screening instrument, and screen-positive infants were then evaluated using the 14-item Early Screening of Autistic Traits Question-

naire. Eighteen children were found to have an ASD, indicating that it is possible to identify unrecognized cases of ASDs as early as 14 months. The items that were most predictive of ASDs were once again social-communicative in nature. "Stereotypical movements" was least predictive, reinforcing the earlier suggestion that social-communicative behaviors are the strongest predictors of ASDs, and repetitive behaviors (or stereotypies) are, perhaps, more indicative of general intellectual disability.[23,115]

The use of the Early Screening of Autistic Traits Questionnaire as a general population screen in its current form would be problematic, as it was found to have a large number of false positives (42 in total); however, none of these were TD children. Although the authors could not determine overall sensitivity, they indicated that it would have been low as their number of identified cases of ASDs was low in comparison with current prevalence rates.[116]

DIAGNOSING AUTISM SPECTRUM DISORDERS IN TODDLERS: INSTRUMENTS AND STABILITY OF DIAGNOSIS

The findings from the screening studies reviewed earlier indicate that it is possible to identify autism spectrum disorders (ASDs) in infancy and toddlerhood. It has also been shown that it is possible to accurately diagnose ASDs as early as 2 years with instruments such as the Autism Diagnostic Interview-Revised (ADI-R),[117] a standardized, semistructured parental interview, and the Autism Diagnostic Observation Schedule (ADOS),[118,119] an observational instrument consisting of 4 modules devised for individuals with varying language abilities. However, it has been found that the ADOS sometimes has lower specificity and sensitivity for classification between autistic disorder (AD) and other ASDs.[120–122] Recently, Gotham et al[122] attempted to improve the sensitivity and specificity of the ADOS in differentiating the various ASDs, by altering the current algorithm. A 12 to 31% increase in specificity in differentiating between the ASDs was achieved with nonverbal children. Furthermore, a replication study by Gotham et al[123] found that the sensitivity and specificity of these revised algorithms approximated or exceeded those of the original algorithms (except for young children with pervasive developmental disorder-not otherwise specified and phrase speech). These revised algorithms are yet to replace the current algorithms, as these findings await further replication with other research samples.

Although the ADOS is the best available instrument for diagnosing ASDs in children as young as 2 years, its use with children younger than 2 years is limited. A toddler version was therefore developed by Luyster et al,[124] with an algorithm developed for all children aged 12 to 20 months and nonverbal children aged 21 to 30 months, and another for verbal children aged 21 to 30 months. The data on 272 children aged 12 to 30 months of age produced excellent specificity and sensitivity values of 93% to 95%. Because of the variability in early development, the authors propose that the scores on the new algorithms should be used to indicate ranges of concern (i.e., little, moderate, and significant concern), rather than using traditional "cut-off" scores. The data await replication with a larger sample, and data on the stability of diagnosis using the toddler version are not yet available.

Given that there are some problems associated with the ADOS in correctly differentiating the ASDs, and with the ADI-R in correctly diagnosing AD in children with mental ages younger than 18 months,[125–127] it has been suggested that the 2 instruments be used together.[121] Le Couteur et al[128] found good agreement between the instruments in a preschool sample aged 24 to 49 months, especially for those with "classic autism" (AD). However, Ventola et al[129] found poor agreement with the ADOS and ADI-R in young children as they did not display enough repetitive behaviors and stereotyped interests to meet the cutoff for AD on the ADI-R. Therefore, Wiggins and Robins[130] excluded the behavior domain on the ADI-R when assessing toddlers at risk for an ASD and found a significant improvement in agreement between the ADI-R and other measures (including the ADOS). These findings indicate that it is advisable to use the ADI-R together with the ADOS, in conjunction with clinical judgment, when diagnosing very young children.

Reliability of Diagnosis at Age 2 Years

Diagnoses of ASDs at approximately 2 years have been found to be accurate and stable over time.[131] Lord,[49] using clinical judgment, found that 27 of 30 children retained their diagnostic classification of an ASD from 2 to 3 years. Eaves and Ho[132] found that 79% of children given a diagnosis of an ASD at age 2½ years retained their diagnosis at age 4½ years. However, the stability of diagnoses for ASDs other than AD was not as stable across time. Turner et al[133] examined the developmental outcomes of 2-year-old children 7 years after they received a diagnosis of an ASD. It was found that 88% of the children who received an ASD diagnosis at age 2 years received the same diagnosis at 9 years. In their study of 77 children aged 16 to 35 months, Kleinman et al[134] reported that 80% remained in the same diagnostic category at 42 to 82 months. As with previous studies, a diagnosis of AD was more stable than that of a pervasive developmental disorder-not otherwise specified diagnosis (85% vs. 47%).

Charman et al,[135] also investigating the outcome of children aged 7 years after their initial diagnosis at 2 years, found that 22 of the 26 children diagnosed with an ASD at 2 years (based on clinical judgment) continued to meet this diagnosis at 9 years. However, their findings on the stability of diagnosis based on psychometric and standardized tests, as opposed to clinical judgment, were not as clear, with children crossing diagnostic boundaries as they aged. Charman et al concluded that the assessment of early social-communication behaviors (using, e.g., the ADOS) gives a better indication of the diagnostic profile of young, nonverbal children than

standard psychometric tests measuring intelligence quotient and language abilities.

In summary, the follow-up studies reviewed earlier indicate that the diagnosis of ASDs is reliable in children aged 2 years. However, it is imperative that the diagnostician has sufficient training and experience in the assessment and diagnosis of ASDs, and uses appropriate tools for young, nonverbal children, which are used in combination with clinical judgment.[43]

SUMMARY AND FUTURE DIRECTIONS

The prevalent finding from studies on autism spectrum disorders (ASDs) in infancy and toddlerhood is that abnormalities in social attention and communication behaviors are evident from the first year of life and are the most predictive early signs of an ASD diagnosis. In the area of social attention, these markers include a lack of eye contact, social interaction, social smiling, imitation, orienting to name call, appropriate facial expressions, and interest and pleasure in others. In the area of communication, these markers include a lack of vocal communication, joint attention skills (protodeclarative pointing, following a point, gaze monitoring, and referencing objects/events), showing and requesting behaviors, and gestures. Impairments in imagination skills, such as the use of pretend play, have also been found to be important markers in late infancy/toddlerhood. Although sensory/motor behaviors and stereotypies are seen in some infants with an ASD, these behaviors may be more indicative of general intellectual disability,[23,115] and these behaviors may not become apparent until at least 3 years in some children.[42,45] Currently, they may not serve as important predictors of ASDs in infancy.

Level 1 screening instruments, using social attention and communication behaviors as key items, have been able to prospectively identify previously unidentified cases of ASDs in community-based samples. A highly predictive, but brief, observational tool containing a checklist of the behaviors that are absent in infants with an ASD would prove invaluable for the detection of these infants, as children who would previously go unrecognized could be identified through routine developmental monitoring and reliably diagnosed at 2 years. This is important because only 50% of parents of children with an ASD suspect a problem before 12 months.[13] However, it is apparent from the studies reviewed here that, as acknowledged by Charman,[136 (p. 1)] there are currently no instruments available with adequate sensitivity and specificity to recommend universal screening. Therefore, there remains a need for more prospective studies of infants conducted in community-based settings, as the few conducted, to date, have reported poor sensitivity on the measures used or have high false-positive rates.

The routine and repeated monitoring of behaviors throughout the infancy period, rather than a single screening at a given age, may prove more useful in detecting ASDs in infancy. The 2 large-scale prospective community-based studies reviewed here used a screening tool at a single given age. In contrast to this approach, the repeated monitoring of infant development will serve to increase the chances of identifying early manifestations of ASDs, consequently increasing the sensitivity of the screening tool used. In addition, repeated sampling will help to track the subtle changes that occur in infants with an ASD overtime[137] and aid investigation into what seems to be a critical period between 12 and 24 months, where a subset of children with an ASD progressively lose cognitive skills, whereas another maintains cognitive abilities.[91,92] Furthermore, the phenomenon of regression is well known to occur during this time period. Thus, future prospective studies should focus on systematically investigating not only the behavioral changes that occur during this important developmental period but also the milestones that children with an ASD reach in relation to those reached by their typically developing peers. In addition to aiding early identification, such a focus on the early development of the ASD phenotype will ultimately contribute to understanding the underlying neuropathology leading to the cognitive and behavioral deficits in ASDs.

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THESIS – Appendix C

PAPER 2 PUBLISHED MANUSCRIPT

Barbaro, J., Ridgway, L., & Dissanayake, C. (2010). Developmental surveillance of infants and toddlers by Maternal and Child Health nurses in an Australian community-based setting: Promoting the early identification of Autism Spectrum Disorders. *Journal of Pediatric Nursing, In Press, Corrected Proof*. doi: DOI: 10.1016/j.pedn.2010.04.007

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ELSEVIER

Developmental Surveillance of Infants and Toddlers by Maternal and Child Health Nurses in an Australian Community-Based Setting: Promoting the Early Identification of Autism Spectrum Disorders☆,☆☆

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Key words:
Autism spectrum disorders;
Infants;
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Developmental surveillance;
Maternal child;
Health nurses;
Screening

Although signs of autism spectrum disorders (ASDs) are evident during the first year of life, few children are diagnosed prior to 3 years. The objective in this article is to highlight the role that primary health care professionals can play in the early identification of ASDs by briefly outlining the successful implementation of The Social Attention and Communication Study. Maternal and child health nurses were trained on the early signs of ASDs, which enabled them to identify these children prior to 2 years. The training procedure used will be outlined, and the early signs that were monitored will be explained in detail. It is recommended that routine monitoring for ASDs in infancy and toddlerhood become standard practice among all primary health care professionals.

PRIMARY HEALTH CARE workers, particularly maternal and child health (MCH) nurses, can play a central role in the early identification of autism spectrum disorders (ASDs). Evidence for their central role comes from the successful implementation of a developmental surveillance program designed to identify infants and toddlers "at risk" for an ASD in a large community-based sample. The different types of ASDs will be discussed first, with attention to the similarities and differences between these related conditions. The Social Attention and Communication Study (SACS), conducted in Melbourne, Australia, will then be described to illustrate how ASDs can be monitored in infants and toddlers during well-baby checks, which are routinely conducted by MCH nurses in a community-based setting. Each of the key behaviors that should be used to identify "at risk" infants and toddlers will be explained in turn, highlighting how developmental surveillance can lead to effective early identification of ASDs.

An evidence base for the implementation of the developmental surveillance program will be provided by (a) briefly outlining the rate of ascertainment of ASDs in the referred sample and (b) inclusion of MCH nurses' evaluation of its implementation. The SACS was undertaken with the ultimate aim of lowering the age at which ASDs are diagnosed so that intervention can begin earlier, leading to better outcomes for the developing child and his or her family. The findings from the SACS and the nurses' evaluations lead to the conclusion that routine monitoring for ASDs should become standard practice among all primary health care professionals.

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Introduction to ASDs

Autism spectrum disorder is an umbrella term used to describe a group of pervasive developmental disorders characterized by a triad of impairments, including qualitative impairments in (a) social interaction, (b) verbal and nonverbal communication, and (c) a restricted repertoire of activities and interests combined with repetitive behaviors and stereotypies (*Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* [*DSM-IV-TR*]; American Psychiatric Association [APA], 2000). ASDs are lifelong neurodevelopmental disorders, with current prevalence rates estimated at 1 in 91 in the USA (Kogan et al., 2009), 1 in 100 in the UK (Baird et al., 2006), and 1 in 160 in Australia (MacDermott, Williams, Ridley, Glasson, & Wray, 2007). The last four decades have seen a vast worldwide increase in the number of individuals diagnosed with an ASD (Wing & Potter, 2002), which is partially attributable to lowering the age of diagnosis, as well as to the broadening of diagnostic criteria to include "milder" cases of ASDs (Gernsbacher, Dawson, & Goldsmith, 2005).

The term *ASD* includes autistic disorder (AD), Asperger's disorder (AspD), and pervasive developmental disorder—not otherwise specified (PDD-NOS). AD involves profound deficits in all three areas of the triad and is associated with a wide range of cognitive functioning (APA, 2000). Approximately three quarters of individuals with AD have an associated intellectual disability (i.e., IQ <70; APA, 2000). Those individuals without a comorbid intellectual disability are classified as having "high-functioning autism" (HFA; Tager-Flusberg, Joseph, & Folstein, 2001). Individuals with AspD closely resemble those with HFA, but they do not show evidence of significant delays in language development that characterizes AD/HFA (APA, 2000). Thus, language is the main criterion differentiating AspD and HFA. However, despite their absence of language delays (LDs), individuals with AspD do have problems in communication, failing to use and understand language in the typical way (APA, 2000). Individuals who do not fulfill the *DSM-IV-TR* (APA, 2000) criteria for a diagnosis of AD or AspD, but who show some of the specified symptoms, are given a diagnosis of PDD-NOS. These individuals may have a late age of onset, atypical or subthreshold symptomatology, or they may display all of these (APA, 2000).

Males are at an increased risk of having an ASD, with the ratio of males to females being 4:1 (Yearing-Allsopp et al., 2003). Although the underlying neuropathology of the ASDs remains unknown, there is much evidence to suggest strong genetic involvement in these conditions. Twin studies indicate that monozygotic twins have a 60% concordance rate for AD and a 71% concordance rate for all ASDs (Bailey et al., 1995). The recurrence rate of ASDs in siblings of affected individuals is estimated to be 2%–8% (Rutter, Silberg, O'Connor, & Simonoff, 1999), which is approximately 20–80 times higher than the risk among the general population (Fombonne, 2005; O'Roak & State, 2008).

Although most children with an ASD show problems in development prior to 12 months, 20% to 30% are reported by their parents to develop "typically" in the first 15 to 21 months of life. These infants reach language and social skill milestones at age-appropriate levels, but then progressively "lose" these skills. The most frequently reported skill loss is language, followed by social skills (Davidovitch, Glick, Holtzman, Tirosh, & Safir, 2000; Siperstein & Volkmar, 2004; Werner & Dawson, 2005). However, it is important to note that most cases of regression do not involve *completely* normal development prior to regression (Richler et al., 2006; Werner, Dawson, Munson, & Osterling, 2005), with some children having lower language abilities than their typically developing peers (Siperstein & Volkmar, 2004).

The phenomenon of regression, along with the increase in prevalence rates discussed earlier, led to a prolonged debate regarding the causative role of the measles–mumps–rubella (MMR) immunization that infants typically receive between 12 and 18 months of age. Despite the media popularity of this supposed "link," empirical studies have shown unequivocally that there is no association between the MMR injection and ASDs (DeStefano, Bhasin, Thompson, Yeargin-Allsopp, & Boyle, 2004; Fombonne, Zakarian, Bennett, Meng, & McLean-Heywood, 2006; Richler et al., 2006).

Importance of Early Detection and Diagnosis

Early identification of ASDs is the first step to facilitating referral and diagnosis. Early diagnosis is crucial because it provides the best opportunity for specialized early intervention, which serves to maximize developmental outcomes for affected children and their families. The benefits of early intervention for children with an ASD are now unquestionable (see Dawson, 2008; Rogers & Vismara, 2008, for an overview) and, if instituted early enough, can serve to move the young child toward a more typical developmental trajectory. Early intervention can also prevent the onset of secondary manifestations of the disorder, which appear later in childhood, such as aggressive or self-harming behaviors, restricted rituals or routines, and severe difficulties socializing with peers (Dawson 2008; Young & Brewer, 2002). Importantly, if a child is referred before a loss in language and social skills, as reported earlier, the impact of early intervention is even greater, as it may prevent some of these losses (Dawson, 2008).

Early detection and diagnosis also mean that the frustrating delays and the resulting distress that families often face when trying to obtain a diagnosis for their child are avoided or minimized (Siperstein & Volkmar, 2004). Indeed, the main factor associated with parental satisfaction in the diagnostic process is early diagnosis (Goin-Kochel, Macintosh, & Myers, 2006; Howlin & Moore, 1997). Thus, it is no surprise that parents want to be told at the earliest possible opportunity if there is any concern about their child's

development or well-being and are more satisfied if their early concerns are accepted and addressed by health care professionals (Brogan & Knussen, 2003).

Monitoring for ASDs in the Community

There is currently no universally recommended screening program for detecting ASDs, despite the American Academy of Pediatrics (American Academy of Pediatrics [AAP], 2007; Johnson & Myers, 2007) calling for routine screening for signs of ASDs in the second year of life. The American Academy of Neurology (Filipek et al., 2000) recommends a 2-step process whereby all children undergo developmental surveillance at every well-child visit, and if identified as at risk for an ASD, an ASD specific screen and follow-up diagnostic testing are recommended. The importance of developmental surveillance over developmental screening, which is a broader concept, has been advocated since the 1980s (Dworkin, 1989). With developmental surveillance, one does not administer a set screen, which rapidly gives an estimate as to a child's risk status. Rather, the skilled observer's judgment about the child is incorporated with any parental concerns about the child's development each time the practitioner comes into contact with the child, not just at set health checks (Curry & Duby, 1994). Dworkin refers to this as "opportunistic surveillance," and the importance of this concept in monitoring early signs of ASDs in the community is emphasized throughout this article.

There is general consensus that MCH nurses and related practitioners (e.g., nurse practitioners, pediatric, "well-baby," and community nurses) are well placed to undertake developmental surveillance of young children to identify those showing early signs of ASDs (Curry & Duby, 1994; Dworkin, 1989; Halpin & Nugent, 2007; Nadel & Poss, 2007; Pinto-Martin, Souders, Giarelli, & Levy, 2005a). In fact, Chakrabarti and Fombonne (2001), in their study of referrals for possible ASDs, found that two thirds of all children diagnosed with an ASD over the period of 2 years were first identified by their health visitor.

In the UK, there has been a move away from using health visitors to conduct routine developmental surveillance of children up to 3½ years, which has raised concerns as to possible lost opportunities to detect ASDs at an earlier age (Halpin & Nugent, 2007; Tebruegge, Nandini, & Ritchie, 2004). Tebruegge et al. (2004) suggest that if developmental surveillance is no longer implemented by health nurses, suitable methods to detect children at risk of developmental disorders, including ASDs, are needed. Sole reliance on the implementation of tools such as the Parents' Evaluation of Developmental Status (PEDS; Glascoe, 1998), which rely on parents raising concerns with their practitioner, is therefore problematic. Although the recommendation is that the PEDS is used as a supplemental assessment during well-baby checks, there is the danger that some health professionals will not undertake further developmental monitoring of a child by using skilled clinical observations if the parents do not raise concerns with them. Young children's development needs to be closely monitored for developmental anomalies despite a lack of parental concern, as many parents and family members do not recognize developmental concerns with their young children, especially in the first year of life (Werner, Dawson, Osterling, & Dinno, 2000). Therefore, lack of, or failure to report, parental concerns does not necessarily imply typical development. Pinto-Martin et al. (2008) have found that the PEDS misses the majority of children who screen positive for an ASD on an ASD-specific tool, with Glascoe, Macias, Wegner, and Robertshaw (2007) also stating that the PEDS alone is not useful in identifying ASDs and must be used in conjunction with an ASD-specific tool.

MCH nurses, who routinely see children at key stages in their development, are not only the best placed to monitor abnormal development but are also the most expert to do so, given their extensive knowledge and training on developmental milestones (Curry & Duby, 1994; Halpin & Nugent, 2007). With a firm knowledge in early child development, the MCH nurse can, through routine developmental surveillance and monitoring, identify potential problems via observation of the child's responses, interactions, and play and can thus serve as leaders in the identification of ASDs in infancy (Curry & Duby, 1994; Nadel & Poss, 2007).

The MCH Service

In the State of Victoria, Australia, infant and child development is monitored through the universal MCH service, which is offered free of charge to all families with children less than 6 years of age (Department of Education and Early Childhood Development [DEECD], 2007a). The major provider of MCH services is local government, which is responsible for the provision of service to metropolitan, rural, and remote areas of the state (DEECD, 2007a). The MCH service program standards identify their role as one of surveillance, screening, and assessment to enable "early detection of, and intervention for, physical, emotional and social factors affecting young children and their families" (DEECD, 2009, p. 5).

The primary aims in this service are to monitor children's growth and development, to promote the health and well-being of families with young children, and to provide anticipatory guidance and support to parents (Australian Nursing Federation [ANF], 1999). The MCH nurses within the service are highly trained, with qualifications in general nursing and midwifery, as well as the Child, Family and Community nursing specialty. As part of the universal MCH service, well-baby checks are scheduled at key ages from birth to 3½ years. Given that 98% of Victorian babies access the MCH service soon after birth and attendance remains relatively high within the first 2 years (DEECD, 2007b), this

universal service has enormous potential to identify infants at risk of a host of developmental disorders, including ASDs.

Implementation of Developmental Surveillance in a Community-Based Setting

Pinto-Martin et al. (2005a), in arguing for the importance of routine screening for ASDs in pediatric primary care, cited various barriers to standardized screening, including costs, large patient volumes, diminished reimbursements for staff, and failure to attend appointments by parents. Issues with screening tools themselves included length, variety, lack of uniformity in regards to their properties, and lack of formal training for practitioners in administration and scoring of the tools. They argue that if developmental screening is to be universal, these issues need to be addressed. Furthermore, it is also recognized that scientific research vastly precedes current practice and that "Integration of routine developmental screening into pediatric primary care is still an unrealized goal" (Pinto-Martin et al., 2005b, p. 1932). It is for this reason that the SACS was launched in metropolitan Melbourne, Victoria, in 2006.

The overall objective of the SACS was to determine whether routine and repeated monitoring, within the MCH service, of key markers of ASDs in infancy (see Barbaro & Dissanayake, 2009, for a review) could be used to prospectively identify infants who will receive a diagnosis of an ASD in a community-based sample. Many of the issues raised by Pinto-Martin et al. (2005a) were addressed in designing the SACS, which used a developmental surveillance approach rather than a screening approach. Relying on a screening tool, which is administered at one point in development, leads to many missed opportunities for identifying at risk children (e.g., Baird et al., 2000; Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006; Swinkels et al., 2006).

The approach used in the SACS was a low-cost one and designed to be implemented in centers with large volumes of children as *part of*, rather than *in addition to*, the well-baby check. The procedure was therefore brief and only added time to the consultation if there was a concern with the child's development.

Training Procedure and Results of the SACS

A cohort of 22,168 children was monitored though 184 MCH centers in 17 local government areas (LGAs) in metropolitan Melbourne, over a 6-month period, between September 2006 and June 2007. The LGAs were chosen based on proximity to facilitate ease of referral, with most centers within a 20-km radius of a Melbourne University, where the study was conducted.

Each child was monitored by their MCH nurse from 8- to 24-months of age; however, children were only referred to the SACS team at the Child Development Unit (CDU) at the University from 12 months of age. The nurses in each LGA received a 2½-hour training workshop. 241 nurses were trained from September to December 2006 to monitor infants' development for the early signs of ASDs during four routine consultations undertaken at 8, 12, 18, and 24 months of age. The workshops focused on typical and atypical social–communicative development, the early (and later) signs of ASDs, as well as the particular items within the MCH record at each age, which were relevant to the detection of ASDs. Items that were most relevant to ASDs, and developmentally appropriate for the age being monitored, were underlined and considered "key" items. Children were considered at risk for an ASD only if they showed a "pattern" of failure on the items of interest, for example, by failing three of the four key items. These behaviors and the criteria for a pass/fail are detailed in Appendix A.

The nurses were instructed to readminister failed items a maximum of three times and were specifically trained to identify when a behavior was *atypical*, as opposed to present or absent. Video clips showing examples of children with and without an ASD were used as part of the training for the behaviors of interest. Nurses were also trained on how to raise concerns with parents of children identified as at risk.

216 at risk children were referred by the nurses to the SACS team at the CDU for a developmental and behavioral assessment. Children at risk, whose caregivers agreed to participate in the study, were initially seen and followed up by the team at 6-monthly visits, until he or she was 24 months old, when a diagnostic assessment was undertaken using the Autism Diagnostic Observation Schedule (Lord et al., 2000), and the Autism Diagnostic Interview—Revised (Lord, Rutter, & Le Couteur, 1994).

110 children, whose parents consented to participation, were assessed at the CDU. Of these, 89 children met criteria for an ASD, resulting in an ascertainment rate (positive predictive value [PPV]) of 81%. Only one typically developing child was referred to the SACS, with the remaining 20 children (18%) meeting criteria for a developmental delay and/or LD. Importantly, 9 of the 10 12-month-olds (PPV: 90%) and 30 of the 38 18-month-olds (PPV: 79%) who were referred to the SACS met criteria for an ASD. The estimated sensitivity and specificity of the SACS, based on the current prevalence rates of 1 in 100 in the UK (Baird et al., 2006), is 83.8% and 99.8%, respectively. The prevalence rates in the UK were used because this was the closest to that found in the SACS of 1 in 119 children. Further discussion of the SACS, including how specificity, sensitivity, and prevalence rates were estimated, is beyond the scope of this article and is detailed in Barbaro and Dissanayake (in press, 2010).

The data show, without question, that not only is it possible to monitor for ASDs in the community, but also that MCH nurses are able to *correctly* identify and refer infants

and toddlers with an ASD as a result of their training on the early signs of ASDs. The remaining children who do not meet criteria for an ASD nonetheless have other developmental problems. The nurses' knowledge of early child development clearly facilitated their ability to successfully monitor signs of ASDs in these very young children. The results strongly indicate that MCH nurses have a key role to play in the early identification of ASDs and other developmental anomalies. The behaviors used to identify ASDs in infants and toddlers in the SACS will be described individually to assist all primary health care professionals, including MCH nurses, to monitor the development of these behaviors.

Early Signs of ASDs

Social Attention and Communication Behaviors

Delayed, absent or abnormal development in the behaviors listed below should be considered "red flags" for an ASD. It is important to note that the presence of any of these behaviors does not exclude the possibility of an ASD. Rather, it is paramount that the *quality* of these behaviors be monitored in addition to their presence or absence. Furthermore, the behaviors listed should not be used in isolation to identify whether a child is at risk for an ASD but should, instead, be considered in combination to indicate "risk." A reference table, summarizing the information below, is provided in Appendix B to enable practitioners to quickly refer to it during their busy consultations. Practitioners can then use this information to fill out the SACS checklists in Appendix A.

Social Games—Peek-a-Boo (8 Months)

When engaging in a game such as peek-a-boo, look for use of eye contact, reciprocal social smiles, anticipatory postures, or imitation of the actions. Many children with ASDs will not engage in many or all of these behaviors during this game with adults.

Eye Contact (8 to 24 Months)

Eye contact should be monitored not only for its presence/absence but also for its quality. Signs of atypical eye contact include a lowered frequency, inconsistency of use (e.g., not making eye contact when giving objects), and the fleeting nature of the contact. Abnormal eye contact is perhaps *the* most important behavior to look for when considering if a child has an ASD.

Turning to Name Call (8 to 24 Months)

Does the child turn to look at others when his or her name is called out? If so, consideration should be given to the number of prompts required for a response or the consistency of the response. Children with ASDs often do not respond when their name is called, *especially* if it is someone other than their parents calling them.

Social Smiling (8 to 24 Months)

Monitoring children as they enter a room is useful to check for spontaneous social smiles. Smiles without directed eye contact are not social and tend to be more typical of children with an ASD.

Imitation (8 to 24 Months)

If a child is not copying things others do, such as poking one's tongue out, waving or clapping, and other common activities, this is a cause for concern. However, some children with an ASD may imitate, so the *presence* of imitation does not exclude a child from having an ASD.

Use and Understanding of Language (8 to 24 Months)

Use of language. Is the child using single syllables and combining these into babble such as gaga/mama/dada by 8 months? Does he or she babble in a conversational manner? Does he or she use 1 to 3 words by 12 months, 5 to 10 words by 18 months, and 20 to 50 words by 24 months? He or she should also be combining 2 words together by 2 years of age.

Understanding of language. Infants should be able to understand "Give me" by 12 months, obey simple instructions (e.g., "Give me the block," without using gestures) by 18 months, and follow simple commands (e.g., "Go and get your shoes," again without using gestures) by 24 months. If a child presents with *both* receptive and expressive LDs, as opposed to an expressive delay alone, they are at a higher risk of having an ASD.

Pointing (12 to 24 Months)

The failure to point (with an extended index finger) by at least 15 months is a strong sign of developmental concern. If the child does point, it must be *combined with* eye contact to be communicative. Some children with an ASD will point to things but will not combine this with eye contact or may only point to *request* things (e.g., a drink, an unreachable object) rather than to "share" or "show" things (e.g., a bird, a plane).

Joint Attention—Following Another's Point and Gaze (12 to 24 Months)

Many children with an ASD fail to *follow* another's point and gaze by either not looking at the target or, instead, looking at the person's hand/finger. Furthermore, they may not alternate their gaze between a person and an object or event for *sharing attention* (not requesting).

Social Gestures (12 to 24 Months)

Children with ASDs typically use fewer social gestures such as clapping and waving. If the child does wave or clap, look for an absence of other gestures like nodding for "yes" or shaking his or her head for "no" (for 18- to 24-month-olds).

Showing: Social Communication (18 to 24 Months)

Does the child show things to others by holding them up or giving them, *combined* with eye contact? This behavior is distinct from giving something as a request, for example, giving a container to be opened or a book to

be read. Showing behaviors are very rarely seen in children with ASDs.

Pretend Play (18 to 24 Months)

Children begin to engage in pretend play at around 15 months and should be doing so by *at least* 18 months. Although some children with ASDs engage in pretend play, they rarely "share" this experience with others or try to incorporate others into their play. When assessing a child's pretend play skills (such as their ability to feed a "teddy"), the behavior should not first be shown, as you want to assess *spontaneous* pretend play. It is important to note that many children with ASDs will engage in functional play (such as pushing a toy car or using a toy phone).

Interest in Other Children—Parallel Play (24 Months)

Does the child play near (not necessarily with) other children? Do they show an interest in other children by watching them play, approaching them, or giving them objects such as toys? Typically developing children will usually show an interest in other children by 24 months, but this is less frequently seen in children with an ASD.

Aberrant Behaviors

Abnormal behaviors are not useful *predictors* of ASDs in infancy and toddlerhood. Firstly, not all children with ASDs will exhibit aberrant behaviors, or if they do, they differ greatly between children. Secondly, although some of these behaviors can occur at any age (e.g., sensory behaviors and interests and subtle repetitive and stereotyped behaviors can occur prior to 12 months, such as hand flapping or prolonged visual examination of lights), they typically emerge after 2 to 3 years of age (Young & Brewer, 2002). Thus, it is important to note that an absence of atypical behaviors in infancy and toddlerhood *does not* exclude the possibility of an ASD. However, knowing what common abnormal behaviors are sometimes seen in very young children with ASDs can assist in identifying these children, especially if they also exhibit deficits in social attention and communication behaviors, as described above.

It should also be noted that many of the aberrant behaviors described below may sometimes be seen in typically developing children. However, typically developing children may not become as invested or preoccupied in these behaviors, so consideration should be given to the amount of time engaged in these behaviors and their intensity. A quick reference table is provided in Appendix C.

Using Another's Hand/Body as a Tool

Young children with an ASD will sometimes manipulate another's hand as if it was a tool. For example, they may pick up someone's hand and *place* it on an object, such as a container, to request it be opened, or the child may use another person's finger to point to pictures in a book.

Repetitive Behaviors

The most common repetitive behaviors include lining up objects and toys and/or sorting them (sometimes arranged according to color, shape, or type); spinning objects such as wheels, lids, toy rings on a table (may be observed in children as young as 12 months); placing their head on the floor or table to observe toys with wheels being rolled from side to side; continuously holding an object in one or both hands; obsession with particular objects or toys and frequently seeking them out or holding them (e.g., circular objects, lights, balls, cars); repeatedly flicking switches such as lights and power points; repeatedly pushing buttons; opening and closing objects or repeatedly throwing objects.

Stereotyped Behaviors

Flapping of the hands or arms is commonly seen in some children with ASDs when they are excited and/or frustrated. Children with ASDs may also walk on tiptoes, spin their body on the spot, or shake/vibrate their body while completing activities or when excited. This latter behavior may also occur with clenched fists and gritted teeth.

Sensory Behaviors and Interests

The most commonly observed sensory behaviors include visual examination of objects by: holding them up and peering at them, using their peripheral vision, or placing them very close to the face; smelling or licking objects; sensitivity to everyday sounds such as a music box, blender, vacuum cleaner, and so on and becoming distressed and/or placing their hands over their ears; repeatedly exploring the tactile properties of objects and surfaces by, for example, feeling materials in-between their fingers such as tags on clothes or people's hair or running sand or dirt though their fingers.

Ritualistic Behaviors and Routines

Parents may report that their child has to drink from a specific bottle, does not like different foods to touch each other on the plate, will only eat certain colored or textured foods, has to put things in certain places, must have all the lights switched on or off or have all the doors in the house opened or closed, and so on. Any other rituals or routines that seem fixed and that the child seems under pressure to complete are also important to note.

Echolalia

Verbal toddlers with an ASD may display echolalia, where they repeat what is said to them. For example, when asked "Can you stack these blocks?" the child repeats, "Stack these blocks." These words are typically repeated with the same intonation as originally said.

Loss of Skills

Skill loss is an important marker for developmental concern. Many children with an ASD may not show typical "regression" as was explained earlier but may, instead, show more subtle losses. Many parents report that their child said "mama/dada" or other first words early on (8 to 12 months of

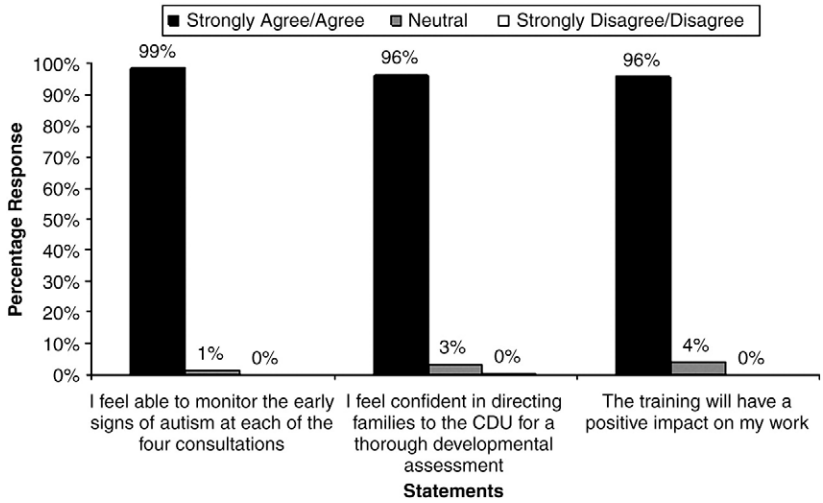

Figure 1 Percentage response by MCH nurses at the initial training evaluation—Time 1.

age), made more eye contact, used to smile more, or wave bye-bye, and so on, but subsequently lost these skills or currently uses them less frequently. Thus, if *any* loss of language or social skills occurs, other signs of ASDs described here should be explored.

Evaluation of the SACS Implementation by MCH Nurses

The MCH nurses who participated in the SACS were asked to evaluate its implementation at three time points: immediately after the initial training workshop (Time 1), 6 to 9 months after commencement of the study (Time 2), and immediately after completion of the study (Time 3). Nurses rated items on a 5-point Likert scale from *strongly agree* to *strongly disagree*. All nurses (241) completed the evaluation at Time 1, 83% of nurses completed the evaluation at Time 2, and 68% of nurses completed the evaluation at Time 3 (the nurses from two councils did not complete an evaluation at the last time point due to non-participation).

Summary data from the evaluation administered after the initial training workshop are presented in Figure 1. On the basis of their training, nurses reported that they felt able to monitor the early signs of ASDs between 8 and 24 months of age and included comments such as, "…will be more diligent in looking at development at 8, 12, 18, and 24 months," "helped me understand at a deeper level the importance and relevance of social attention and communication signs." They also felt confident in being able to refer infants at risk of an ASD and reported that the training will have a positive impact on their work: "…the study will not to be difficult to incorporate into practice," "…a great opportunity to participate in evidence based practice."

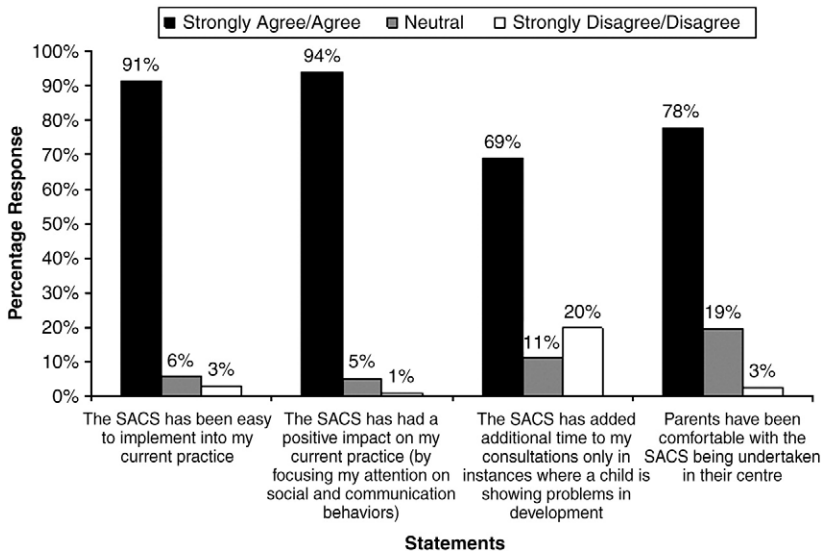

Figure 2 Percentage response by MCH nurses at the 6- to 9-month evaluation—Time 2.

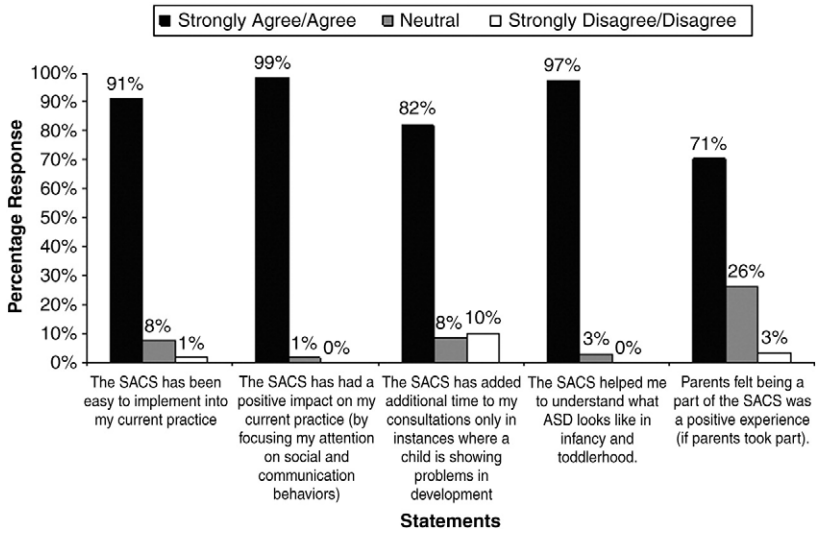

Figure 3 Percentage response by MCH nurses at the final evaluation—Time 3.

At the 6- to 9-month evaluation (Figure 2), most nurses reported that the SACS was easy to implement into their current practice, had a positive impact on their current practice, and that it did not take much additional time to include as part of their regular checks, with most nurses agreeing that additional time was added only in instances where a child was showing problems in their development: "If a child has a developmental problem, the consult takes longer but not because we are using SACS." Most of the parents were also reported as being comfortable with the SACS being undertaken at their centers: "Parents are interested and fascinated with this—has led to healthy discussion," "…my ability to discuss concerns with parents has been enhanced."

At the completion of the study, the nurses reported that the SACS helped them to understand the presentation of ASDs in infancy and toddlerhood (Figure 3). For those nurses who referred children to the SACS, most reported that parents felt being part of the SACS was a positive experience: "Excellent study. My knowledge was reinforced and I'm now more confident in handling this with parents. Parents have also become more aware of necessity for diagnosis and help in looking for concerns."

Figure 4 indicates that the nurses were very confident in looking for signs of ASDs at each of the consultations at both the 6- to 9-month evaluation and the final evaluation: "I cannot thank you enough for the knowledge and confidence I have gained in picking up the children," "This study has been empowering to help me look for signs of ASD. I am much more confident in looking for the signs." Finally, the nurses reported that they would like to see the model implemented permanently to help identify ASDs as early as possible: "I wish we had this type of training regularly throughout our practice," "The best tool and the best study I have ever been involved with."

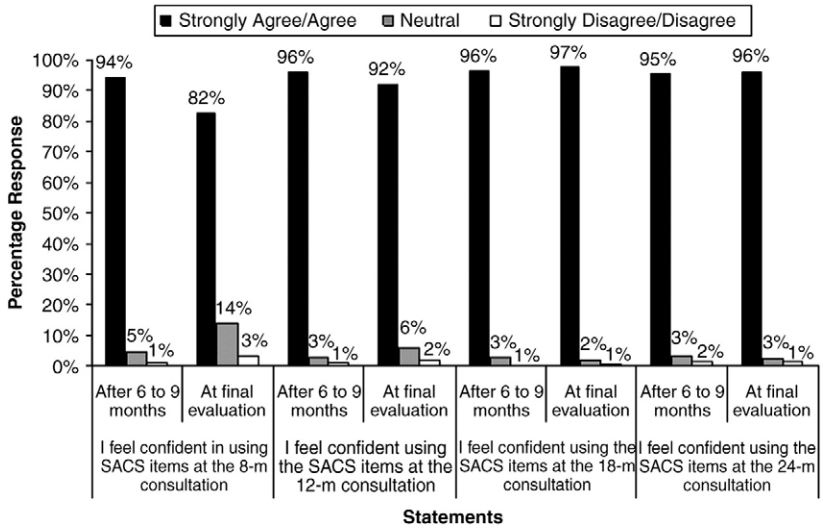

Figure 4 Percentage response by MCH nurses of their confidence in looking for signs of ASDs at each age—Time's 2 and 3.

Future Directions

Implementation of Developmental Surveillance of Social Attention and Communication Behaviors

On the basis of the results from the SACS and the nurses' evaluations of its implementation, it is argued here that developmental surveillance of social attention and communication behaviors should be undertaken universally and preferably within children's regular health checks during their second year of life (Curry & Duby, 1994; Dworkin, 1989; Filipek et al., 2000; Pinto-Martin et al., 2005a). By training MCH nurses on the early signs of ASDs, it has been possible to prospectively identify infants with an ASD in a community-based setting as early as 12 months of age.

Although the Victorian MCH service differs from other Australian and international early childhood services, the SACS procedure could be easily incorporated into well-child checks carried out by other primary health care workers, for example, health visitors in the UK or pediatricians and pediatric nurses in the USA. The SACS utilized behaviors already monitored as part of the health checks by MCH nurses, and these are behaviors that are universally monitored by primary health care workers (i.e., eye contact, social smiling, imitation, and so on). Thus, any primary heath care worker involved with infants and toddlers could monitor the behavioral items used in the SACS to identify risk for an ASD.

The repeated monitoring of children from 8 months of age makes it possible to identify more children at risk for an ASD rather than relying on a once-off screening of children at a given age. The latter approach has been adopted in other large-scale community-based studies (Baron-Cohen, Allen, & Gillberg, 1992; Dietz et al., 2006; Swinkels et al., 2006) with limited success. A move away from a "screening" model and toward a "developmental surveillance" model is recommended here, whereby all children are monitored by primary health care workers for signs of abnormal development, focusing on the early signs of ASDs. The importance of education about the early characteristics of ASDs and the value of early identification and intervention cannot be underestimated.

Appendix A. SACS items completed by MCH nurses when a child was identified as at risk for an ASD

8-MONTHS: If answer NO to BOTH underlined items, child is 'AT RISK'		12-MONTHS: If answer NO to 3 of the 4 underlined items, child is 'AT RISK'	
Social games – peek-a-boo Start a game of peek-a-boo with the child. Does the child reciprocate?	YES/NO		
Eye contact Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?	YES/NO	**Eye contact** Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?	YES/NO
Turning to name call Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you)	YES/NO	**Turning to name call** Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you)	YES/NO
Social smiling Has the child smiled while making eye contact with you? If not, smile at the child. Does s/he smile back? (Do not use physical contact to elicit a smile)	YES/NO	**Social smiling** Has the child smiled while making eye contact with you? If not, smile at the child. Does s/he smile back? (Do not use physical contact to elicit a smile)	YES/NO
Imitation Get the child's attention and clap your hands in front of the child *OR* 'Smack' your lips in front of the child. Does s/he imitate you?	YES/NO	**Imitation** Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'. Does s/he imitate you?	YES/NO
Use of language • Does the child use syllables (e.g., ba, da, ra)?	YES/NO	**Use of language** • Does the child babble (e.g., saying agaga, adaba, mama, dada) in a conversational like manner?	YES/NO
• Does s/he combine these sounds into babble (e.g., saying agaga, adaba, mama, dada)?	YES/NO	• Does the child speak 1–3 recognisable words?	YES/NO

Appendix A (*continued*)

8-MONTHS: If answer NO to BOTH underlined items, child is 'AT RISK'		12-MONTHS: If answer NO to 3 of the 4 underlined items, child is 'AT RISK'	
Does the child enjoy cuddles with the parent?	YES/NO	**Understanding of language** Show the child a block and place it beside him/her. Then ask, "Give me the block." Does s/he give you the block?	YES/NO
Has the child been attending to / seem interested in sounds during the session?	YES/NO	**Pointing** Get a teddy bear, show it to the child and say "This is teddy." Then put the bear across the room (where the child can see it) and say, "Where's teddy?" Does the child point to the bear and look at your face?	YES/NO
		Joint attention: following another's point and gaze Get the child's attention and then point to an object across the room and say 'WOW, look at that!' Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)?	YES/NO
		Social gestures Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child). Does s/he wave back?	YES/NO
		Does the child enjoy cuddles with the parent?	YES/NO
		Has the child been attending to / seem interested in sounds during the session?	YES/NO

NB/ Items in italics were monitored as part of the SACS but are not described in the text as they have subsequently been found not to be important markers of ASDs in infancy and toddlerhood.

18-months: If answer NO to 3 of the 4 underlined items, child is 'AT RISK'		24-months: If answer NO to 3 of the 5 underlined items, child is 'AT RISK'	
Eye contact Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?	YES/NO	**Eye contact** Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?	YES/NO
Turning to name call Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you)	YES/NO	**Turning to name call** Call the child's name. Does s/he turn to look at you? (Make sure child is not already looking at you)	YES/NO
Social smiling Has the child smiled while making eye contact with you? If not, smile at the child. Does s/he smile back? (Do not use physical contact to elicit a smile)	YES/NO	**Social smiling** Has the child smiled while making eye contact with you? If not, smile at the child. Does s/he smile back? (Do not use physical contact to elicit a smile)	YES/NO
Imitation Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'. Does s/he imitate you?	YES/NO	**Imitation** Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'. Does s/he imitate you?	YES/NO
Use of language • Does the child use 5–10 words?	YES/NO	**Use of language** • Does the child use 20–50 words?	YES/NO
• Does the child understand many more words?	YES/NO	• Does the child use some two-word phrases (e.g., want drink)?	YES/NO

Appendix A (*continued*)

18-months: If answer NO to 3 of the 4 underlined items, child is 'AT RISK'		24-months: If answer NO to 3 of the 5 underlined items, child is 'AT RISK'	
Understanding of language • Show the child a block and place it beside him/her. Then ask, "Give me the block." Does s/he give you the block? • Get the child's attention. Say 'point to your eyes/nose/mouth'. Does s/he point to his/her eyes/nose/mouth?	YES/NO YES/NO	**Understanding of language** Show the child a teddy bear and place it beside him/her. Then ask, "Give me teddy." Does s/he give you the teddy?	YES/NO
Pointing Get a teddy bear, show it to the child and say "This is teddy." Then put the bear across the room (where the child can see it) and say, "Where's teddy?" Does the child point to the bear and look at your face?	YES/NO	**Pointing** Get a teddy bear, show it to the child and say "This is teddy." Then put the bear across the room (where the child can see it) and say, "Where's teddy?" Does the child point to the bear and look at your face?	YES/NO
Joint attention: following another's point/gaze Get the child's attention and then point to an object across the room and say 'WOW, look at that!' Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)?	YES/NO	**Joint attention: following another's point/gaze** Get the child's attention and then point to an object across the room and say 'WOW, look at that!' Does s/he look at where you are pointing at (as opposed to just looking at your hand/arm)?	YES/NO
Social gestures Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child). Does s/he wave back?	YES/NO	**Social gestures** Elicit the social routine of waving bye-bye (e.g., pretend to leave room and wave bye-bye to the child). Does s/he wave back?	YES/NO
Showing: social communication Does the child try to communicate with the parent in a SOCIAL manner? (i.e., not just to request food or an object – ask parent)	YES/NO	**Showing: social communication** Does the child try to communicate with the parent in a SOCIAL manner? (i.e., not just to request food or an object – ask parent)	YES/NO
Pretend play Give the child a toy cup and pot. Say "Can you pour a drink and drink it?" Does the child pretend to pour a drink and/or drink it? (Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy)	YES/NO	**Pretend play** Give the child a toy cup and pot. Say "Can you pour a drink and drink it?" Does the child pretend to pour a drink and/or drink it? (Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy)	YES/NO
		Interest in other children (parallel play) Does the child play near (not necessarily with) other children? (ask parent)	YES/NO
Loss of skills Ask the parent if the child has lost ANY language or social skills at ANY age. Has the child lost any skills?	YES/NO	**Loss of skills** Ask the parent if the child has lost ANY language or social skills at ANY age. Has the child lost any skills?	YES/NO
Does the child ever come to the parent for affection or comfort? (ask parent)	YES/NO	*Does the child ever come to the parent for affection or comfort? (ask parent)*	YES/NO
Does the child enjoy cuddles with the parent?	YES/NO		

NB/ Items in italics were monitored as part of the SACS but are not described in the text as they have subsequently been found not to be important markers of ASDs in infancy and toddlerhood.

Appendix B. Checklist of social attention and communication behaviors

CHILD ID:	AGE (in months):		
Behavior	Age to look for	Atypical behaviors to look for	Typical (+) or Atypical (-)?
Social games: peek-a-boo	8-months	Lack of eye contact, social smiles, imitation, anticipatory postures	
Eye contact	8- to 24-months	Absent, lowered frequency inconsistent, fleeting	
Turning to name call	8- to 24-months	Doesn't/rarely turns when you or parent calls name	
Social smiling	8- to 24-months	Doesn't/rarely smiles in response to another person	
Imitation	8- to 24-months	Doesn't/rarely imitates others	
Use of language	8- to 24-months	Hasn't reached appropriate milestones for expressive language	
Understanding of language	8- to 24-months	Doesn't follow instructions appropriate for his/her age	
Pointing	12- to 24-months	Doesn't/rarely points with an index finger while combining this with eye contact	
Joint attention: following another's point or gaze	12- to 24-months	Doesn't/rarely looks to where you are pointing or looking	
Social gestures	12- to 24-months	Doesn't/rarely uses gestures, e.g., nodding or shaking head	
Showing: social communication	18- to 24-months	Doesn't/rarely shows other people toys/objects	
Pretend play	18- to 24-months	Doesn't pretend to feed a teddy bear or pour a drink	
Interest in other children (parallel play)	24-months	Doesn't seem interested in other children	

Appendix C. Checklist of abberant behaviors

CHILD ID:	AGE (in months):	
Behavior	Atypical behaviors to look for	Present (+) or Absent (-)?
Using another's hand/ body as a tool	Places another's hand on an object to request; using another's finger to point	
Repetitive behaviors	- Lining up/sorting/spinning objects - Places head on the floor/table to observe toys rolled side to side - Continuously holds object/s in one or both hands - Obsession with particular objects: frequently seeks them out, or holds them - Repeatedly: flicks switches/pushes buttons/opens and closes objects/throws objects	
Stereotyped behaviors	- Flaps hands/arms - Walks on tiptoes - Spins body on spot - Shakes/vibrates body (can occur with clenched fists and gritted teeth)	
Sensory behaviors and interests	- Visual examination of objects (peering, using peripheral vision, placing very close to face) - Smells/licks objects - Distress to everyday sounds, hands over ears - Feels materials in-between fingers	
Ritualistic behaviors and routines	- Has to drink from a specific bottle - Does not like different foods to touch - Will only eat certain colored/textured foods - Has to put things in certain places - Must have all lights switched on/off, or have all the doors opened/closed - Any other rituals/routines that seemed fixed and the child seems under pressure to complete	
Echolalia	Repeats words/sentences that other people have said. May be same intonation.	
Loss of skills	Loss of ANY language of social skills	

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THESIS – Appendix D

PAPER 3 PUBLISHED MANUSCRIPT

Barbaro, J., & Dissanayake, C. (2010). Prospective identification of Autism Spectrum Disorders in infancy and toddlerhood using developmental surveillance: The Social Attention and Communication Study (SACS). *Journal of Developmental and Behavioral Pediatrics, 31,* 376-385.

Prospective Identification of Autism Spectrum Disorders in Infancy and Toddlerhood Using Developmental Surveillance: The Social Attention and Communication Study

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ABSTRACT: ***Objective:*** **Despite behavioral markers of autism spectrum disorders (ASDs) being evident within the first year of life, there remains little research on the prospective identification of these children in a community-based setting before 18 months. The aim in the Social Attention and Communication Study was to identify infants and toddlers at risk of an ASD during their first 2 years.** ***Methods:*** **A total of 241 Maternal and Child Health nurses were trained on the early signs of ASDs at 8, 12, 18 and 24 months. Using a developmental surveillance approach with a community-based sample, a cohort of 20,770 children was monitored on early social attention and communication behaviors. Those infants/toddlers identified as "at risk" were referred to the Social Attention and Communication Study team from 12 months for developmental and diagnostic assessments at 6 monthly intervals, until 24 months.** ***Results:*** **A total of 216 children were referred, with 110 being further assessed. Of these, 89 children were classified with an ASD at 24 months, and 20 children had developmental and/or language delays, resulting in a Positive Predictive value of 81%. The estimated rate of ASDs in the Social Attention and Communication Study cohort ranged from 1:119 to 1:233 children. Estimated sensitivity ranged from 69% to 83.8%, and estimated specificity ranged from 99.8% to 99.9%.** ***Conclusion:*** **Developmental surveillance of social and communication behaviors, which differ according to the age at which the child is monitored, enables the accurate identification of children at risk for ASDs between 12 and 24 months. Education on the early signs is recommended for all primary health care professionals to facilitate early identification of ASDs.**

*(J Dev Behav Pediatr 31:*376–385, 2010) **Index terms:** autism spectrum disorders, developmental surveillance, screening, infants, toddlers, prospective identification, community-based.

Autism spectrum disorders (ASDs) are among the most severe and debilitating neurodevelopmental disorders affecting children and include individuals who meet criteria for autistic disorder, Asperger's disorder, or Pervasive Developmental Disorder-Not Otherwise Specified.[1] Current prevalence rates of the combined ASDs are currently 1 in 160 in Australia,[2] 1 in 100 in the United Kingdom,[3] and 1 in 91 in the United States.[4] Retrospective videotape analyses and parental report studies provide valuable evidence that symptoms of ASDs are present during infancy. Indeed, ~50% of parents of children with an ASD report having concerns before 12 months of age, with many more reporting recognition of abnormalities between 12 and 24 months.[5–7]

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The signs of ASDs in infancy and toddlerhood consistently identified from these retrospective studies fall within the realm of social attention and communication. These "red flags" include lack of eye contact, social smiles, imitation, response to name call, interest and pleasure in others, emotional expression, directed vocalizations, joint attention skills (pointing to "show," following a point, monitoring others' gaze, and referencing objects/events), requesting behaviors, and gestures (e.g., waving, clapping, nodding, and shaking head). Imagination skills, such as pretend play, have also been found to be deficient in late infancy and toddlerhood for many children with an ASD (see Barbaro and Dissanayake,[8] for a review). Although sensory and motor behaviors and stereotypies are seen in some infants with an ASD, they are also indicative of general intellectual disability,[9,10] with many children not showing these behaviors until the age of ~3 years.[11,12]

Despite knowledge of the early signs of ASDs, the average age of diagnosis is 3.1 years for autistic disorder, 3.9 years for Pervasive Developmental Disorder-Not Otherwise Specified, and 7.2 years for Asperger's disorder.[13] Therefore, screening tools have been developed to identify ASDs in infancy and toddlerhood to facilitate early referral, diagnosis, and most importantly intervention,

because this provides the best opportunity to promote positive developmental outcomes for affected children and their families.[14,15]

Prospective Studies

Prospective studies attempt to identify children with ASDs who have not previously been identified with developmental problems. They are highly desirable as the researcher can attempt to elicit the behaviors of interest identified as early markers at a particular age and under standardized conditions, allowing comparison between different groups and at different time points in the child's life. Furthermore, these behaviors can be studied longitudinally, so that the relationship between early deficits and later behavioral manifestations can be examined. Few prospective studies have been conducted in the general population (Level 1 screening studies), with many more focusing on the siblings of children with an ASD (ASD-sibs), because they are at a genetically increased risk of developing an ASD.[16–18]

High-risk sibling studies have been an invaluable source of information on the very early development of ASDs. Capable of investigating the early ASD phenotype, risk markers of ASDs have been found from 12 months of age and include: a combination of impaired language and social communicative development; abnormal visual tracking, attention and sensory orienting behaviors; behavioral manifestations such as behavioral reactivity, difficulties with transitions and impaired motor control, and subtle stereotyped behaviors such as spinning, rotating, and unusual visual exploration of objects.[8,17]

Although many recent studies have been conducted with ASD-sibs, high-risk samples are unique, because siblings have grown up in an environment already affected by ASDs. Indeed, children with ASDs from multiplex families are higher functioning in cognitive and adaptive skills than those from singleton families.[19] Thus, numerous factors need to be considered as possible influences contributing to developmental differences, including early symptom recognition, intervention, affected parenting styles because of exposure to intervention techniques, and parental stress.[20]

Prospective studies conducted in community-based samples are therefore preferable for investigating the early ASD phenotype. They typically use a Level 1 screening tool at a single age in a community health service or general medical practice setting (see Barbaro and Dissanayake,[8] for a review). Unfortunately, few studies have been conducted, and the large-scale screening studies using the Checklist for Autism in Toddlers (CHAT) at 18 months[21,22] and the Early Screening of Autistic Traits Questionnaire (ESAT) at 14/15 months[23,24] have poor sensitivity. Although the specificity of the CHAT was excellent (98%) at 18 months, its sensitivity was only 38%, missing >60% of children diagnosed with an ASD at 7 years. The sensitivity of the ESAT was unable to be estimated but would have been low based on current prevalence rates, because only 18 children with ASDs were identified out of 31,724 children at 14/15 months.

Smaller community-based studies using the modified CHAT (M-CHAT)[25] and Infant-Toddler Checklist (ITC)[26] have also reported problems. The positive predictive value of the M-CHAT between 16 and 30 months was only 11% when used alone and 65% when used with a follow-up phone interview. The ITC, although having excellent sensitivity between 9 and 24 months (93%), identified 813 children as needing further developmental surveillance out of a sample of 5385 children. Only 56 of these children received a diagnosis of an ASD, indicating that the ITC was unable to distinguish between children with ASDs from those with developmental or language delays. Therefore, although the American Academy of Pediatrics[27] recommends routine screening for ASDs in the second year of life, there are currently no tools with sufficient specificity and sensitivity available for universal use.

The less than optimal outcomes to date from the large-scale screening studies may be because the screening tools (CHAT and ESAT) were administered at a single age, leading to many missed opportunities for identifying "at risk" children. Furthermore, the smaller community-based screening studies (using M-CHAT and infant-toddler checklist), in an attempt to increase sensitivity, identified many children without ASDs, albeit with other general developmental and language problems. In contrast to this approach, the routine and repeated monitoring of key behaviors throughout infancy and toddlerhood may serve to improve the identification of ASDs, consequently increasing sensitivity whilst decreasing the number of false positive cases.

Developmental Surveillance Through the Maternal and Child Health Service

Primary health care professionals, such as Maternal and Child Health (MCH) nurses and related practitioners, are the best placed and most expert to undertake developmental surveillance of young children to identify those showing early signs of ASDs, given their extensive knowledge and training on developmental milestones.[28,29] Parental report, although useful for informing professionals about infrequent behaviors, is prone to incorrect memory recall, recall biases, distortion of events, and other problems.[30] Thus, it remains important that all health care professionals, particularly early childhood nurses, monitor children for abnormal development through skilled observations as well as through parental report.

In the State of Victoria, Australia, infant and early child development is monitored through the MCH service by trained MCH nurses. The Social Attention and Communication Study (SACS) reported here was conducted through this universal service and used a developmental surveillance approach. The MCH service is offered free of charge to all families with children younger than 6 years, with an emphasis on child and maternal health surveillance and screening. As part of

this service, well-baby checks are scheduled at key ages from birth to 3½ years, and key developmental milestones are routinely monitored and recorded at these consultations. Given that 98% of Victorian babies access the MCH service soon after birth, with attendance remaining relatively high within the first 2 years,[31] this service has enormous potential to identify infants at risk of ASDs.

The aim in the Social Attention and Communication Study was to determine whether routine and repeated monitoring of social attention and communication behaviors, previously found to be key markers of ASDs in infants and toddlers, could be used to prospectively identify children with an ASD in a community-based sample. It was hypothesized that these behaviors will serve to identify infants with ASDs through their routine MCH assessments by at least 18 months. However, it was anticipated that detection may even be possible at 12 months. It was also hypothesized that using a developmental surveillance approach would increase the chances of accurately identifying children with ASDs at 2 years of age and younger.

METHOD

Participants

A total of 22,168 children were monitored though 184 Maternal and Child Health (MCH) centers in 17 local government areas (LGAs) in metropolitan Melbourne, between September 2006 and 2008. Fourteen centers (including a whole LGA) were subsequently excluded because of noncompliance, with the final number of monitored participants included in the data analyses being 20,770 children. The number of children initially monitored at each age was: 5,723 8-month-olds, 5,286 12-month-olds, 5,334 18-month-olds, and 4,427 24-month-olds. The cohort initially monitored at 8 months (n = 5,723) was monitored by the nurses at all ages (i.e., 8, 12, 18, and 24 months). Similarly, those that were initially monitored at 12 months (n = 5,286) were monitored at 12, 18, and 24 months, and so on.

The LGAs were chosen based on proximity to facilitate ease of referral, with most centers within a 20 km radius of La Trobe University, Bundoora Campus. The socioeconomic status of the LGAs was mostly high, with the mean socioeconomic indexes for areas score for the LGAs in the Social Attention and Communication Study (SACS; $M = 1066$) being slightly higher than the mean socioeconomic indexes for areas score in metropolitan Melbourne ($M = 1033$). Therefore, the centers included in the SACS were comparable with those not included in metropolitan Melbourne.

Procedure

Maternal and Child Health Nurse Training and Social Attention and Communication Study Items

After the approval from the Victorian Department of Human Services and the La Trobe University Human Ethics Committees, the coordinators of the MCH centers in each LGA were invited to participate in the study. A pilot phase was implemented at an LGA local to the University for 1 month.

The nurses in each LGA (N = 241) received a 2½-hour training workshop, held between September and December 2006, to monitor children's development using skilled observations during their routine consultations at 8, 12, 18, and 24 months. The workshops focused on typical and atypical social communicative development, the early (and later) signs of ASDs, and the particular items within the MCH record that were relevant to the detection of ASDs.

Behavioral items for monitoring were selected on the basis of the literature on the signs of ASDs in infancy and toddlerhood, the majority of which were already part of the routine MCH consultations. Items most relevant to ASDs, and developmentally appropriate for the age being monitored, were underlined and considered "key" items. Children were considered "at risk" for an ASD only if they showed a "pattern" of failure on the items of interest; for example, by failing 3 of the 4 "key" items. Important markers of ASDs that were not part of the MCH consultations at the age being assessed were added to these checks as "extra items" and only monitored if a child was identified as "at risk."

A summary of the behaviors monitored, highlighting the "key" and "extra items," are outlined in Table 1. The nurses were provided with a sheet detailing how each

Table 1. Behaviors Monitored at Each Age, Including "Key" (K) and "Extra" (E) Items

Behavior	Age at Which Behavior Was Monitored			
	8 mo	12 mo	18 mo	24 mo
Social games—peek-a-boo	√			
Interest in sounds	√	√		
Eye contact	√(K)	√(K)	√(K)	√(E)
Turning to name call	√(K)	√(K)	√(E)	√(E)
Use/understanding of language	√	√	√	√
Imitation	√(E)	√(E)	√(E)	√(K)
Social smiling	√(E)	√(E)	√(E)	√(E)
Enjoys & seeks cuddles/ affection/comfort	√	√	√	√
Pointing		√(K)	√(K)	√(K)
Gestures—waving		√(K)	√(K)	√(K)
Joint attention—following point		√(E)	√(E)	√(E)
Pretend play			√(K)	√(K)
Social communication (showing behaviors)			√	√(K)
Loss of skills			√(E)	√(E)
Parallel play				√

Pass/fail criteria: 8 months: fail 2 key items; 12 and 18 months: fail 3 of 4 key Items; 24 months: fail 3 of 5 key items.

specific item was to be monitored at each age (these are detailed in Barbaro et al[32] and are available on request). For example, "has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does s/he make eye contact with you?"

The nurses were instructed to readminister "failed" items a maximum of 3 times and were trained to identify when a behavior was atypical, as opposed to present/absent. For example, nurses were trained to identify when eye contact was atypical because of its absence, inconsistency, infrequency, or when it was not used in combination with other behaviors such as pointing or giving objects when requesting. Video clips of children with and without an ASD were used in training the behaviors of interest.

In instances where the nurse was unable to elicit a particular behavior because of the child being ill, unhappy, or asleep, parental/caregiver report was used. Nurses were required to probe for specific and detailed examples of the behavior, to make a judgment as to whether the behavior was, in fact, typical or atypical.

Reliability of Training

To determine reliability of the nurses' monitoring of the behavioral items, the first author visited 27 of the MCH centers (~10%) participating in the study to co monitor these items during routine child check-ups. Fifty-two items were assessed across the 4 ages. Percentage agreement, calculated for items assessed at each age, was ≥0.90 for all the items and ≥0.83 for each individual item, with the exception of 3 items, which ranged between 0.59 and 0.70. (These 3 were "extra items," and the lower reliability scores were because of a large percentage of nurses not scoring these items. This is not problematic for the data reported in this article as they were not used to refer children to the SACS.)

Protocol for Referrals

Nurses were instructed to only refer children from 12 months onward. Thus, no 8 month data will be presented in this article. Once identified "at risk" for an ASD, the nurses administered the "extra items," and counseled parent(s) about concerns regarding the child's development in social attention and communication. The nurses were instructed to refrain from using the terms autism or ASD. Parents were told that the monitored behaviors were important developmental milestones and were referred to the SACS team for a thorough developmental and behavioral assessment to clarify the child's developmental status. They were then given an informed consent form for completion, to be sent to the team.

Assessment Protocols for "At Risk" Children

Children identified by their nurse as "at risk," whose parent(s) consented to participate in the study, were initially seen and then followed-up by the SACS team at their Child Development Unit (CDU) at 6 monthly visits, until 24 months of age. All children were assessed in a laboratory playroom: one researcher conducted the assessment, whereas the other operated 3 video cameras remotely from an observation room. The videotapes were used to assist in scoring the assessments. Children were either seated at a table or brought to the floor on a play mat, as determined by the activity, and a parent was present during the assessments. These assessments, undertaken at each age, are outlined in Table 2.

Table 2. Assessments Undertaken at the CDU at Each Age

12- and 18-mo Visits	24-mo Visit
Administered assessments	
Mullen Scales of Early Learning[33]	Mullen Scales of Early Learning
Early Social and Communication Scales[34]	Autism Diagnostic Observation Schedule[36,37]
Imitation/name call/spontaneous play tasks. Empathy tasks (18 mo only)	Imitation/empathy tasks
CHAT-23 (18 mo only)[35]	
Parental Questionnaires	
Demographic Questionnaire	Demographic Questionnaire
Infant-Toddler Checklist-CSBS-DP[38]	Autism Diagnostic Interview-Revised[40x]
The Early Development Interview[39] (reformatted into questionnaire)	
CHAT-23 (18 mo only)	

NB, the data from many of these assessments will be presented in subsequent papers. CDU, Child Development Unit; CHAT, checklist for autism in toddlers; CSBS-DP, Communication and Symbolic Behavior Scales–Developmental Profile.

On the basis of the assessments undertaken at the CDU, children were classified as autistic disorder (AD; those children showing signs of "classic" autism); ASD (children showing signs of an ASD, but who did not meet criteria for autistic disorder); developmental and/or language delay (DD/LD; children showing signs of developmental and/or language delay, but not AD or ASD), and typically developing, which was confirmed at their 24-month assessment. A child was classified as "AD/ASD" at 18 months only if s/he showed very clear signs. This classification was made based on clinical judgment using developmental history, data from all assessments, and parental questionnaires. At 24 months, a diagnostic assessment was undertaken using the Autism Diagnostic Observation Schedule,[36,37] an observational instrument consisting of 4 modules devised for individuals with varying language abilities. Module 1, designed for preverbal children, was used. The Autism Diagnostic Interview-Revised,[40] which is a standardized, semistructured parental interview, was also used. The first author, J.B., was trained to research reliability on both instruments. Research has shown that it is possible to accurately diagnose ASDs as early as 2 years of age using the Autism Diagnostic Interview-Revised and the Autism Diagnostic Observation Schedule together and in combination with clinical judgment.[41,42] Further-

more, diagnoses at 24 months have been found to be stable over time.[8,43–46]

Detailed reports were written on the basis of each of the assessments and parental questionnaires completed at each age, with copies sent to parents and, with parental permission, to the MCH nurses. All children who showed developmental and/or language delays at any age, and/or met criteria for an ASD, were referred to government Specialist Children's Services teams for early intervention and a full diagnostic work-up, and speech pathology services if they also had language delays.

RESULTS

Sample Characteristics

A total of 216 "at risk" children were referred by their Maternal and Child Health (MCH) nurse to the Social Attention and Communication Study (SACS) team. Of these, 124 consent forms were received. Because 14 children were either withdrawn from the study by their parents before their visit to the CDU or did not attend their scheduled assessment, a total of 110 children were assessed. There were 10 12-month assessments conducted (2 children assessed at 12 months only; 8 children assessed at 12, 18, and 24 months); 46 18-month assessments conducted (8 children assessed at 18 months only; 30 children assessed at 18 and 24 months; 8 children assessed at 12, 18, and 24 months), and 100 24-month assessments (62 children assessed at 24 months only; 30 children assessed at 18 and 24 months; 8 children assessed at 12, 18, and 24 months). In total, 156 assessments were conducted at the CDU. The average time between referral and assessment at the CDU was just >3 weeks for all the children.

Of the 110 children assessed, 89 were classified with an ASD (39 AD and 50 ASD), which was confirmed at their 24-month assessment. (Ten children did not return for their 24-month assessment [2 children at 12 months and 8 children at 18 months]. In these cases, a best estimate classification [BEC] was made based on clinical judgment using developmental history, and all assessments and parental questionnaires conducted to date (detailed in Method). We have been informed by their MCH nurses that 2 of the children given a BEC of an ASD [first seen at 12 and 18 months, respectively] have subsequently been diagnosed with an ASD or are receiving intervention for an ASD. No information is currently available on the remaining 8 children.) Only one typically developing child was referred to the CDU and assessed at 18 and 24 months, but was omitted from all analyses, with the remaining 20 children meeting criteria for DD/LD. Therefore, the SACS has an overall positive predictive value of 81%. At each of the ages, the SACS has a positive predictive value of 90% at 12 months, 79% at 18 months, and 81% at 24 months. Tables 3–5 present the characteristics of the samples assessed at each age.

Developmental status was assessed using the Mullen Scales of Early Learning.[33] Means and standard deviations of the standardized scores were calculated for each of the scales and are presented in Tables 3–5. However, comparison of performance between each of the groups is better illustrated using age-equivalent scores, because many T scores across each of the assessments (21%) were three or more standard deviations below the mean (i.e., T = minimum score of 20).[47] Verbal mental age was therefore calculated by combining age equivalent scores from the receptive and expressive language scales, and nonverbal mental age was calculated by combining age equivalent scores from the visual reception and fine motor scales.

Both verbal and nonverbal mental ages are lowest in children who met criteria for AD in comparison with the ASD and DD/LD. Moreover, more males than females were

Table 3. Sample Characteristics—12-mo CDU Assessment (N = 10)

	Group					
	AD (n = 3)		ASD (n = 6)		DD/LD (n = 1)	
	M (SD)	95% CI	*M* (SD)	95% CI	*M* (SD)	95% CI
Age in months						
Chronological	13.7 (1.2)	—	12.7 (0.5)	—	15.0 (—)	—
Nonverbal	12.0 (4.3)	±4.9	11.5 (2.2)	±1.8	16.5 (—)	—
Verbal	9.2 (2.9)	±3.3	9.0 (2.5)	±2.0	8.0 (—)	—
Overall mental	10.6 (3.6)	±4.1	10.3 (2.2)	±1.8	12.3 (—)	—
T score						—
Visual reception	29.7 (6.5)	±7.4	37.0 (9.2)	±7.4	47.0 (—)	—
Fine motor	43.7 (20.1)	±22.8	44.7 (10.8)	±8.7	53.0 (—)	—
Receptive language	28.0 (5.2)	±5.9	30.8 (7.3)	±5.9	20.0 (—)	—
Expressive language	31.3 (3.8)	±4.3	38.2 (10.6)	±8.5	28.0 (—)	—
Gender (M/F)	2/1		5/1		1/0	

CDU, Child Development Unit; AD, autistic disorder; ASD, autism spectrum disorder; DD/LD, developmental and/or language delay; M, male; F, female.

Table 4. Sample Characteristics–18-mo CDU Assessment (N = 45[a])

	Group					
	AD (n = 16)		ASD (n = 21)		DD/LD (n = 8)	
	M (SD)	95% CI	*M* (SD)	95% CI	*M* (SD)	95% CI
Age in months						
Chronological	19.2 (1.0)	—	19.1 (1.2)	—	19.9 (1.6)	—
Nonverbal	17.3 (2.3)	±1.1	17.5 (2.9)	±1.2	17.4 (1.9)	±1.3
Verbal	9.2 (2.2)	±1.1	12.0[b] (1.5)	±0.6	13.4[b] (2.0)	±1.4
Overall mental	13.2 (1.9)	±0.9	14.8[c] (1.8)	±0.8	15.4[c] (1.5)	±1.0
T score						
Visual reception	37.6 (8.5)	±4.1	39.0 (9.7)	±4.2	37.0 (7.5)	±5.2
Fine motor	44.0 (10.9)	±5.3	44.9 (11.8)	±5.0	42.1 (6.5)	±4.5
Receptive language	20.6 (2.5)	±1.2	24.4[c] (5.0)	±2.1	25.5[c] (4.5)	±3.1
Expressive language	26.3 (4.6)	±2.2	31.4[b] (4.9)	±2.1	35.0[b] (4.3)	±3.0
Gender (M/F)	12/4		20/1		5/3	

CDU, Child Development Unit; AD, autistic disorder; ASD, autism spectrum disorder; DD/LD, developmental and/or language delay; M, male; F, female.[a]Typically developing child excluded. [b]Significantly different from AD, $p < .01$. [c]Significantly different from AD, $p < .05$.

identified as "as risk," with an overall ratio of ~3:1, with the ratios being highest amongst the AD/ASD groups.

Prevalence of Autism Spectrum Disorders in the Social Attention and Communication Study Cohort

The rate of ASDs in the SACS sample, using just those children that were assessed and given a classification of an ASD (i.e., 89 of 20,700), is 1:233. Combining the number of children assessed who had a classification of an ASD, with 81% of those who were referred as "at risk" and not assessed, results in an estimated rate of 1:119 children for ASDs in the sample monitored for the SACS (a figure of 81% was used as this was the ascertainment rate–positive predictive value–for ASDs in the assessed sample). Taking a more conservative approach and using only 50% of the referred but not assessed sample results in a rate of 1:146 cases of ASDs, which is still lower than current Australian prevalence rates of 1:160.[2] Figure 1 details the calculation of the rate of ASDs in the SACS sample.

Specificity and Sensitivity

As the entire cohort of children initially monitored could not be followed up, the "true" specificity and sensitivity of the SACS cannot be calculated at this stage. However, it is possible to estimate these figures based on current prevalence rates for the combined ASDs. Using the assessed sample only (n = 110) and the current prevalence rates in Australia of 1:160,[2] the estimated sensitivity and specificity is 69.0% and 99.9%, respectively. Using the entire referred sample of children (N =

Table 5. Sample Characteristics–24-mo CDU Assessment (N = 99[a])

	Group					
	AD (n = 37)		ASD (n = 42)		DD/LD (n = 20)	
	M (SD)	95% CI	*M* (SD)	95% CI	*M* (SD)	95% CI
Age in months						
Chronological	25.2 (1.6)	—	25.6 (2.2)	—	25.8 (2.7)	—
Nonverbal	19.1 (2.9)	±0.9	21.4[b] (2.7)	±0.8	21.3[c] (3.6)	±1.6
Verbal	11.0 (2.7)	±0.9	15.8[b] (4.1)	±1.2	17.6[b] (3.5)	±1.5
Overall mental	15.1 (2.5)	±0.8	18.6[b] (2.9)	±0.9	19.5[b] (3.3)	±1.4
T score						
Visual reception	30.9 (7.6)	±2.5	35.8[c] (8.1)	±2.5	36.6[c] (9.9)	±4.3
Fine motor	36.0 (11.1)	±4.0	40.7 (9.0)	±2.7	37.8 (11.0)	±4.8
Receptive language	20.3 (1.6)	±0.5	26.3[b] (9.2)	±2.8	32.2[b,d] (10.4)	±4.5
Expressive language	23.9 (4.1)	±1.3	31.7[b] (7.4)	±2.2	32.5[b] (6.5)	±2.8
Gender (M/F)	27/10		34/8		14/6	

CDU, Child Development Unit; AD, autistic disorder; ASD, autism spectrum disorder; DD/LD, developmental and/or language delay; M, male; F, female. [a]Typically developing child excluded. [b]Significantly different from AD, $p < .01$. [c]Significantly different from AD, $p < .05$. [d]Significantly different from ASD, $p < .05$.

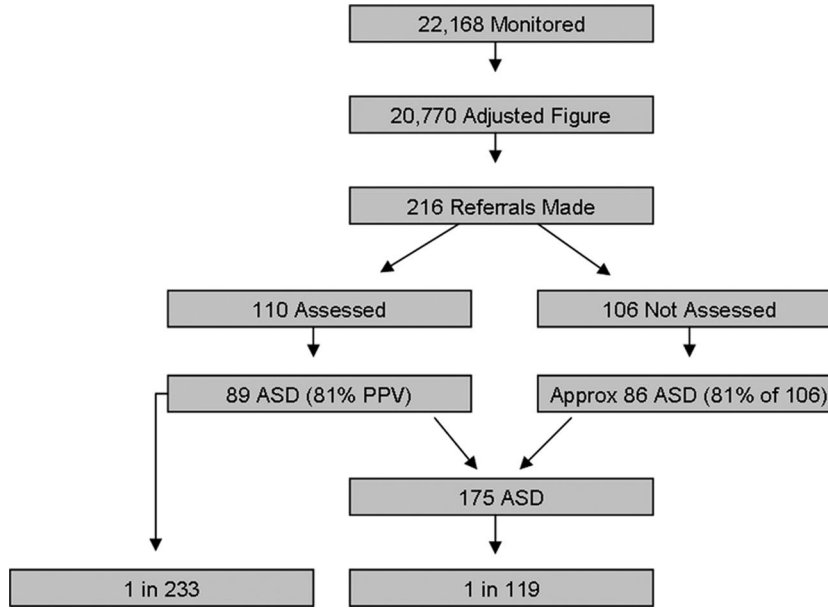

Figure 1. Flow chart detailing calculation of the rate of ASDs in the SACS sample.

216), sensitivity is improved. Because the estimated rate of ASDs using this sample (1:119) is higher than current Australian prevalence rates (1:160), estimated sensitivity cannot be calculated based on this rate. Thus, using the UK rate of 1:100, which is closest to the estimated rate of 1:119, the estimated sensitivity of the SACS is 83.8%, and estimated specificity is 99.8%.

DISCUSSION

This is the first large-scale study to demonstrate that it is possible to prospectively identify infants at risk of ASDs in a community-based sample from 12 to 24 months of age. The social attention and communication behaviors, previously found to be key markers of ASDs in infants and toddlers,[8] served to prospectively identify these infants via their routine Maternal and Child Health assessments from 12 months, supporting the first hypothesis. The repeated monitoring of children from 8 to 24 months, unlike previous studies that have screened children at only one time point, has resulted in a high ascertainment rate with few false positives. Thus, the second hypothesis, that using a developmental surveillance approach will increase the accuracy of identifying children with an ASD at 2 years of age and younger, was supported.

The implementation of developmental surveillance of social attention and communication behaviors, across 4 routine consultations, to identify infants at risk of ASDs in a community-based setting resulted in a positive predictive value (PPV) of 81%. The rate of ASDs found in the Social Attention and Communication Study (SACS) for all children assessed was 1:233, which is lower than the current Australian prevalence rate of 1:160.[2] However, estimating the prevalence on the entire referred sample results in a rate of 1:119 children, which more closely approximates that of the UK rate of 1:100.[3] The estimated specificity and sensitivity of the assessed sample was 69% and 99.9%, respectively. Inclusive of all referrals made to the CDU and calculated using prevalence data from the UK,[3] which was closest to the estimated rate of ASDs in the SACS sample (1:119), the estimated sensitivity was 83.8%, and estimated specificity was 99.8%.

The SACS did not have a large number of false positives, and had an excellent PPV, which contrasts with the findings following use of the Modified Checklist for Autism for Toddlers (M-CHAT)[25] and Infant-Toddler Checklist (ITC)[26] in community-based samples. Importantly, with one exception, all children who did not meet criteria for an ASD (19%) had either developmental and/or language delays. The high PPV found here indicates that the nurses did effectively observe and record infants' behavioral responses on the items of interest, and selectively referred "at risk" infants and toddlers to the SACS team. The training received by the nurses on the early signs of ASDs clearly contributed to the high PPV. The SACS not only accurately identified children "at risk" of ASDs in a community-based sample but was able to do so from as early as 12 to 18 months for some children. Thus, very early identification is not limited to those already at risk of an ASD, such as ASD-sibs, but is possible at a universal level with adequate education of health care professionals on the early signs.

The current results indicate that primary health care professionals, such as Maternal and Child Health nurses, are able to correctly identify and refer infants and toddlers with an ASD with a high level of accuracy as a result of their training on the early signs of ASDs. With one exception, the remaining children that they referred also have developmental problems, therefore benefiting from earlier identification. The nurses' extensive knowledge of early child development clearly facilitated their

ability to successfully monitor signs of ASDs in very young children, after training on these signs. The results strongly indicate that child health nurses and related professionals have a central role to play in the early identification of ASDs and other developmental anomalies. Furthermore, given the similarity in mean socioeconomic scores in the 17 local government areas included in the SACS to that reported for the greater metropolitan Melbourne area, the findings reported here are likely to be generalizable to the local government areas not included in this study.

Given the high level of accuracy, it is unfortunate that only a few 12-month-old infants were referred to the SACS team. There are three possible reasons for this low referral rate at 12 months: (1) nurses were hesitant about raising concerns with parents at this early age; (2) many children were not yet showing social and communication deficits; and (3) the behavioral items were not sufficiently sensitive at 12 months. On the strength of the findings from retrospective studies indicating that some deficits are apparent as early as 6 months, more extensive training and reassurance of the nurses about their level of accuracy may lead to higher identification rates at 12 months. However, surveillance at 18 and 24 months is especially important because reliance on very early signs alone will fail to identify those children who subsequently regress and those with few, mild, or subtle symptoms at 12 months.

These results highlight the importance of repeated monitoring of children across ages, rather than the administration of a single screen at a given age. Zwaigenbaum et al,[48] when reporting on the properties of the M-CHAT, also emphasized the importance of repeated assessment. When used in a community-based sample with a follow-up phone interview, the PPV of the modified checklist for autism in toddlers was lower for younger children (28% for 16- to 23-month-old infants) and increased for those older than 24 months (61%).[49]

A developmental surveillance approach, rather than reliance on screening for ASDs at one age, is advocated here on the basis of the combined findings. Furthermore, the repeated monitoring of children for ASDs should be completed with a tool that is designed to monitor different behaviors that are developmentally appropriate for the age at which it is administered. The approach used in the SACS allowed nurses to monitor the progress of children on the same items previously monitored, and assess their performance on new, developmentally appropriate, behaviors.

Limitations

Despite its obvious strengths, the limitations of the SACS should be noted. Foremost amongst them was that the sensitivity and specificity were each estimated based on the current prevalence rates reported in other studies as it was not possible to calculate "true" specificity and sensitivity. To do so, the entire sample of 20,770 children would need to be followed-up. Because of the enormity of this task, we are currently planning a study where children from a subset of the local government areas will be monitored at school entry for an ASD diagnosis. This approach will identify which, if any, children were missed in the SACS in these specific local government areas, thereby providing additional information on sensitivity and specificity, as well as prevalence rates. Furthermore, as ~50% of children referred to the SACS team were not seen as their parents did not provide consent for a developmental assessment, the rate of ASDs in the SACS sample was estimated based on all referrals, rather than just those who were assessed at the CDU. This is, necessarily, a limitation of community-based studies. However, estimating ASD prevalence was not a focus within the SACS, and the prevalence rate estimated here should be treated with caution.

Another possible limitation is that our conclusions are based on diagnostic classifications at 24 months of age. However, as mentioned previously, research shows that an ASD diagnosis at this age is both accurate and stable across time, given the diagnostician has sufficient training and experience in the assessment and diagnosis of ASDs and uses appropriate tools for young, nonverbal children, which are used in combination with clinical judgment.[46] Lord,[43] using clinical judgment, found that 90% of children retained their diagnostic classification of an ASD from 2 to 3 years of age. Turner et al[44] found that 88% of the children who received an ASD diagnosis at age 2 years received the same diagnosis at 9 years of age. Charman et al[45] found that ~85% of children diagnosed with an ASD at 2 years (based on clinical judgment) continued to meet this diagnosis at 9 years of age. Most recently, Paul et al found that all of the 37 15- to 25-month-old infants who received a clinical diagnosis of an ASD retained this diagnosis 2 years later. We are currently following up all children assessed at the CDU when they are between 4 and 5 years of age, with the aim of further establishing the stability of an ASD classification at 2 years of age.

Future Directions

The success of the SACS in identifying children with an ASD, as well as children with a developmental and/or language delay, indicates that the behavioral items used are applicable during Level 1 developmental surveillance. Analyses are now underway to identify which of these items best predicts a diagnosis of an ASD at 24 months (Barbaro and Dissanayake, in preparation). These specific items could then be used during Level 2 surveillance to more accurately identify those children with ASDs as opposed to other developmental disorders. It is at this stage that tools like the Autism Detection in Early Childhood[50] and the Screening Tool for Autism in Two-Year-Olds[51] should be implemented, before referral, for a full diagnostic work-up.

CONCLUSION

Previous attempts to develop a universal ASD screening tool, to prospectively identify ASDs in community-based samples, have been unsuccessful as a result of the single administration of a tool at a single age or the administration of the same tool at different ages. In contrast, the SACS, in using a developmental surveillance approach, repeatedly monitored different, developmentally appropriate, behaviors in a large cohort of infants from 8 months of age. This approach, combined with the training of Maternal and Child Health nurses on the early signs of ASDs, served to increase the chances of accurately identifying early manifestations of the disorder.

It is argued here that developmental surveillance of social attention and communication behaviors should be undertaken universally and preferably within children's regular health checks during their second year of life. By training Maternal and Child Health nurses on the early signs of ASDs, which, importantly, differ at each age, it has been possible to prospectively identify infants with an ASD in a community-based setting from 12 to 24 months of age. This developmental approach to the identification of ASDs is recommended, because it recognizes the ever changing and dynamic nature of children's early social and communication skills.

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