

**DEVELOPMENT OF A NEW SCALE TO ASSESS HYPERACTIVITY,
IMPULSIVITY, AND INATTENTIVE BEHAVIOURS ACROSS
NEURODEVELOPMENTAL DISORDERS**

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Notice 1

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General Declaration

In accordance with Monash University Doctorate Regulation 17 the following declarations are made:

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes 3 papers submitted for publication. The core theme of the thesis is the development of a new rating scale to measure attention, hyperactivity, and impulsivity in children with neurodevelopmental disorders. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the candidate, working within the Centre for Developmental Psychiatry and Psychology, Southern Clinical School and the School of Psychological Sciences under the supervision of Associate Professor Kylie Gray and Professor Kim Cornish. The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of Chapters Eight, Nine and Ten my contribution to the work involved the following:

Thesis chapter	Publication title	Publication status	Nature and extent of candidate's contribution
Eight	Development of a new attention rating scale for children with intellectual disabilities: The Scale of Attention in Intellectual Disability (SAID)	Submitted	70% contribution by candidate. This included formulation of project design, data collection, data analysis, and writing manuscript.
Nine	The Scale of Attention in Intellectual Disability (SAID): Factor analysis of a new rating scale for children with intellectual disabilities	Submitted	70% contribution by candidate. This included formulation of project design, data collection, data analysis, and writing manuscript.
Ten	Evaluation a new attention rating scale across neurodevelopmental disorders: The Scale of Attention in Intellectual Disability	Submitted	70% contribution by candidate. This included formulation of project design, data collection, data analysis, and writing manuscript.

Signed:

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I love you all,
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Abstract

Difficulties with attention, impulsivity, and hyperactivity are thought to be at least as common, if not more so, among children with intellectual disability (ID) as they are in typically developing children. Although rating scales exist that are able to measure ADHD symptomatology, few if any can reliably measure the range and severity of behaviours within the ID population. Limitations to existing measures include the inappropriateness of some items for children operating within the intellectually disabled range, the lack of replicability of the factor structure, and/or that they have not been used or validated in ID populations.

This study aimed to develop and evaluate a new teacher completed rating scale to measure ADHD symptomatology in children with ID. Phase 1 involved the identification of behaviours related to hyperactivity, impulsivity and inattention that were specific to children with ID, including a review of existing rating scales, diagnostic manuals, and observational and descriptive data from existing research. These behaviours were organised into a rating scale: the Scale of Attention in Intellectual Disability – Teacher version (T-SAID). Focus group discussions were held with nine health professionals (six psychologists and three paediatricians) and nine teachers who worked in special schools. Comments and feedback from these discussions were used to further refine the scale.

Phase 2 involved a community survey of 176 teachers who completed the T-SAID for children aged 5 to 13 years from mild to severe/profound ID. Diagnoses of the children included autism spectrum disorder (ASD), Down Syndrome (DS) and idiopathic ID. The results indicated that the T-SAID is a reliable and valid measure for use with children with ID. It had excellent internal consistency and strong test-retest reliability. It had strong convergent validity with corresponding subscales on the Conners Third edition and the

Developmental Behaviour Checklist – Teacher version and moderate divergent validity with the total score on the Vineland Adaptive Behaviour Scales – Second edition. The T-SAID also had good content validity and good discriminant validity across children with a diagnosis of ADHD and those who did not. An exploratory factor analysis of the T-SAID yielded a four factor solution: *Hyperactivity/Impulsivity*, *Inattention*, *Following Instructions*, and *Verbal Communication*.

When comparing the T-SAID total score across degrees of ID, regression analyses revealed that children with severe/profound ID exhibited a greater breadth of behaviours compared with those who had mild or moderate ID, and these behaviours were significantly more severe. There was also a significant negative effect for age, suggesting that as children age their ADHD symptomatology decreases, with fewer behaviours exhibited and these behaviours being less severe. Cross-syndrome comparisons suggested that children with ASD had a significantly greater breadth of hyperactive/impulsive behaviours than those with DS or idiopathic ID. Children with ASD also had significantly greater difficulties with behaviours that make up the *Verbal Communication* subscale than children with DS or idiopathic ID, and that the intensity of these behaviours was also significantly greater.

This study has successfully developed a reliable and valid measure for identifying ADHD symptomatology in children with ID. Further research would be needed to establish its utility in clinical, school and research settings. Integrating this scale with neuropsychological and clinical research holds exciting promise for enhancing our understanding of the nature of difficulties with attention and hyperactivity/impulsivity within the ID population.

CHAPTER 1 DEFINING TYPICAL AND ATYPICAL ATTENTION AND ACTIVITY

The ability to pay attention and to maintain appropriate levels of activity across situational contexts are essential aspects of successful everyday functioning. Both attention and activity are complex constructs that can be observed and measured at both the cognitive and behavioural levels. Attention can be conceptualised by its various facets (e.g., sustained, divided, selective) but activity is somewhat more difficult to define being a concept that is generally defined by its excess (hyperactivity) or paucity (inactivity, or at its most extreme, catatonia). This chapter examines attention and activity at both the cognitive and behavioural levels, as well as summarising the research of both the typical development of attention across childhood and adolescence, and atypical development at the behavioural and clinical diagnostic levels, namely attention-deficit hyperactivity disorder (ADHD).

1.1 What is attention?

1.1.1 Attention in everyday life

Attention refers to behaviours that may be manifest in academic, occupational or social situations. It is characterised by a cluster of behaviours which can include difficulties with paying attention to detail and making careless errors. In the classroom, it may also manifest in failure to complete a task or not carrying out instructions or requests. It is also related to organisational difficulties such as lack of time management, submitting work that is disorganised, incomplete or out of sequence, and forgetting scheduled appointments or activities (American Psychiatric Association, 2013).

1.1.2 Attention in a controlled environment

At the cognitive level, attention has been defined by processes that were initially thought to be integrated into a single functional entity, mediated by distinct neuroanatomical regions (Mirsky, Anthony, Duncan, Ahearn, & Kellam, 1991). This concept has been revised, however, and rather than being a unitary process it is now widely believed that attention

covers a multitude of processes including selective, sustained, and shifting attention (Cornish & Wilding, 2010).

Selective attention is the ability to focus on a particular stimulus, attend to what is relevant, and ignore other sources of distraction. While earlier models proposed that selective attention occurred either through early selection (a limited amount of incoming information being processed while other inputs are excluded by a filter; e.g., Broadbent, 1958) or late selection (analysing as much input as possible and selecting the most important information as late in the sequence as possible; e.g., Deutsch & Deutsch, 1963), more recent findings offer a compromise between these two conflicting views. One such explanation is the load theory which suggests that there are variations in the point that information is selected and the degree of processing carried out on unattended information depending on the task (e.g., Lavie, Hirst, de Fockert, & Viding, 2004). This infers that selection is not all-or-nothing but instead depends on other aspects of the task, such as the perceptual load required by the incoming information and the current load already being held in the control processes (Cornish & Wilding, 2010).

Sustained attention can be conceptualised in two parts: short-lived switching and holding attention when a significant event or warning signal occurs (phasic arousal) and the ability to maintain concentration over time (tonic arousal; Cornish & Wilding, 2010).

Signal detection theory is one popular explanation for the difficulty experienced in sustaining attention over time. This theory assumes that signals must be detected against a background of random disturbance called “noise” and that performance varies across individuals and time depending upon factors such as physiological state (e.g., fatigue), experience, and expectations (Tanner & Swets, 1954). Response in the presence or absence of a signal results in four different categories: correct detection (stimulus present, response present), missed signal (stimulus present, response absent), false alarm (stimulus absent,

response present), and correct rejection (stimulus absent, response absent). In low-input situations, few targets appear in the presence of few other distractions. Individuals tend to miss more targets over time not due to a decline in the efficiency of processes detecting the input, but because they become more conservative in the amount of evidence required before registering a signal detection (Stroh, 1971). In high-input situations, perceptual processes are likely to become more inefficient over time. High-input situations involve tasks that are demanding (e.g., when input is continuous and target detection is frequent) and have a high perceptual load. Sustained exposure to such situations leads to an overload of processing mechanisms and deterioration of efficiency (Cornish & Wilding, 2010).

Shifting attention is the ability to divide attention flexibly and adaptively between different tasks. Many theories have been suggested to explain this process. The original filter theory suggests that there is a central bottleneck in information processing which limits dual-task performance, and that individuals are only able to process one stream of information at a time (Broadbent, 1958). Multi-tasking, therefore, could only be achieved by rapidly switching between tasks. Others have posited that attention is a flexible system which can allocate resources to different tasks provided that the total load is not too high (e.g., Kahneman, 1973). A study conducted by Allport and colleagues (1972) extended this further, suggesting that resources could be shared even when conducting complex tasks. No consensus has been reached on explaining the process of shifting attention. More recent evidence has suggested that individuals can demonstrate time sharing between tasks in some conditions, but debate continues as to how this process takes place (Styles, 2006).

1.2 Typical development of attention and activity

The development of attention typically begins as early as infancy, with the infant's attention span and capacity to concentrate increasing as they develop into a toddler, child, and adolescent. Toddlers begin the development of sustained attention through goal-directed

behaviours in their play such as stacking blocks (Ruff & Capozzoli, 2003). This can be enhanced further by adults who may encourage sustained attention by observing a child playing with an object and then encouraging further play with it by showing the child a different function or use (e.g., observing a child handling a bell and then the adult rings it to encourage further exploration by the child; Berk, 2011).

Although only limited research has examined the typical developmental of sustained attention in children, the majority of researchers agree that it develops rapidly through childhood up to the age of 10 years, with gradual improvements thereafter as they move into adolescence (Betts, McKay, Maruff, & Anderson, 2006; Klenberg, Korkman, & Lahti-Nuuttila, 2001; Manly et al., 2001; Rebok et al., 1997). A recent study supported this developmental trajectory, but suggested that sustained and selective attention functions were closely related in early childhood before subdividing in later childhood (Steele, Karmiloff-Smith, Cornish, & Scerif, 2012). Researchers attempting to explain the underlying neural basis of sustained attention have suggested that this occurs through gradually increasing myelination of the central nervous system. They argue that it is not until early adolescence that the reticular formation (the area of the brain responsible for attention regulation) becomes fully myelinated (Shaffer, 2010).

Selective attention also increases with age as children become better at focusing on a given task while ignoring distractions, and as they enhance their capacity to multi-task. Development is believed to transition in the second and third years of life from attention influenced by novelty of objects and events towards more cognitive factors such as planning and goal-setting (Ruff & Capozzoli, 2003). It continues to develop at a steady rate up until the age of approximately 10 years (Klenberg, et al., 2001; Manly, et al., 2001; Rebok, et al., 1997; Steele, et al., 2012). As children move into adolescence, the rate of development plateaus but their capacity continues to steadily increase (Klenberg, et al., 2001). The

importance of distinguishing a child's attention to structured tasks as opposed to self-directed play or physical activity has also been emphasised (Tandon, Si, Belden, & Luby, 2009). A child's capacity to attend to structured tasks is believed to be a more important predictor of future attentional capacities than their ability to attend to activities of their own choice.

Response inhibition is the ability to inhibit the prepotent response to an event (Barkley, 1997a; Logan, Schachar, & Tannock, 1997) with a deficiency in this area being described as poor impulse control or impulsivity. The ability to inhibit responses has been demonstrated to improve significantly between 24 and 36 months of age (Gerardi-Caulton, 2000). In one study of Finnish children aged 3 to 12 years, inhibition developed rapidly up to the age of 7 years and then levelled off thereafter (Klenberg, et al., 2001). In another study, steady development was reported throughout childhood and reached maturity at approximately 12 years of age (Bunge, Dudukovic, Thomason, Vaidya, & Gabrieli, 2002). Interpretation of inhibitory control development is difficult to compare across studies given the different tasks used. The above findings do, however, suggest an increase in development throughout childhood which reaches maturity by adolescence if not earlier. This skill decreases later in life (B. R. Williams, Ponesse, Schachar, Logan, & Tannock, 1999), thus suggesting inhibitory control has an inverted U shape of development.

Although excess in activity is one of the most widely researched behaviour problems in childhood, the developmental precursors are still yet to be fully understood, thus making it difficult to define "normal" levels of activity in early child development. One theory suggests that normal activity levels relate to the capacity to self-regulate (Barkley, 1997a). Self-regulation is a construct which captures a variety of different processes including affect regulation and behaviour inhibition, and relates to the individual's capacity to delay responding to events that elicit emotional responses, especially those that are negative such as anger. The greater the capacity for delaying response, the more likely it is that the individual

can gather the necessary information to understand the different facets of an event. This has the potential to moderate their initial internal emotional response and modify their external display of emotion to others. Between 3 and 4 years of age, children begin developing the ability to use coping mechanisms such as self-generated strategies to regulate sadness and anger (Cole, Dennis, Smith-Simon, & Cohen, 2009). Typically developing young children become increasingly more capable of self-regulation as they move into preschool and early primary school, and these skills continue to develop through adolescence (Eisenberg & Sulik, 2012; Rothbart & Bates, 2006). The ability to self-regulate behaviour has also been reported to predict lower maladjustment, lower peer aggression, and greater social competence in childhood and adolescence (Eisenberg & Sulik, 2012; Olson, Lopez-Duran, Lunkenheimer, Chang, & Sameroff, 2011).

1.3 Atypical development of attention and activity: The case of attention-deficit hyperactivity disorder

Attention-deficit hyperactivity disorder (ADHD) belongs to a group of childhood-onset developmental disorders. It is recognised as a developmental disorder across most cultures, although a few academics have questioned whether it is a social construct limited to Western culture (e.g., Amaral, 2007; Anderson, 1996; Timimi & Taylor, 2004). ADHD is characterised by a pattern of inattention, impulsivity and hyperactivity that impairs the individual's functioning across different environments e.g., at home and at school. Although diagnosis can be made at any age, the behaviours must be present before a child turns twelve (American Psychiatric Association, 2013).

ADHD is a condition which affects approximately 5-7% of children (American Psychiatric Association, 2000; Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007; Willcutt, 2012) and attention difficulties – generally excluded from prevalence studies – impact upon an even greater number of young people (Ramtekkar, Reiersen, Todorov, &

Todd, 2010; Tennant & Conaghan, 2007). This statistic represents a significant proportion of individuals, and the difficulties associated with attention can have a significant, negative impact throughout childhood, adolescence and into adulthood, particularly if they do not receive optimal treatment and intervention (e.g., Barkley, Fischer, Smallish, & Fletcher, 2006; Hoza et al., 2005).

1.3.1 Diagnostic criteria

The conceptualisation and diagnostic criteria for ADHD have evolved with successive editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 1968, 1980, 1987, 1994, 2000, 2013) and the International Classification of Diseases (ICD; World Health Organization, 1992) which can present challenges when attempting to make direct comparisons across studies.

Attention-deficit hyperactivity disorder was labelled as hyperkinetic disorder in the DSM-II (American Psychiatric Association, 1968), with a focus on the symptoms related to motor disturbance. In the DSM-III (American Psychiatric Association, 1980), the condition was labelled attention-deficit disorder (ADD) and was defined in two separate domains of inattention and hyperactivity. Therefore, it was possible to be diagnosed with ADD while only satisfying the criteria in one of these domains. The DSM-III-R reconceptualised ADD into a single diagnostic category, but also added impulsivity to the criteria. The DSM-IV-TR and DSM-5 (American Psychiatric Association, 2000, 2013) conceptualise ADHD as a two-dimensional disorder consisting of clustered symptoms of hyperactivity/impulsivity and inattention, allowing a diagnosis to be made based on the presence of behaviours in one or both domains. This has resulted in three possible subtypes but impairment must be observed in more than one setting. While previously an exclusionary criteria, the DSM-5 allows for the comorbid diagnosis of ADHD in children with an autism spectrum disorder diagnosis.

The ICD-10 is the latest in a series of classifications endorsed by the World Health Organisation that can be traced back to the 1850s. This system has two separate diagnoses that ADHD can be classified under: *disturbance of activity and attention* and *hyperkinetic conduct disorder*. Under this system, hyperkinetic conduct disorder is considered to be a more severe form of ADHD. The ICD-10 (World Health Organization, 1992) criteria for both disorders are more stringent than the DSM-5 (American Psychiatric Association, 2013), requiring a minimum number of symptoms to be present across all three dimensions (hyperactivity, impulsivity and inattention) and all criteria must be met across at least two situational contexts. Unlike the DSM-5, the ICD-10 lists mood and anxiety disorders as exclusionary criteria.

1.3.1.1 Age and diagnostic criteria

The DSM-5 (American Psychiatric Association, 2013) describe the specific criteria regarding age of onset, subtypes, and number of symptoms required to meet the threshold for a diagnosis of ADHD. The DSM-5 has increased the age of onset from seven to 12 years, responding to research calling for this change (e.g., Kieling et al., 2010; Polanczyk et al., 2010). It is also supported by research suggesting that inattentive symptoms are identified at a later age than hyperactive symptoms (Lahey et al., 1994) which had called into question the validity of the age of onset criteria in diagnosing inattention in the DSM-IV-TR (Waschbusch, King, & Gregus, 2007). The DSM-5 has decreased the number of symptoms required for diagnosis in adolescents and adults from six to five, consistent with suggestions made in prior research studies (e.g., Ramtekkar, et al., 2010).

Although these changes have been met with some concerns about increased prevalence or false positives (Frances, 2010), recent longitudinal birth cohort studies have attempted to address these issues. One study found that increasing the age of onset to 12 years had a negligible impact on existing prevalence rates, correlates, and risk factors

(Polanczyk, et al., 2010). Another study suggested that after a 5 year follow-up, the age when symptoms first appeared was recalled as being significantly higher (i.e., 6 to 18 months later) for both parent and self-report. In 46% of these cases, while still meeting symptom and impairment criteria for ADHD, their increased reported age of onset would mean that they would no longer have been diagnosed with ADHD (Todd, Huang, & Henderson, 2008) under the DSM-IV-TR. This finding would appear to support the increased age of onset criteria, but also questions whether it is appropriate in all cases. Adolescents and adults may have difficulty recalling symptoms in the earlier stages of their life, or, as the above study suggests, may have altered recall of the age when their symptoms first appeared when asked at a later date. The implication is that this may actually exclude some people (who meet symptom and impairing criteria) from diagnosis due to their inability to meet the age of onset criteria, and therefore restrict their access to treatment.

The applicability of the DSM-IV-TR (American Psychiatric Association, 2000) criteria for ADHD were questioned for very young children. One study suggested that symptom persistence should be increased from 6 months, as specified in the DSM-IV-TR, to 9 months in preschool children (Kollins et al., 2006). It has also been suggested that modifications may be needed to increase the sensitivity of these criteria in 3 and 4 year old children (Tandon, et al., 2009). For example, descriptors such as *often makes careless mistakes* may not be applicable as many young children are rarely placed in situations or given tasks where such behaviours could be observed. Similarly, other descriptors such as *has difficulty organising tasks or activities* may reflect behaviours that would be observed in many young children, and therefore the discriminant validity between a child with attention difficulties and one without would be low. The issues raised in these studies persist in the DSM-5 (American Psychiatric Association, 2013) which has retained symptom persistence at 6 months, and contains similar behavioural descriptors to the DSM-IV-TR. At the present

time, a determination about which criteria would need to be modified to assist with diagnosing ADHD in young children is yet to be conducted.

1.3.1.2 Gender and diagnostic criteria

It is well established in the literature that boys are diagnosed with ADHD more frequently than girls. It has been suggested that this may be because the diagnostic criteria for ADHD are more descriptive of boys rather than girls (Ohan & Johnston, 2005; Staller & Faraone, 2006). Others have suggested that girls are more likely to present with inattentive type which are less likely to be referred for treatment (J. Biederman et al., 2002) and that children with these inattentive, internalising behaviours may be more difficult to identify.

In response to these observations, it has been suggested that the diagnostic criteria may need to be changed so that separate classifications exist across genders (Rohde, 2008). One study has gone so far as to outline possible “female sensitive” items that could be used when diagnosing ADHD and other clinical diagnoses in females (Ohan & Johnston, 2005).

This view has not, however, met with universal agreement. Several studies have suggested that ADHD symptoms do not differ across genders (Monuteaux, Mick, Faraone, & Biederman, 2010), even when making comparisons across countries (Nøvik et al., 2006) and when using a non-referred community sample (J. Biederman et al., 2005). Monuteaux and colleagues (2010) stated that the differences in presentation are due to contrasts in comorbid psychopathology, although an earlier study suggested no differences across genders (J. Biederman, et al., 2005). Another study made gender comparisons across subtypes but while few differences were noted, group assignment relied on parent report of symptoms rather than a clinical diagnosis so these conclusions should be interpreted with caution (Graetz, Sawyer, & Baghurst, 2005). Further research is needed to examine the possibility of gender differences, and the interaction of comorbid psychopathology and ADHD subtypes, using larger sample sizes.

1.3.2 Theories of ADHD

One of the most common theories of ADHD suggests that its symptoms arise from a deficit in executive functioning. Executive functioning has been defined as a set of cognitive processes that maintain a problem solving set in order to attain a goal (Welsh & Pennington, 1988). It represents a “top down” processing model whereby incoming information is held in the working memory while simultaneously integrating knowledge about the current context. These two processes aid in the individual’s decision-making process about the best strategy or action to take in a given situation (Willcutt, Doyle, Nigg, Faraone, & Pennington, 2005).

Under this theory, ADHD symptoms arise due to deficits relating to specific executive functioning processes: namely response inhibition and working memory (Barkley, 1997b; Gioia, Isquith, Guy, & Kenworthy, 2000; Pennington & Ozonoff, 1996). A meta-analytic review of studies that examined the validity of this theory found that children and adolescents with ADHD exhibited significant impairment in all areas of executive functioning when compared with typically developing children. This was observed in both clinic and community samples, even after controlling for variables such as diagnostic criteria used, general intelligence, presence of a language disorder, and academic achievement (Willcutt, et al., 2005). The authors suggested that the most impaired areas of executive functioning were in the areas of response inhibition, working memory, planning, and vigilance which supported the conclusions drawn in many of the studies included in their analysis. They also emphasised, however, that the effect sizes were insufficient to suggest that weaknesses in executive functioning explained the symptoms of ADHD in all individuals. Other researchers have suggested that working memory impairments may be present in children with the inattentive subtype, but reported little or no evidence of such deficits within the hyperactive subtype (Gathercole & Alloway, 2006).

Delay aversion has been presented as another possible theory of ADHD. It

relates to the behavioural tendency to prefer small, immediate rewards as opposed to larger, delayed rewards (Antrop et al., 2006; Sonuga-Barke, Taylor, Sembi, & Smith, 1992), but that this behaviour may be reduced with the addition of stimulation during the delay interval (Antrop, et al., 2006). In settings where children are unable to choose between immediate and delayed rewards (such as during a classroom activity), they may systematically attempt to reduce the perceived time spent in “delay” (that is, the time spent on the current activity before moving on to another). This may be achieved by the child attending to other aspects of their environment in an attempt to make it more interesting and absorbing, which may be manifest through inattention or hyperactivity (Sonuga-Barke, 2005; Sonuga-Barke, et al., 1992). A recent study found that delay aversion was related to inattentive symptoms rather than hyperactivity symptoms (Paloyelis, Asherson, & Kuntsi, 2009), although others have suggested that the opposite is true (Solanto et al., 2001). Despite these conflicting findings, it does raise the possibility that delay aversion cannot be generalised to all children with ADHD, and may be specific to severity or symptomatology.

Information processing theory relates to the way incoming information is attended to, filtered, and processed in the brain through encoding, retention and retrieval (G. A. Miller, 1956). In children with ADHD, it is proposed that information processing deficits limit their ability to understand incoming information. Research has focused on specific areas such as visual (Weiler, Bernstein, Bellinger, & Waber, 2002) and central auditory processing disorders (CAPD; Jerome, 2000; Riccio & Hynd, 1996). Studies of visual processing disorders among children with ADHD have primarily focused on performance in visual search tasks. One study comparing children with ADHD inattentive type and/or dyslexia found that the children with ADHD inattentive type (with or without dyslexia) had greater difficulties with visual processing after controlling for inattention (Weiler, et al., 2002). Studies examining CAPD have been inconsistent, with some suggesting that it is common in

children with ADHD (Riccio & Hynd, 1996; Riccio, Hynd, Cohen, & Hall, 1994), whereas others have suggested it is more commonly associated with learning disabilities (Gomez & Condon, 1999; Weiler, et al., 2002). The variation across studies may be partly related to a lack of consensus among professionals regarding how CAPD is measured or assessed (Cacace & McFarland, 1998; Riccio & Hynd, 1996).

While none of the theories discussed above – or any other theories that have been put forward – provides the single explanation of the cause of ADHD, all of them enhance our understanding of its symptomatology. Indeed, many researchers support the position that ADHD is a heterogeneous disorder and is likely to be complex and multifactorial (e.g., Sergeant, Geurts, Huijbregts, Scheres, & Oosterlaan, 2003; Sonuga-Barke, 2005). This would suggest that a single theory or cause is improbable, and that a combination of cognitive and motivational models may enhance our understanding of ADHD and other developmental disorders (Willcutt, et al., 2005).

1.3.3 Demographic, genetic and environmental correlates

One of the consistent findings of ADHD prevalence studies, irrespective of the country that the study was conducted, is that a greater number of males are diagnosed compared with females (Polanczyk, et al., 2007; Polanczyk & Jensen, 2008; Staller & Faraone, 2006). It should be noted, however, that the ratio of males to females is thought to be lower in children with predominantly inattentive ADHD (Lahey, et al., 1994) and those with intellectual disability (Pearson, Yaffee, Loveland, & Lewis, 1996).

Research has suggested that the severity and frequency of some ADHD symptoms has an inverse relationship with age. This has been reported irrespective of whether syndromatic (i.e., still met full diagnostic criteria) or symptomatic persistence (i.e., continued to present with impairing symptoms but failed to meet full diagnostic criteria) were examined (J. Biederman, Mick, & Faraone, 2000; J. Biederman et al., 2006; Faraone, Biederman, & Mick,

2006; J. C. Hill & Schoener, 1996). These studies have suggested that as children get older, impulse control improves and level of hyperactivity declines (J. Biederman, et al., 2000; DuPaul, Power, Anastopoulos, & Reid, 1998; Fischer, Barkley, Smallish, & Fletcher, 2002), although inattentive behaviours appear to persist over time (Barkley, 2006c; J. Biederman, et al., 2000; DuPaul, et al., 1998).

Although the underlying cause of ADHD is not yet known, there are a number of contributing factors that may exacerbate symptoms. Genetic factors such as disorders which are known to present with attention difficulties as part of their behavioural phenotype (e.g., Fragile X Syndrome; R. J. Hagerman, 1999; Royal College of Psychiatrists, 2001), or a family history of ADHD or attentional difficulties (Bennett, Levy, & Hay, 2007; Hay, Bennett, Levy, Sergeant, & Swanson, 2007) can increase the likelihood of a child meeting the criteria for this diagnosis. Neurological factors such as pre-natal exposure to illicit drugs (Milberger, Biederman, Faraone, Guite, & Tsuang, 1997) or smoking (Milberger, et al., 1997; Thapar et al., 2003), exposure to certain central nervous system infections (e.g., encephalitis; Gau, Chang, et al., 2008), traumatic brain injury (McKinlay, Grace, Horwood, Fergusson, & MacFarlane, 2010), and neurotoxin exposure (e.g., lead poisoning; Hussain, Woolf, Sandel, & Shannon, 2007; Mendola, Selevan, Gutter, & Rice, 2002), can also result in a greater likelihood of being diagnosed with ADHD. While family dysfunction is no longer believed to cause ADHD, it has been suggested that it may contribute to the exacerbation or amelioration of symptoms in an individual with this diagnosis (S. B. Campbell & Ewing, 1990).

1.3.4 Long-term outcomes

Research examining adults with ADHD has consistently reported that this diagnosis can have a significant, negative impact on the individual throughout childhood, adolescence, and into adulthood, particularly if they do not receive optimal treatment and intervention. Children and adolescents with a diagnosis of ADHD can face significant difficulties in their

everyday lives, such as lower academic achievement (Barkley, et al., 2006; Polderman, Boomsma, Bartels, Verhulst, & Huizink, 2010), less popularity among peers (Hoza, et al., 2005; Waschbusch & Sparkes, 2003), friendship difficulties (Barkley, 2006b; Normand, Schneider, & Robaey, 2007), and lower self-esteem (Barkley, 2006b; Graetz, Sawyer, Hazell, Arney, & Baghurst, 2001). Negative outcomes that have been reported in adults with a current and/or childhood diagnosis ADHD have included lower occupational status (Mannuzza, Klein, Bessler, Malloy, & LaPadula, 1993), fewer close friendships (Barkley, et al., 2006), greater frequency of alcohol consumption (Barkley, Fischer, Smallish, & Fletcher, 2004; Greenfield, Hechtman, & Weiss, 1988), increased likelihood of involvement in adverse driving outcomes such as car accidents and traffic violations (Thompson, Molina, Pelham, & Gnagy, 2007), and illicit substance dependence or abuse (J. Biederman, et al., 2006; Mannuzza, et al., 1993; Nigg et al., 2005). One study by Greenfield and colleagues (1988), however, reported that negative life outcomes were associated with only current moderate to severe ADHD symptoms, whereas those with residual or no symptomatology as adults had outcomes that were similar to the control group who had no history of an ADHD diagnosis.

In some of these studies negative long-term outcomes were independent of comorbid conduct disorder or oppositional-defiant disorder (Barkley, et al., 2004, 2006; Thompson, et al., 2007), with comorbid diagnoses additively contributing to the severity of negative life outcomes. In other studies, however, these diagnoses were not controlled for in the analyses (J. Biederman, et al., 2006; Mannuzza, et al., 1993) so it is possible that adults with comorbid disruptive behaviour disorders may have different outcomes to those adults with ADHD alone, or in combination with other comorbid disorders.

1.3.5 Comorbid psychopathology

Comorbid psychopathology is very common in people with a diagnosis of ADHD, with reported conditions including conduct disorder in children and adolescents (August,

Realmuto, MacDonald, Nugent, & Crosby, 1996; Barkley, 2006b; Smalley et al., 2007), antisocial personality disorder in adults (J. Biederman, et al., 2006; Fischer, et al., 2002) and anxiety in children, adolescents and adults (Bloemsma et al., 2013; Bowen, Chavira, Bailey, Stein, & Stein, 2008; CME Institute of Physicians, 2007). While oppositional defiant disorder has also been reported in children and adolescents (August, Realmuto, Joyce, & Hektner, 1999; August, et al., 1996; Posner et al., 2007; Smalley, et al., 2007), one study suggested that it is more common among those with hyperactive/impulsive and combined subtypes, and less common in children with the inattentive subtype (Kadesjo, Hagglof, Kadesjo, & Gillberg, 2003).

CHAPTER 2 ISSUES OF COMPLEXITY IN DIAGNOSING ADHD IN INTELLECTUAL DISABILITY

This chapter will review some of the complexities encountered by clinicians when diagnosing ADHD in children with intellectual disability. These include difficulties encountered by clinicians in determining the child's mental age, diagnostic overshadowing, and conflicting guidelines across diagnostic manuals.

Intellectual disability (alternatively referred to as mental retardation or learning disability in some countries; Department of Health, 2001; World Health Organization, 2007) is defined by the American Association on Intellectual and Developmental Disabilities (2010) as any individual with significant limitations in both adaptive behaviour and intellectual functioning in terms of their conceptual, social and practical skills, with an age of onset before 18 years. Some people with intellectual disability (ID) have a known etiology such as a chromosomal disorder, neurofibromatosis, or tuberous sclerosis (see section 3.2 below for an exploration of some of these diagnoses and syndromes). For 30-50% of children, however, there is no organic cause (Percy, 2007) and this is believed to account for many individuals with mild ID (Volkmar, Dykens, & Hodapp, 2007). It has been suggested that a combination of familial (i.e., a family history of lower intellectual ability; Iarocci & Burack, 1998) and environmental factors (e.g., lack of oxygen at birth; Harris, 2006; Mendola, et al., 2002) may increase the likelihood of being diagnosed with ID, but these are only possible contributing factors and do not imply causation.

ADHD in children with ID has historically been reported as difficult to diagnose. Some researchers have questioned the origin of inattentive symptoms among children with ID, while others have suggested that attention difficulties may be related to their cognitive deficits rather than being a comorbid diagnosis (Antshel, Phillips, Gordon, Barkley, & Faraone, 2006; Guerin, Buckley, McEvoy, Hillery, & Dodd, 2009). The guidelines in the DSM-IV-TR (American Psychiatric Association, 2000) recognised that ADHD should be diagnosed if the deficits exhibited were significantly disruptive and/or inappropriate for the

child's developmental level, but provided very little guidance on how to make this determination (Antshel, et al., 2006). This limitation has carried over in the DSM-5 (American Psychiatric Association, 2013) which also does not provide any further guidelines related to this issue.

Difficulties may also arise in determining the child's mental age when attempting to ascertain whether the behaviours exhibited are significantly inappropriate (Barkley, 2006a; Schaughency & Rothlind, 1991), particularly in children with severe or profound ID. Some researchers have suggested that once correcting for mental age, there is a lack of strong evidence for the presence of attention difficulties in children with ID (Burack, Evans, Klaiman, & Iarocci, 2001). Other researchers, however, have suggested that there is no need to correct for mental age when considering a child's level of hyperactivity, and that the interpretation of behaviours should be based on chronological age (Handen, Janosky, & McAuliffe, 1997; Pearson & Aman, 1994). Handen and colleagues (1997) found no difference in symptom severity in the majority of analyses when using either chronological or mental age. It should be noted, however, that the study conducted by Pearson and Aman (1994) used the Peabody Picture Vocabulary Test to determine mental age, which may have distorted the potential correlations between mental age and hyperactivity. Difficulties related to identifying the mental age of some children, confusion about whether to use mental or chronological age when considering behaviours, and difficulties in conceptualising the term "excessive" in relation to attention difficulties, may all contribute to a lack of confidence among clinicians in diagnosing ADHD in this group.

Diagnosing ADHD among children with ID can also be problematic due to the issue of diagnostic overshadowing bias. This term refers to the tendency of clinicians, in the presence of ID, to regard accompanying mental health issues as less salient and specific (Jopp & Keys, 2001; Mason & Scior, 2004). It has been suggested that this bias also exists with

attention difficulties, with clinicians tending to perceive these behaviours as being part of having ID rather than as a distinct comorbid problem (Deb, Dhaliwal, & Roy, 2008). A recent and growing body of literature, however, suggests that children with comorbid ID and ADHD form a distinct subgroup, and that some children who have ID display few or no difficulties with attention (Hastings, Beck, Daley, & Hill, 2005).

Two recently published diagnostic manuals have attempted to address these issues: the Diagnostic Criteria for Psychiatric Disorders for use with adults with Learning Disabilities/Mental Retardation (DC-LD; Royal College of Psychiatrists, 2001) and the Diagnostic Manual - Intellectual Disability (DM-ID; P. Lee & Friedlander, 2007). Both recognise the limitations of the ICD-10 (World Health Organization, 1992) and DSM-IV-TR (American Psychiatric Association, 2000) in making diagnostic decisions when a person has ID, and appreciate that psychiatric conditions may present differently among adults within this group. The two diagnostic manuals do contain some differences, however, in their criteria for diagnosing ADHD in children and adults with ID.

The DC-LD (Royal College of Psychiatrists, 2001) conceptualises ADHD as a three-dimensional disorder, namely hyperactivity, impulsivity, and inattention. It suggests that the diagnosis of ADHD should be made based on the presence of behaviours in all three domains but impairment must be observed in more than one setting and be persistent over time. The DC-LD also contains two distinct diagnoses, depending upon whether the person has known childhood onset (the behaviours were present before the age of seven) or unknown age of onset. The unknown age of onset category acknowledges the possible lack of available written developmental history, or an inability to obtain information regarding early development from the individual or their family. It does emphasise, however, that the presence of attention difficulties must be known to be long-standing based on the available history. The DC-LD lists mood disorders and drug-induced psychoses as exclusionary

criteria, and similar to the DSM-5 (American Psychiatric Association, 2013) it allows autism spectrum disorder as a comorbid diagnosis.

One of the limitations of the DC-LD (Royal College of Psychiatrists, 2001) is that its diagnostic criteria reflect symptomatology in adults, and therefore the behaviours may not be readily applicable to children and adolescents. It is also unclear why behaviours in all three domains (hyperactivity, impulsivity, and inattention) must be present for a diagnosis to be made. Available research does not seem to suggest that individuals with ID are more likely to present with symptoms in all three domains. It would seem more useful to diagnose ADHD based on the presence of behaviours in one or more domains, resulting in diagnostic subtypes (e.g., predominantly inattentive) similar to the DSM-5 (American Psychiatric Association, 2013).

The DM-ID (P. Lee & Friedlander, 2007) also recognises ADHD as a comorbid disorder in individuals with ID. In developing their diagnostic criteria, the authors contend that as the DSM-IV-TR criteria for ADHD were based on observed behaviour, few modifications were needed for individuals with ID. Further to this, the editors of the DM-ID contend that differential diagnostic criteria were not required to account for degree of ID (Fletcher, Loschen, Stavrakaki, & First, 2007). The only major change suggested by the authors is that when assessing developmentally inappropriate inattention, hyperactivity and/or impulsivity, the informant should consider the child's behaviour compared with peers of comparable mental *and* chronological age, and not younger typically developing children of comparable developmental age. They provide some common clinical examples of inattention and hyperactivity to assist the clinician. Similar to the DC-LD (Royal College of Psychiatrists, 2001), they have relaxed the age of onset criteria (i.e., before the age of 7 years) and noted the acceptability of formulating a diagnosis even in the absence of written developmental history.

The DM-ID (P. Lee & Friedlander, 2007) conceptualises ADHD in the same manner as the DSM-5 (American Psychiatric Association, 2013), namely as a two-dimensional disorder consisting of clustered symptoms of inattention and hyperactivity/impulsivity. It allows for a diagnosis to be made based on the presence of behaviours in one or both domains resulting in three possible subtypes (predominantly inattentive, predominantly hyperactive or combined) but impairment must be observed in more than one setting and be persistent over time. They stated that caution must be exercised when making an ADHD diagnosis and emphasised that the behaviours must result in clinically significant impairment in social, academic or occupational functioning that specifically related to hyperactivity, impulsivity or inattention and not just ID. The authors did not, however, go into further detail about how this distinction should be made or identify the symptomatic threshold for clinically significant impairment. Consistent with the ICD-10 (World Health Organization, 1992), the DM-ID listed mood disorders, drug-induced psychoses and autism spectrum disorder as exclusionary criteria.

Although these two manuals contain some differences in their diagnostic criteria, namely whether all three behaviours (impulsivity, hyperactivity and inattention) need to be present to make a diagnosis and their exclusionary criteria, both publications represent a positive step in recognising the differences in presentation of comorbid disorders (including ADHD) among people with ID. Future research in this area may result in greater consensus across the DM-ID (P. Lee & Friedlander, 2007) and DC-LD (Royal College of Psychiatrists, 2001).

CHAPTER 3 COGNITIVE AND BEHAVIOURAL PHENOTYPES OF ATTENTION AND ACTIVITY IN CHILDREN WITH INTELLECTUAL DISABILITY

Initially thought to be a homogenous group, research in this area suggests that differences in attention and hyperactivity may exist in children with intellectual disability depending on their cognitive and behavioural phenotypes (see Cornish & Wilding, 2010 for a comprehensive review) and that there are divergent trajectories in the development of these behaviours (e.g., Cornish, Scerif, & Karmiloff-Smith, 2007; Scerif, Longhi, Cole, Karmiloff-Smith, & Cornish, 2012). In this chapter, inattention and hyperactivity/impulsivity are examined among children with idiopathic (unknown cause) intellectual disability and across four neurodevelopmental disorders where ADHD symptoms have commonly been studied: autism spectrum disorder, Down Syndrome, Fragile X Syndrome, and Williams Syndrome. While the majority of studies have used typically developing children as a comparison group (either matched for chronological or mental age), a limited number of cross syndrome studies are also described which provide a more meaningful and complete picture of these difficulties within the area of intellectual disability.

3.1 Idiopathic intellectual disability

Although research examining the prevalence of ADHD in idiopathic intellectual disability (hereafter referred to as ID) is scant, it is believed to be at least as common, if not more so, as the prevalence among typically developing children (Neece, Baker, Blacher, & Crnic, 2011; Royal College of Psychiatrists, 2001; Seager & O'Brien, 2003). Studies have reported prevalence estimates from 4% to 70% of children with ID meeting the criteria for ADHD (Dekker & Koot, 2003; Feinstein & Reiss, 1996; Hastings, et al., 2005; Lindblad, Gillberg, & Fernell, 2011). Similar to sampling issues in research examining the prevalence of ADHD in typically developing individuals (Polanczyk & Rohde, 2007), it has been concluded that the variance in the estimates of ADHD in populations with ID is due to use of samples that do not allow direct comparisons to be made such as: convenience samples;

clinical samples where comorbid conditions are more likely to be identified; and samples including children with syndromes where attention difficulties are a common feature such as Fragile X Syndrome. Inconsistencies in prevalence estimates may also have arisen as some studies did not provide reliable information on how ID and/or ADHD were diagnosed, or they included children who were in the borderline range of intellectual functioning. The studies do however demonstrate that a substantial proportion of children with ID present with symptoms that are within the clinical range for ADHD.

Several longitudinal studies have suggested that hyperactivity decreases from childhood to adolescence. These included a sample of adolescents with severe ID (Chadwick, Kusel, Cuddy, & Taylor, 2005), and another with individuals ranging from mild to profound ID (Tonge & Einfeld, 2003). Some studies, however, have suggested the trend of decline may differ in children with ID. A longitudinal study suggested that the decline in hyperactive symptoms starts later in children with ID than in children who are typically developing (Einfeld, Tonge, Gray, & Taffe, 2007) and a cross-sectional study suggested that children with ID showed a larger decrease in attention problems from age 6 to 18 compared with typically developing children (de Ruiter, Dekker, Verhulst, & Koot, 2007). The inclusion of children with borderline intellectual functioning in this sample makes it difficult to be certain that this trajectory would apply to children strictly within the ID range. Further research is needed to support the finding that hyperactivity decreases with age and whether it mirrors the trend observed in typically developing children with ADHD (J. Biederman, et al., 2000; DuPaul, et al., 1998; Fischer, et al., 2002), or whether it follows a different trajectory.

In a study comparing ADHD symptoms across degrees of ID, O'Brien (2000) drew upon a community sample of young adults (18 to 22 years). He reported a positive association between the prevalence of ADHD and degree of intellectual disability, with the proportion increasing dramatically in the groups with moderate (25%) and severe (29%) ID.

A comparative study conducted in children and adolescents also suggested that hyperactivity symptoms increased with severity of ID (Rojahn et al., 2010), although given half the sample had missing data for degree of ID, the generalisability of these findings is unclear. The findings of these studies do, however, suggest that ADHD symptoms are common not only in children with ID, but in adolescents and young adults as well. Further research would be needed to confirm an association between severity of ADHD symptomatology and ID.

Several early studies used observational data to describe the behaviours associated with ADHD among children with ID. These studies suggested that ADHD symptoms were higher in children with ID compared with those who were typically developing matched by chronological age (Epstein, Cullinan, & Gadow, 1986; Fee, Matson, & Benavidez, 1994). Two studies conducted by Handen and colleagues (1994, 1998) observed children with ID in classroom settings and attempted to be more specific about the behaviours related to attention difficulties. Their first study found that those meeting the criteria for ADHD were more fidgety and less likely to stay on task during individual (but not group) activities, less interested during group activities, and more restless during either individual or group activities (Handen, et al., 1994). In their second study the children who met the criteria for ADHD were more likely to engage in vocalisations during play (such as humming or talking to oneself) and played with a greater variety of toys for shorter periods of time. They were also less likely to stay on task during an academic activity and more likely to impulsively touch toys located on a nearby table when they had been explicitly instructed not to do so (Handen, et al., 1998). The authors also included a group of children who met the criteria for both ADHD and conduct disorder, but no significant differences were reported across the ADHD and ADHD/conduct disorder groups. Given that neither of these studies included typically developing children with ADHD, it is unclear whether these behaviours are unique or more frequent in children with ID and ADHD.

All of these studies had shortcomings in their methodology. They all used a rating scale that had not been developed for use with children or adolescents with ID (Conners Rating Scales; Conners, 1989). Use of this rating scale could impact on the validity of the results as it may have misrepresented children with ID as having more severe symptoms than actually occurred within this group. For example, it contains items that are developmentally inappropriate for children with ID such as *Fails to complete assignments*. This behaviour could be endorsed by teachers for many children with ID, when assignments may rarely if ever be given to children functioning at this level. Further, this behaviour may be observed irrespective of the presence of comorbid ADHD. Two of the studies (Epstein, et al., 1986; Fee, et al., 1994) identified ADHD in children by using a checklist completed by teachers and teacher aides rather than a formal diagnosis. It should also be noted that these studies used criteria from previous editions of the DSM (American Psychiatric Association, 1980, 1987). Changes to the diagnostic criteria make it difficult to draw direct comparisons between children diagnosed with ADHD in these studies and those being diagnosed in the present day.

A number of neuropsychological studies have also examined the attention profiles of children with ID. Two studies reported that children with ID and ADHD had significantly greater difficulties compared with those who had ID alone in selective attention but no group differences were observed in sustained attention (Melnik & Das, 1992; Pearson, et al., 1996). A possible explanation for these differences in attentional processes is that selective attention was considered a more cognitively demanding process that increased the information-processing load to a greater degree (Melnik & Das, 1992).

Studies comparing children with ID with typically developing children matched for mental age have yielded inconsistent findings that are difficult to interpret. The use of different age groups and a variety of tasks make direct comparisons across studies difficult. The inclusion of children with borderline intellectual functioning in the 'ID group' may have

also diluted potential observed differences (Baker, Neece, Fenning, Crnic, & Blacher, 2010; Henry & MacLean, 2002; van der Molen, van Luit, & Jongmans, 2007).

Lastly, emerging research from genetics has suggested that copy number variants (CNVs, or large, chromosomal deletions or duplications) occur at a higher rate in children and adolescents with ADHD and ID (N. M. Williams et al., 2010). This study drew upon individuals aged 5 to 17 years from the United Kingdom and Iceland, and found that children with ADHD and ID had 5.69 times the average number of CNVs compared with a typically developing control group (although it should be noted that psychiatric data was not available for this group, and therefore it is possible not all individuals in this group would be defined as typically developing). Children with ADHD but without ID also had an elevated number of CNVs (1.68 times), therefore suggesting that children with ADHD had a significant excess of deletions or duplications. This represents the potential for new developments in understanding genetic risk variants in ADHD if these results are replicated in future studies.

3.2 Diagnoses with intellectual disability as a known cause

Inattentive and hyperactive symptoms are commonly identified in children with a number of known causes of ID including autism spectrum disorder, Cri Du Chat Syndrome (also known as 5p-), Down Syndrome, Fragile X Syndrome, velocardiofacial (also known as DiGeorge or 22q11 Deletion Syndrome), and Williams Syndrome (Cornish & Wilding, 2010; Dykens, 2000). Recently it has been suggested that it may not be the disorders themselves, but rather the gene deletions common across disorders, that may result in attention difficulties (Scharf & Mathews, 2010). These authors suggested that this might occur in combination with genetic and environmental factors, but their position still needs to be verified by further research.

Four diagnoses with ID and ADHD symptoms as a common part of their presentation are described below. While attempts have been made to describe the profile of each group,

these conclusions are only preliminary and must be interpreted with caution due to a number of constraints: a) most studies recruited children and the findings may not necessarily generalise to toddlers or adolescents as the developmental trajectory in each group cannot be assumed to be static or linear; b) different aspects of inattention and hyperactivity were measured using different instruments making direct comparisons difficult; c) the floor effects reported in some studies mean that the abilities for some children could not be measured (even when using simple measures developed for children who cannot yet read such as the Day-Night Task; Diamond & Taylor, 1996; Hooper et al., 2008) and therefore differences may not necessarily be representative of all children in that syndrome group; and d) measurement of ID was often imprecise and used screening instruments rather than standardised measures of intelligence, resulting in some studies estimating the degree of intellectual impairment.

3.2.1 Autism spectrum disorder

Autism spectrum disorder (ASD) is a childhood-onset developmental disorder characterised by deficits in social communication and restricted, repetitive patterns of behaviour (American Psychiatric Association, 2013). Prior to the 1990s, the prevalence of autism was estimated to be approximately 4.7 per 10,000 whereas recent research has reported a median estimate of 62 per 10,000 for all pervasive developmental disorders (or 1 in 160 children; Elsabbagh et al., 2012). Approximately 70 to 80% of children with ASD also have severe cognitive delays with many functioning in the moderate to severe range of intellectual disability (Fombonne, 2005). In this subsample, the median prevalence estimate increases to 17 per 10,000 (Elsabbagh, et al., 2012). Studies have consistently reported a greater number of males diagnosed with ASD compared with females, although the disparity is more pronounced in children with high-functioning autism, Asperger's Syndrome or pervasive developmental disorder – not otherwise specified, at approximately 6 to 8 males for

every female (Fombonne, 2005). The ratio of males to females is markedly lower among children with ASD and ID, particularly at the severe to profound level where the ratio is 2 males to every female (Fombonne, 2005).

3.2.1.1 Studies examining the attention profile of children with ASD

The DSM-5 has changed its diagnostic criteria to allow ASD and ADHD to be made as comorbid diagnoses. Previously ASD was one of the exclusionary criteria for ADHD in both the DSM-IV-TR (American Psychiatric Association, 2000) and ICD-10 (World Health Organization, 1992). Despite this only recent change, children, adolescents, and adults presenting with symptoms that satisfied the diagnostic criteria for both disorders have been reported since the 1990s (e.g., Ghaziuddin, Tsai, & Alessi, 1992; Yoshida & Uchiyama, 2004). Academics and practitioners alike recognised the utility of a comorbid diagnosis if the individual satisfied the criteria for both disorders (Frazier et al., 2001; Goldstein & Schwebach, 2004; Holtmann, Bolte, & Poustka, 2005; Reiersen, Constantino, & Todd, 2008; Rohde, 2008; Simonoff et al., 2008), and studies anecdotally reported that psychologists and neurologists were making this dual diagnosis and disregarding the diagnostic guidelines as a result of these convictions (Ghaziuddin, Welch, Mohiuddin, Lagrou, & Ghaziuddin, 2010; Jensen, Larrieu, & Mack, 1997).

Irrespective of adherence to the diagnostic criteria, the presence of attention-deficit hyperactivity *symptoms* have been commonly identified in individuals with ASD (Ghaziuddin, et al., 2010; Rommelse, Franke, Geurts, Hartman, & Buitelaar, 2010). This has been reported in both clinic-based (Frazier, et al., 2001; Gadow, DeVincent, & Pomeroy, 2006; Goldstein & Schwebach, 2004; Hartley, Sikora, & McCoy, 2008; Hattori et al., 2006; D. O. Lee & Ousley, 2006; Leyfer, Folstein, et al., 2006; Sturm, Fernell, & Gillberg, 2004; Witwer & Lecavalier, 2010) and population-based samples (Keen & Ward, 2004; Simonoff, et al., 2008).

Research attempting to identify the behavioural phenotypes of inattention and hyperactivity in children with ASD has been inconsistent. Several studies have suggested that children with Asperger's Syndrome or high-functioning autism have high levels of inattention (Klin, Pauls, Schultz, & Volkmar, 2005; D. O. Lee & Ousley, 2006; Sinzig, Walter, & Doepfner, 2009; Yoshida & Uchiyama, 2004) while comparative studies have suggested that inattention is observed in children with ASD irrespective of their level of cognitive functioning (Estes, Dawson, Sterling, & Munson, 2007; Konstantareas & Stewart, 2006; Mahan & Matson, 2011). Comparative studies have reported that hyperactivity is more severe in children with ASD and ID (Estes, et al., 2007), while others have reported similar severity across children with high functioning autism and those with ASD and ID (Kaat, Lecavalier, & Aman, 2013; Lecavalier, 2006; Mahan & Matson, 2011). Recent studies have also noted age and gender differences, with one study suggesting that males with high functioning autism have greater levels of hyperactivity than females (May, Cornish, & Rinehart, 2013) and another suggesting that increasing age is associated with lower levels of hyperactivity in children with ASD (Kaat, et al., 2013).

It should be noted, however, that several of these studies had shortcomings in their research designs. Several of the comparative studies had mixed samples of children with ASD and ID and those with high functioning autism (D. O. Lee & Ousley, 2006; Mahan & Matson, 2011; Sinzig, et al., 2009). This made the sample sizes of each group smaller and thus reduced their ability to generalise to specific groups or to children with ASD in general. The study by Estes and colleagues (2007) drew their conclusions from parent (primarily mother) reports which were not confirmed by clinical evaluation or observations. These findings would need to be replicated in larger samples and with information obtained from various informants to determine their generalisability.

A limited number of neuropsychological studies have examined the cognitive phenotype of children with ASD. They have reported that children with ASD had greater attention difficulties compared with typically developing or intellectually disabled children and adolescents after controlling for mental age and IQ (Burack, 1994). Sustained attention appears to be an area of strength, even when compared with children who were typically developing (Garretson, Fein, & Waterhouse, 1990; Johnson et al., 2007). Selective attention has been identified as being comparable to (Iarocci & Burack, 2004) or better than (Jarrold, Gilchrist, & Bender, 2005; Joseph, Keehn, Connolly, Wolfe, & Horowitz, 2009) their typically developing peers. Christ and colleagues (2007; 2011) conducted two studies examining inhibitory control among children with high-functioning autism. They found that the children with autism experienced difficulties in some areas of inhibitory control when compared with children who were typically developing.

3.2.2 Down Syndrome

Down Syndrome is one of the most common genetic syndromes causing ID. It is caused by a third copy of chromosome 21 (trisomy 21) with three genetic subtypes: 95% are non-familial, sporadic cases arising from non-disjunction; up to 5% are translocations of a portion of chromosome 21 to other chromosomes, usually chromosome 14; and 1-2% are mosaics, where both trisomy 21 and normal cell lines occur in the same individual (McInerny, Adam, Campbell, Kamat, & Kelleher, 2009). The prevalence of Down Syndrome births in Victoria, Australia has declined over the last 20 years, primarily due to an increase in cases diagnosed prenatally which have resulted in termination of pregnancy. Each year, between 45 and 60 babies are born with Down Syndrome in Victoria, with an overall natural occurrence of approximately 1 in 650 live births (Collins, Muggli, Riley, Palma, & Halliday, 2008). This decline in prevalence is similar to rates reported in the United Kingdom (J. K. Morris & Alberman, 2009) but contrasts with studies conducted in Europe and the United

States where the prevalence has either remained relatively stable (Loane et al., 2013) or has increased (de Graaf et al., 2011; Shin et al., 2009) over the same period of time.

3.2.2.1 Studies examining the attention profile of children with Down Syndrome

Studies examining the prevalence of ADHD in individuals with Down Syndrome have yielded conflicting results. Earlier studies reported conservative estimates of between 4 and 8% (Dykens, 2007; McCarthy & Boyd, 2001), similar to that of typically developing children (Willcutt, 2012) while a more recent study reported a prevalence rate of 43% with children being diagnosed by a paediatric neurologist (Ekstein, Glick, Weill, Kay, & Berger, 2011). The small sample sizes, symptom identification (current versus retrospective), and different diagnostic classifications all contribute to the difficulty in determining prevalence.

Studies examining the behaviour phenotype have reported that children with Down Syndrome have greater levels of inattention compared with children who are typically developing (Cornish, Steele, Monteiro, Karmiloff-Smith, & Scerif, 2012; Nygaard, Smith, & Torgersen, 2002; van Gameren-Oosterom et al., 2011). Older studies have reported that hyperactive symptoms were more frequently observed in boys with Down Syndrome compared with girls, or compared with boys who were typically developing (Royal College of Psychiatrists, 2001), but that these symptoms decreased in adolescence (Stores, Stores, Fellows, & Buckley, 1998). Recent research has also suggested that children with Down Syndrome (irrespective of gender) aged 4 to 9 years have greater severity of hyperactivity compared with typically developing controls (Cornish, Steele, et al., 2012), but when compared with children and adolescents with other neurodevelopmental disorders, their severity was significantly lower (Einfeld, et al., 2007). Taken together, this research suggests that children with Down Syndrome have difficulties with inattention and hyperactivity, but

they appear to decrease in adolescence and these symptoms are less severe than children with other neurodevelopmental disorders.

Neuropsychological studies examining the cognitive phenotype have attempted to identify a unique attention ‘signature’ or profile of individuals with Down Syndrome. Two studies have identified sustained attention as a relative strength (Breckenridge, Braddick, Anker, Woodhouse, & Atkinson, 2013), and reaching a level comparable to that of typically developing children matched for mental age (Cornish, Scerif, et al., 2007). In the area of selective attention, toddlers with Down Syndrome were reported to perform similarly to their typically developing peers (matched for mental age) on a task requiring them to touch large circles on a screen in the presence of smaller distractor circles. In childhood, however, they performed significantly worse than typically developing children or children with Fragile X Syndrome on a task requiring them to circle particular items on a map within a time limit. Cornish and colleagues (2007) suggested a developmental trajectory in selective attention abilities with toddlers performing similarly to their typically developing peers (matched for mental age), but demonstrating a deterioration in selective attention skills in childhood before improving again in adulthood. The conclusions drawn in these studies were however based on small, cross-sectional samples; longitudinal studies with larger sample sizes are needed to confirm these findings.

3.2.3 Fragile X Syndrome

Fragile X Syndrome is an X-linked genetic disorder which affects approximately 1 in 2500 males and females worldwide (P. J. Hagerman, 2008), and approximately 8665 people in Australia (L. Brown, 2010). It is the most common hereditary cause of ID in males, but the level of cognitive impairment is more variable in females as they possess one X chromosome with the gene mutation and one without (Cornish, Gray, & Rinehart, 2010; R. J. Hagerman, 2002). Fragile X Syndrome is caused by a defect in the

Fragile X Mental Retardation-1 (FMR1) gene located near the end of the long arm of the X chromosome (Cornish et al., 2008). This FMR1 gene is “turned off” in affected individuals leading to a lack of production of a specific protein (FMRP) and results in a unique constellation of strengths and weaknesses that can affect individuals across their lifespan.

Despite the increased likelihood of ID among children with Fragile X Syndrome, particularly in males (Alanay et al., 2007; R. J. Hagerman, 2006), they do not exhibit the typical global deficits characterised by those with ID. Their unique ‘signature’ of clinical and cognitive strengths and difficulties differentiates them from other developmental disabilities (Cornish, Turk, & Hagerman, 2008). In some areas, their reported deficits are similar to their peers who have ID whereas on other tasks their performance is similar to children matched for mental age (Cornish et al., 2004). Specifically, children with Fragile X Syndrome are reported to have strengths in vocabulary (van der Molen et al., 2010), recognising visual details in faces (Turk & Cornish, 1998), and recalling meaningful verbal information (Munir, Cornish, & Wilding, 2000a). They may however exhibit deficits in the areas of recalling non-meaningful information (Munir, et al., 2000a) and pragmatic language (Cornish, Sudhalter, & Turk, 2004). They may also exhibit difficulties with social interaction and reciprocity similar to those seen in children with ASD (Einfeld, Tonge, & Turner, 1999), although it has been suggested that the functions of these behaviours may serve very different purposes across the two diagnoses (Cornish, Turk, et al., 2008). Approximately one third of all children with Fragile X Syndrome are thought to have ASD as a comorbid diagnosis (R. J. Hagerman, 2006).

3.2.3.1 Studies examining the attention profile of children with Fragile X Syndrome

Many children with Fragile X Syndrome are reported to exhibit symptoms of inattention, impulsivity and hyperactivity that are consistent with ADHD (Hatton et al., 2002;

Royal College of Psychiatrists, 2001; K. Sullivan et al., 2006). A family survey examining comorbid psychopathology in children with Fragile X Syndrome found that inattentive behaviours were rated as a significant problem in 84% of males and 67% of females, and hyperactivity was rated as a significant problem in 66% of males and 30% of females (Bailey, Raspa, Olmsted, & Holiday, 2008).

Several studies have attempted to describe the behavioural phenotype of attention difficulties in Fragile X Syndrome. An early study reported that boys with Fragile X Syndrome displayed significantly higher levels of inattention and distractibility compared with those with ID, although levels of hyperactivity were similar (Turk, 1998). Another early study of females with Fragile X Syndrome suggested that they had significantly higher hyperactive symptoms compared with a control group of girls with other neurodevelopmental disorders. Further, girls with Fragile X Syndrome and ID had significantly higher levels of hyperactivity than those with Fragile X and average intelligence (Lachiewicz & Dawson, 1994). There is some evidence to suggest that ADHD symptoms do not decrease with age in children with Fragile X Syndrome (Cornish, Turk, et al., 2008), although a longitudinal study of adolescents suggested that this decrease may happen later (i.e., between 16 and 19 years; Einfeld, et al., 2007) than it does in typically developing children with ADHD (e.g., J. Biederman, et al., 2006).

A large number of studies have examined the cognitive phenotype of children with Fragile X Syndrome. Studies examining attention difficulties have reported that sustained attention is a comparative strength (Cornish, Scerif, et al., 2007; Munir, Cornish, & Wilding, 2000b; K. Sullivan et al., 2007), although their performance is significantly lower than their typically developing peers both in childhood (Cornish, Cole, Longhi, Karmiloff-Smith, & Scerif, 2013; Scerif, et al., 2012), and adulthood (Cornish, Munir, & Cross, 2001). Selective attention is an area of greater weakness compared with sustained attention, with moderate

difficulties observed in childhood (Munir, et al., 2000b) which are proposed to persist into adulthood (Cornish, et al., 2001).

Difficulty with inhibitory control has also been identified among individuals with Fragile X syndrome (Cornish & Wilding, 2010; Loesch et al., 2003). In a study by Sullivan and colleagues (2007), boys with Fragile X Syndrome were compared with typically developing children matched for mental age. Results suggested that while response inhibition was similar across the two groups at the beginning of the task, they diverged significantly over the 3 minute duration, and by the end of the task the boys with Fragile X Syndrome were experiencing significantly greater difficulties with inhibitory control. They also suggested that boys with Fragile X Syndrome who met diagnostic criteria for ADHD hyperactive subtype had significantly more difficulties with response inhibition over time compared with those who did not meet criteria, although this was based on teacher ratings and not clinical diagnoses. The findings of this study support a proposed developmental trajectory of inhibition difficulties that seem to appear in infancy (Scerif, Cornish, Wilding, Driver, & Karmiloff-Smith, 2004), persist into childhood (Cornish, Scerif, et al., 2007; Hooper, et al., 2008; Scerif, Cornish, Wilding, Driver, & Karmiloff-Smith, 2007), and later into adulthood (Cornish, et al., 2001). Cornish and colleagues (2004) have suggested that this inhibitory control deficit may contribute to some of the behaviours consistent with ADHD such as impulsivity. They conceded however, that this is only the initial step in understanding the difficulties with inattention and hyperactivity experienced by some children with Fragile X Syndrome.

3.2.4 Williams Syndrome

Williams Syndrome is a genetic disorder characterised by a microdeletion of a sequence of genes on the long arm of chromosome 7 (Kaplan, Wang, & Francke, 2001). It is a relatively rare disorder with the prevalence estimated to be around 1 in 20,000 (C. A.

Morris & Mervis, 1999), although a more recent estimate has suggested it is more common at a rate of 1 in 7,500 (Stromme, Bjornstad, & Ramstad, 2002). This syndrome is not usually hereditary and occurs in equal rates across genders.

Cognitive impairment is a common feature of individuals with Williams Syndrome, although not all have ID (Bellugi, Lichtenberger, Jones, Lai, & St George, 2000; Mervis & John, 2010). Their personality is characterised as being hypersocial (Jones et al., 2000) with an excessive display of empathy (Kaplan, et al., 2001) and use of verbose, florid language (Kaplan, et al., 2001). Similar to children with Fragile X Syndrome, they do not exhibit the typical global deficits characterised by those with ID, and have a distinctive behavioural and cognitive profile. They have comparative strengths in the areas of processing eye gaze and facial expressions (Riby, Doherty-Sneddon, & Bruce, 2008), but weaknesses in executive functioning (Rhodes, Riby, Park, Fraser, & Campbell, 2010) and visuo-spatial construction tasks (Pani, Mervis, & Robinson, 1999). Their verbal thinking and reasoning skills develop at a faster rate than their nonverbal abilities. The discrepancy between these two areas appears to get wider with age, although their verbal ability remains significantly below age appropriate levels (Jarrold, Baddeley, & Hewes, 1998).

3.2.4.1 Studies examining the attention profile of children with Williams Syndrome

ADHD is considered to be one of the most common comorbid disorders in children with Williams Syndrome (Dodd & Porter, 2009), with one brain imaging study suggesting that these difficulties were correlated with structural differences in grey/white matter morphology (L. E. Campbell et al., 2009). Prevalence estimates are scant, but two studies have suggested that ADHD symptoms are present in 65 to 100% of children and adolescents (Leyfer, Woodruff-Borden, et al., 2006; Rhodes, Riby, Matthews, & Coghill, 2011).

An examination of the behavioural phenotype suggests that inattention is more frequently reported than hyperactivity (Leyfer, Woodruff-Borden, et al., 2006), with some suggestion that this may be an ‘intrinsic’ characteristic of Williams Syndrome (Gagliardi, Martelli, Tavano, & Borgatti, 2011). The limited research available suggests no significant gender differences in the diagnosis of ADHD among children with Williams Syndrome, although a trend towards a higher proportion of males has been reported (Dodd & Porter, 2009; Leyfer, Woodruff-Borden, et al., 2006).

The limited number of studies makes it difficult to determine whether the behavioural phenotype of inattention and hyperactivity described is representative of children with Williams Syndrome. High rates of inattentive and hyperactive symptoms have been reported by parents (Mervis & Klein-Tasman, 2000; Rhodes, et al., 2011; Rhodes, et al., 2010). A cross-sectional study has suggested that hyperactivity prevalence decreases with age and conversely, inattentive symptoms increase with age (Leyfer, Woodruff-Borden, et al., 2006), while an Australian longitudinal study found that ADHD symptoms decreased with age more markedly in adolescents with Williams Syndrome than those with other neurodevelopmental disorders (Einfeld, et al., 2007). Earlier findings from this longitudinal study reported that parents were significantly more likely to endorse the items *overactive* and *short attention span* on the Developmental Behaviour Checklist, although whether these children actually met the criteria for ADHD was not explored (Einfeld, Tonge, & Florio, 1997; Tonge & Einfeld, 2003).

Several studies have also examined the cognitive phenotype but these have been limited to studies of toddlers. One study suggested that sustained attention is an area of strength, with toddlers with Williams Syndrome performing as well as typically developing controls (J. H. Brown et al., 2003). Selective attention, however, has been identified as an area of comparative weakness (Cornish, Scerif, et al., 2007; Scerif, et al., 2004). Brown and

colleagues (2003) further suggested that attention difficulties do not emerge until later in development among individuals with Williams Syndrome. They speculated that as children with Williams Syndrome develop, increasing demands are placed on their cognitive skills. These interactions place a greater burden on attentional capacity which then manifest as attention difficulties in later childhood and adulthood. Further studies are needed in order to confirm this speculation, and to explore the developmental trajectory of attention and hyperactivity into childhood and adolescence within this group.

3.2.5 Cross-syndrome studies

At the behavioural level, cross-syndrome and longitudinal comparisons have suggested that children and adolescents with Down Syndrome generally have fewer ADHD symptoms compared with those with ID (Einfeld, et al., 2007; Turk, 1998), Fragile X Syndrome (Einfeld, et al., 2007; Turk, 1998), ASD (Einfeld, et al., 2007), or Williams Syndrome (Cornish, Steele, et al., 2012; Einfeld, et al., 2007; Papaeliou et al., 2012). Further, a longitudinal study suggested that ADHD symptoms decline slowly through adolescence into early adulthood across neurodevelopmental disorders, and that this decline is greater in males than females (Einfeld, et al., 2007). ADHD symptoms have also been compared in two studies of children with ID, Down Syndrome and ASD. Both studies found that children with ASD had more severe hyperactivity and impulsivity than the other groups (Bradley & Isaacs, 2006; Hastings, et al., 2005), but there were no differences for inattention (Bradley & Isaacs, 2006).

Neuropsychological studies comparing children with different causes of ID represent a new direction in understanding children with attention difficulties, as they attempt to tease out aspects of attention across diagnostic groups. These studies suggest that attention difficulties in children with ID are not homogenous, and that differences may exist depending on the child's behavioural phenotype (Vicari & Carlesimo, 2006). Further, they suggest that

while some attention difficulties may appear similar at the behavioural level, this does not infer that they operate in identical ways at the cognitive level (Cornish & Wilding, 2010).

Two related studies examined inhibitory control in boys with Fragile X and Down Syndromes, and typically developing children matched on mental age classified as either poor or good attenders (as measured by the ACTeRS; Ullman, Sleator, & Sprague, 1984). Their findings suggested that boys with Fragile X Syndrome had significantly greater difficulties with inhibitory control compared with boys with Down Syndrome or typically developing boys, irrespective of whether they were identified as poor or good attenders (Munir, et al., 2000b; Wilding, Cornish, & Munir, 2002).

Studies examining components of cognitive attention have also revealed differences across syndromes. A study of toddlers suggested that the visual sustained attention of those with Down Syndrome was significantly shorter than those with Williams Syndrome or controls matched for mental age (J. H. Brown, et al., 2003), but a more recent study of slightly older children (aged 3 to 6 years) found no differences across groups (Breckenridge, et al., 2013). Auditory sustained attention was also identified to be stronger in children with Down Syndrome than those with Williams Syndrome (Breckenridge, et al., 2013).

The conclusions drawn above are highly speculative given that cross-syndrome studies are limited. Those studies that have been conducted generally compared either one or two syndromes with a typically developing group, and most contained small sample sizes. Studies examining sustained attention, selective attention, and inhibition across ages and syndrome groups suggested that the development of attention is not linear and that it is important to examine performance at different ages to gain further information about the developmental trajectories across and within syndromes (Cornish & Wilding, 2010; Karmiloff-Smith, 2009). Further research across a greater number of syndrome groups, both longitudinal and cross-sectional, is needed to yield more conclusive evidence regarding the

development of attention and the differences across known and idiopathic causes of ID. More cross-syndrome studies contrasting hyperactive symptoms are also needed.

**CHAPTER 4 CURRENT CHECKLISTS AND RATING
SCALES MEASURING SYMPTOMS OF INATTENTION,
HYPERACTIVITY, AND IMPULSIVITY**

The use of rating scales and checklists to identify behaviours characteristic of ADHD can be used to assist with diagnosis (Chan, Hopkins, Perrin, Herrerias, & Homer, 2005). In some studies this has been the only method of identifying and classifying ADHD (e.g., Gunter, Arndt, Riggins-Caspers, Wenman, & Cadoret, 2006) and therefore the diagnostic accuracy and representativeness of these samples is likely to be questionable given the potential for response bias by the respondent(s) and the diagnostic validity of the measures used. The generally accepted diagnostic procedure advocates a multi-informant approach that involves obtaining information from the parents, teachers, and the child if possible (Barkley, 2006c) as well as obtaining a developmental history, behavioural observations, and possibly data from laboratory testing (Reid & Maag, 1994).

Issues of inter-observer agreement are often an issue, with variation across teacher and parent observations reflected in the low inter-rater reliability of many rating scales and checklists (Barkley, 2006c). Some have suggested that low inter-rater reliability should be expected as different behaviours may be observed across different settings (van der Ende, 1999). Alternatively, reliability may differ due to the way behaviour is defined by the observer. For example, an item such as *fidgety* may be rated by one individual as occurring *sometimes* but by another as occurring *often*, as observers may have different perspectives, tolerance levels, and thresholds for reporting behaviour (Reid & Maag, 1994; van der Ende, 1999). A third alternative is that a teacher may be more attuned to identifying atypical behaviour due to their exposure to many children in their classroom and across their career, whereas a parent may be accustomed to their child's behaviour and may perceive problems as being less severe, or being of no concern at all (K. Sullivan, et al., 2006).

Despite the many rating scales and checklists available to measure ADHD and attention difficulties, comparatively few have been clinically validated in populations of children and adolescents with ID, and even fewer have been specifically developed for this

population. This chapter will review the different rating scales that measure ADHD symptomatology, their psychometric properties, and their reliability and validity for children and adolescents with ID. With the exception of the Conners (whose recently released third edition limits its inclusion in independent studies; Conners, 2008), only studies examining the most recent edition of each rating scale will be included in this review.

The framework used to determine the inclusion and suitability of the scales in our review was determined by selecting those that have been used extensively in studies to screen for ADHD symptoms in both population-based samples and in atypical samples of children. Further, we included some lesser known scales that have been developed for children with ID given their relative scarcity. The most recent version of 14 scales were therefore reviewed. Of these 14 scales, five specifically measure ADHD symptoms in typically developing children and two in children with ID. A further seven scales measure ADHD symptoms within the context of broader behavioural and emotional problems; four in typically developing children and three in children with ID. Measures that contained subscales measuring aspects related to ADHD symptomatology but did not specifically measure hyperactivity, impulsivity or inattention (e.g., the inhibit and working memory subscales of the Behaviour Rating Inventory of Executive Function; Gioia, et al., 2000) were excluded from the review.

4.1 Measures with a focus on attention deficit hyperactivity disorder and/or attentional difficulties designed for use with typically developing children

4.1.1 ADD-H Comprehensive Teacher Rating Scale - Second edition (ACTeRS-2)

The second edition of the ACTeRS (Ullman, Sleator, & Sprague, 2000) is a 24-item rating scale completed by teachers and contains four subscales: *attention*, *hyperactivity*, *social skills* and *oppositional behaviour*. Each item is ranked on a 5-point Likert scale from *almost never* to *almost always*. The ACTeRS-2 has separate norms for boys and girls

reported in percentile ranks, and can be administered to children from preschool to Year Eight.

The premise for developing this scale specifically for teachers is because the authors believed that behaviours related to ADHD are more likely to manifest themselves in the classroom, and therefore teachers are the best informants to observe and report upon them (Ullman, et al., 2000). Despite this assertion, the ACTeRS-2 also has two other scales – parent and self-report – to provide additional information for the clinician of the child’s behaviour across different settings.

The psychometric properties of the ACTeRS-2 are described in Table 4.1. The authors report sound psychometric properties for the teacher version (Ullman, et al., 2000), although an independent study suggested that it had inadequate discriminant validity to distinguish across ADHD subtypes (Forbes, 2001). For the parent version, only the internal consistency was reported (Ullman, et al., 2000). No independent studies have evaluated the psychometric properties of the parent version.

4.1.1 ADHD Rating Scale-IV (ADHD-RS-IV)

The ADHD Rating Scale-IV (DuPaul, et al., 1998) was developed as a revised version of the ADHD Rating Scale (DuPaul, 1991) to reflect changes to diagnostic criteria in the DSM-IV (American Psychiatric Association, 1994). It contains a home version completed by the parent or caregiver and a school version completed by the teacher for children or adolescents aged 5 to 18 years. A preschool version has also been released (McGoey, DuPaul, Haley, & Shelton, 2007). Each version has 18 items with 9 items on the *inattention* and *hyperactivity-impulsivity* subscales respectively. Each item is rated on a 4-point Likert scale from *never or rarely* to *very often*. Raw scores are then converted to percentile scores based on normative data for gender and age.

Table 4.1

Psychometric Properties of Measures with a Focus on Attention-Deficit Hyperactivity Disorder and/or Attentional Difficulties for Use with Typically Developing Children

Scale	Psychometric properties reported by authors	Independent studies with typically developing children
ADD-H Comprehensive Teacher Rating Scale – Second edition, Parent form (ACTeRS-2)	Ullman et al. (2000) Fair to excellent internal consistency for the five subscales ($\alpha = .78 - .96$)	None to date
ADD-H Comprehensive Teacher Rating Scale – Second edition, Teacher form (ACTeRS-2)	Ullman et al. (2000) Excellent internal consistency across the four factors ($\alpha = .92 - .97$) Strong test-retest reliability over 4 weeks ($r = .78 - .82$) Moderate inter-rater reliability across teachers ($r = .51 - .73$) Good discriminant validity between children with ADHD and typically developing children Good discriminant validity between children with ADHD and children with a learning disability	Erford & Hase (2006) <i>Typically developing children between kindergarten and Grade 5</i> Good to excellent internal consistency across the four factors ($\alpha = .89 - .93$) Strong test-retest reliability over 30 days ($r = .80 - .89$) Low to moderate convergent validity with the factors from the Conners Teacher Rating Scale -Revised ($r = -.42 - -.53$) Moderate specificity for inattentive and hyperactive types (.81 and .88 respectively) but lower sensitivity for both types (.77 and .81 respectively) Forbes (2001) <i>Typically developing children between Grades 1 and 6</i> Strong convergent validity with the Conners Teacher Rating Scale - Revised ($r = -.54 - -.72$) ¹

¹ Correlations are negative as lower scores on the ACTeRS compared with higher scores on the Conners, indicate greater severity of symptoms

ADHD Rating Scale – IV – Home
version (ADHD-RS-IV)

DuPaul et al. (1998)

Good to excellent internal consistency ($\alpha = .88 - .94$)
Strong test-retest reliability over four weeks ($r = .78 - .86$)

Moderate inter-rater reliability across parent and teacher ratings ($r = .40 - .45$)

Considerable variability in convergent validity with the Conners Parent Rating Scale ($r = .28 - .81$)

Inadequate sensitivity (.57) but excellent specificity in diagnosing ADHD – inattentive (.91). low sensitivity (.76) but excellent specificity (.91) in diagnosing ADHD – combined

Good discriminant validity between children with ADHD and typically developing children in both clinic and school samples

Good discriminant validity between children with ADHD inattentive or combined subtypes in both clinic and school samples

Power et al. (1998)

Moderate inter-rater reliability across parent and teacher ratings ($r = .30 - .41$)

Inadequate sensitivity but excellent specificity in diagnosing inattentive or combined ADHD (varied depending on cutpoint used)

Good discriminant validity between children with

Low convergent validity with the Conners Parent Rating Scale – Revised ($r = -.01 - -.43$)

Low discriminant validity - unable to distinguish children with hyperactive/combined ADHD from those with the inattentive subtype

The psychometric properties have been examined in Korean (Kim et al., 2005) and Icelandic (Magnusson, Smari, Gretarsdottir, & Prandardottir, 1999) language adaptations using typically developing children. It has also been examined in a number of studies using physician ratings (e.g., Dopfner et al., 2006; Zhang, Faries, Vowles, & Michelson, 2005)

	ADHD and typically developing children in a school sample	
ADHD Rating Scale - IV – School version (ADHD-RS-IV)	<p>DuPaul et al. (1998)</p> <p>Good to excellent internal consistency ($\alpha = .88 - .96$)</p> <p>Strong test-retest reliability over four weeks ($r = .88 - .90$)</p> <p>Considerable variability in convergent validity with the Conners Teacher Rating Scale ($r = .29 - .88$)</p>	None to date
Conners - Third edition (Conners 3) ² Parent form	<p>Conners (2008)</p> <p>Good to excellent internal consistency across subscales ($\alpha = .83 - .94$)</p> <p>Strong test-retest reliability over two to four weeks ($r = .67 - .91$)</p> <p>Moderate to strong inter-rater reliability across parent and teacher ratings ($r = .52 - .67$)</p> <p>Strong convergent validity between the Conners 3 subscales that measured attention difficulties with the CBCL Attention problems subscale ($r = .70 - .92$)</p> <p>Strong convergent validity between the Conners 3 subscales that measured attention difficulties with the BRIEF inhibit and working memory subscales ($r = .60 - .78$)</p> <p>Good discriminant validity between children with ADHD and typically developing children</p> <p>Good discriminant validity between children with ADHD and children in other clinical groups (diagnosed</p>	None to date

² Psychometric properties relate to full-length Conners 3 forms

	by a psychiatrist or psychologist) Limited discriminant validity between children with hyperactive/impulsive and inattentive subtypes of ADHD	
Conners - Third edition (Conners 3) Teacher form	Conners (2008) Fair to excellent internal consistency across subscales ($\alpha = .77 - .95$) Strong test-retest reliability over two to four weeks ($r = .72 - .83$) Strong convergent validity between the Conners 3 subscales that measured attention difficulties with the CBCL Attention problems subscale ($r = .72 - .76$) Strong convergent validity between the Conners 3 subscales that measured attention difficulties with the BRIEF inhibit and working memory subscales ($r = .61 - .92$) Good discriminant validity between children with ADHD and typically developing children Good discriminant validity between children with ADHD and children in other clinical groups (diagnosed by a psychiatrist or psychologist) Limited discriminant validity between children with hyperactive/impulsive and inattentive subtypes of ADHD	None to date
Swanson, Nolan & Pelham Checklist – Fourth edition (SNAP- IV)	Swanson (1992) Psychometric data not reported. Validity implied as items are formulated from the DSM-IV but no psychometric analyses to support this conclusion	Solanto & Alvir (2009) <i>Parent and teacher ratings for typically developing children and children referred for attention difficulties</i> Fair to excellent internal consistency for parent ratings ($\alpha = .71 - .92$) Excellent internal consistency for teacher ratings ($\alpha =$

.90 – .97)

Considerable variability in convergent validity with corresponding subscale items on the Conners Rating Scales – Revised for teacher ratings ($k = .31 - .79$) and parent ratings ($k = .37 - .72$)

Stevens, Quittner, & Abikoff (1998)

Teachers rating videotapes of a typically developing child and one with ADHD or ODD

Good to excellent internal consistency

($\alpha = .84 - .95$)

Used MTA-SNAP-IV

Bussing et al. (2008)

Parent and teacher ratings for typically developing children

Fair to good internal consistency for parent ratings ($\alpha = .79 - .90$)

Excellent internal consistency for teacher ratings ($\alpha = .92 - .96$)

Moderate inter-rater reliability across parent and teacher ratings ($r = .43 - .49$)

Good discriminant validity between children who met diagnostic criteria for ADHD and typically developing children for parent ratings

The psychometric properties have also been examined in Chinese (Gau et al., 2009; Gau, Shang, et al., 2008) and Portuguese (Mattos, Serra-Pinheiro, Rohde, & Pinto, 2006) language adaptations

Strengths and Weaknesses of ADHD
Symptoms and Normal Behaviour
Scale (SWAN)

Swanson et al. (2005)
Psychometric data not reported.

Young, Levy, Martin & Hay (2009)
Excellent internal consistency ($\alpha = .94 - .96$)
Good discriminant validity between children with
ADHD (any subtype) and typically developing children

The psychometric properties have been examined in a
French language adaptation (Robaey, Amre, Schachar, &
Simard, 2007) using typically developing children with a
suspected diagnosis of ADHD

The psychometric properties of the ADHD-RS-IV are described in Table 4.1. The convergent validity of the school version with the Conners Teacher Rating Scale (CTRS) are variable, but all other properties are strong (DuPaul, et al., 1998). No independent studies, however, have examined the psychometric properties of the school version. The home version of this scale has variable psychometric properties. It has good to excellent internal consistency, strong test-retest reliability, moderate inter-rater reliability, and good discriminant validity between children with ADHD and those who are typically developing. Similar to the school version, it has variable convergent validity with the Conners Parent Rating Scale (CPRS). The authors also reported that while the ADHD-RS-IV home version has inadequate to low sensitivity in diagnosing ADHD inattentive and combined subtypes, it has excellent specificity (DuPaul, et al., 1998; Power, et al., 1998).

4.1.2 Conners Third edition (Conners 3)

The Conners Third edition (Conners, 2008) has separate forms completed by parents and teachers for children and adolescents aged 6 to 18 years, as well as a self-report scale for children and adolescents aged 8 to 18 years. It aims to evaluate symptoms of ADHD and related disorders, and makes direct reference to the diagnostic criteria for ADHD set out in the DSM-IV-TR (American Psychiatric Association, 2000). Short (39 to 43 items) and long (105 to 110 items) forms are available which ask the respondent to respond on a 4-point scale from *not true at all (never, seldom)* to *very much true (very often, very frequently)*. The items are grouped under the following subscales: *inattention, hyperactivity/impulsivity, learning problems, executive functioning, aggression, and peer relations*. It also measures behaviours consistent with oppositional defiant and conduct disorders which may be observed in children with ADHD.

The teacher version of this scale has fair to excellent internal consistency and strong test-test reliability (see Table 4.1; Conners, 2008). It also has strong convergent validity with

the relevant subscales measuring attention difficulties on the Child Behaviour Checklist Teacher Report Form (CBCL TRF) and the Behaviour Rating Inventory of Executive Function Teacher Form (BRIEF). The authors reported good discriminant validity between children with ADHD, children with other clinical disorders and typically developing children, but limited discriminant validity to distinguish across ADHD subtypes.

The parent version of this scale has good to excellent internal consistency, strong test-retest reliability and moderate to strong inter-rater reliability across parent and teacher ratings (see Table 4.1; Conners, 2008). It also has strong convergent validity with the corresponding subscales measuring attention difficulties on the Child Behaviour Checklist (CBCL) and Behaviour Rating Inventory of Executive Function Parent Form (BRIEF). The authors reported good discriminant validity between children with ADHD, children with other clinical disorders and typically developing children, but limited discriminant validity to distinguish across ADHD subtypes. No independent studies to date have examined the psychometric properties of the parent or teacher version.

4.1.3 Swanson, Nolan & Pelham Checklist – Fourth edition (SNAP-IV)

The SNAP-IV (Swanson, 1992) is a checklist completed by parents or teachers and has 90 items. The initial 40 items relate to ADHD (with two subscales: *hyperactivity* and *inattention*) and oppositional defiant disorder (ODD). The remaining 50 items relate to behaviours taken from 15 DSM-III-R (American Psychiatric Association, 1987) diagnoses which the author proposed may overlap with or masquerade as ADHD symptoms. There is also a shorter, 26 item version with 18 items relating to ADHD and 8 items relating to ODD. This version is sometimes referred to as the MTA-SNAP-IV as it was used in the Multimodal Treatment Study for ADHD (The MTA Cooperative Group, 1999). The SNAP-IV is freely available from the author's web site (Swanson, n.d.) but lacks age- and gender-based norms.

There is no psychometric data published by the author for the SNAP-IV (Swanson, 1992). Face validity could be implied given that the items were formulated from DSM-III-R (American Psychiatric Association, 1987) diagnostic criteria but this is speculative. Independent studies have suggested that the SNAP-IV has fair to excellent internal consistency for parent ratings and good to excellent internal consistency for teacher ratings (see Table 4.1; Solanto & Alvir, 2009; Stevens, et al., 1998). Its convergent validity with the CPRS-R and CTRS-R had significant variation across subscales for both parent and teacher ratings varying from weak to strong (Solanto & Alvir, 2009).

4.1.4 Strengths and Weaknesses of ADHD Symptoms and Normal Behaviour Scale (SWAN)

The SWAN (Swanson, et al., 2005) is a revision of the SNAP-IV (reviewed above; Swanson, 1992) with the items reworded in a positive (strength-based) manner e.g., *Often talks excessively* became *Modulate verbal activity (control excess talking)*. As with the MTA-SNAP-IV (The MTA Cooperative Group, 1999), it consists of 18 items, with nine related to inattention and the other nine related to hyperactivity/impulsivity. Like the SNAP-IV (Swanson, 1992), it does not have separate scales for parents and teachers.

Unlike other rating scales that use diagnostic cut-points, the SWAN conceptualises ADHD on a 7-point continuum ranging from *far below average* to *far above average*, yielding a normal distribution of scores. The use of a strength-based scale is considered preferable as it reduces the likelihood of over-inflating the proportion of children having problems which can occur when using a truncated, problem-based scale (Hay, et al., 2007).

There is no psychometric data published by the authors of the SWAN (Swanson, et al., 2005). Limited psychometric data from an independent study reported that the SWAN had excellent reliability and good discriminant validity between children with ADHD (any subtype) and typically developing children (see Table 4.1; Young, et al., 2009).

4.1.5 Limitations of these measures

A significant limitation of the SNAP-IV (Swanson, 1992) and SWAN (Swanson, et al., 2005) is that the reliability and validity of these scales has not been established given the lack of psychometric data. While the ADHD-RS-IV (DuPaul, et al., 1998) reports on its psychometric properties, the reliability and validity of the home version is variable. The lack of independent studies examining the psychometric properties of this scale also makes it difficult to verify its reliability and validity. Along with the ACTeRS-2 (Ullman, et al., 2000), the SNAP-IV (Swanson, 1992) and SWAN (Swanson, et al., 2005) also lack age-based norms despite considerable research suggesting developmental differences in attention and hyperactivity across different ages (Faraone, et al., 2006; J. C. Hill & Schoener, 1996).

The SNAP-IV (Swanson, 1992) and ADHD-RS-IV (DuPaul, et al., 1998) both provide clinical cut-off points delineating typical functioning from clinical attentional difficulties, although flaws in both designs suggest their discriminant validity may be limited. In the case of the SNAP-IV, the assignment of children as ADHD and/or ODD was based on teacher ratings and not formal diagnostic criteria. For the ADHD-RS-IV, the authors devised different cut-off points depending upon: (a) whether the scale is being used as a screening or diagnostic tool; (b) whether an ADHD – combined or ADHD – inattentive diagnosis is being investigated; and (c) whether the user wishes to screen/diagnose ADHD or “rule out” this diagnosis.

Another limitation inherent to the ACTeRS-2 (Ullman, et al., 2000), SNAP-IV (Swanson, 1992) and SWAN (Swanson, et al., 2005) is that they lack details regarding the demographic characteristics of their samples. The extent to which the samples used in their development are representative of the wider population are therefore unclear. The ADHD-RS-IV (DuPaul, et al., 1998) drew upon a diverse population of American children from a range of cultural backgrounds but their normative data may need to be interpreted with

caution in cross-cultural studies. Students from an African-American background scored consistently higher than students who were Caucasian (Reid et al., 1998). The majority of children in this sample were also middle class, so the results may not generalise to children from different socioeconomic backgrounds.

In scoring the ADHD-RS-IV, a total can be calculated with up to three missing items on each subscale (or 33% of the total number of items; DuPaul, et al., 1998). This could potentially result in lower scores that may misrepresent the child's hyperactive/impulsive and/or inattentive behaviours and may lead to incorrect conclusions being drawn about the child's difficulties in these areas (Demaray, Elting, & Schaefer, 2003).

One of the limitations of the Conners 3 (Conners, 2008) is the length of the long form, with over 100 items being impractical for use as a clinical or screening tool. There is also some repetition, thus calling into question the inclusion of some items. Other items are designed to assess the validity of the ratings with generalised statements which some respondents may choose to omit (e.g., *Behaves like an angel*), thus defeating the purpose of their inclusion.

4.1.6 Use with children and adolescents with ID

Of the five measures reviewed above, only one has been included in studies examining the psychometric properties in children or adolescents with ID, namely the Conners Rating Scales (Conners, 1997, 2008). Given the relatively recent release of the Conners 3 (Conners, 2008), independent studies that have used this instrument are not yet available. For the purpose of this review, research on the properties of its predecessor, the Conners' Rating Scales – Revised (Conners, 1997) will be reported upon.

While the Conners Parent and Teacher Rating Scales – Revised (CPRS-R, CTRS-R; Conners, 1997) has been used in many studies of children with ID, few have validated its use within these populations (Guerin, et al., 2009). One study examined the utility of these scales

among children and adolescents with mild to severe ID (Deb, et al., 2008). As a screening tool for ADHD, the CPRS-R was found to have excellent sensitivity (.90) but inadequate specificity (.67). The CTRS-R was found to have inadequate sensitivity (.69) and specificity (.67). The authors also found the inter-rater reliability across parents and teachers was unacceptably low ($r = .17$). The findings suggested that while the CPRS-R may be able to distinguish between children with ID with or without ADHD, the CTRS-R was unable to make this distinction. The authors noted that 13 items (46.4%) on the CTRS-R were dependent upon the child being verbal, thus invalidating the measure for children who do not have meaningful communication skills. They also questioned the validity of many items on the CTRS-R and suggested that it would not be a useful measure for rating children with severe or profound ID.

4.2 Measures with a focus on attention deficit hyperactivity disorder and/or attentional difficulties designed for use with children with ID

4.2.1 Attention-Distracton, Inhibition-Excitation Classroom Assessment Scale (ADIECAS)

Developed by Peter Evans (1975, in Evans & Hogg, 1984) as part of his doctoral thesis, the ADIECAS has 16 items and was developed specifically to examine inattention and hyperactivity in children with ID. The items are completed by the classroom teacher and each item is ranked on a scale of 1 to 7, with higher scores indicating higher severity. The authors reported that two dimensions can be extracted from the scale: *inattention/excitation* (IE) and *attentiveness/distractibility* (AD). The IE subscale measures behaviours such as how well a child can restrain their actions, inhibit their responses, and coordinate their movements. The AD subscale measures behaviours such as the ability to work well on a set task, resist disruptions and distractions, attend well to instructions, and persevere.

The ADIECAS has moderate to strong test-test reliability but only weak to moderate inter-rater reliability across teachers (see Table 4.2; Evans & Hogg, 1984). An independent study of children with severe ID suggested that the ADIECAS has fair to excellent internal consistency (Strand, Sturmey, & Newton, 1990). Its convergent validity with the CTRS-R reported significant variation for teacher ratings from very weak to strong (Buckley, Hillery, Guerin, McEvoy, & Dodd, 2008; Guerin, et al., 2009). A comparison of the factor structure of the ADIECAS across studies provided by Guerin and colleagues (2009) suggested little consistency to the composition of items within the subscales, with the only consistent finding being that all studies extracted the IE and AD subscales (albeit with different items).

4.2.2 Attention Checklist (AC)

The Attention Checklist (AC) was developed specifically for children and adolescents with ID (Das, 1986, in Das & Melnyk, 1989) with a focus on inattentive behaviours. It was designed to be completed by teachers and contains 12 items that are rated on a 4-point scale from *not at all* to *pretty much*. The authors reported that the AC has excellent internal consistency and high convergent validity with the CRS (see Table 4.2; Das & Melnyk, 1989).

4.2.3 Limitations of these measures

While both the ADIECAS (Evans, 1975 in Evans & Hogg, 1984) and AC (Das, 1986 in Das & Melnyk, 1989) have the advantage of being developed specifically to measure ADHD symptoms in children with ID, neither tool is a valid measure to use within this population. The psychometric properties of the ADIECAS are variable, and its factor structure has yielded inconsistent findings across studies (Evans & Hogg, 1984; Strand, et al., 1990; Turner, Sloper, & Knussen, 1991). The psychometric properties of the AC are reported to be strong by the authors, but there have been no independent studies that can confirm these robust findings.

Table 4.2

Psychometric Properties of Measures with a Focus on Attention-Deficit Hyperactivity Disorder and/or Attentional Difficulties for Use with Children with Intellectual Disability

Scale	Psychometric properties reported by authors	Independent studies with children with ID
Attention-Distraction, Inhibition-Excitation Classroom Assessment Scale (ADIECAS)	<p>Evans & Hogg (1984)</p> <p>Moderate to strong test-retest reliability over one month ($r = .51 - .83$)</p> <p>Weak to moderate inter-rater reliability across teachers ($r = .37 - .71$)</p>	<p>Guerin et al. (2009)</p> <p><i>Children and adolescents with moderate to severe ID</i></p> <p>Good to excellent internal consistency ($\alpha = .83 - .92$)</p> <p>Considerable variation in convergent validity with the Conners Teacher Rating Scale ($r = .37 - .72$)</p> <p>Buckley, Hillery, Guerin, McEvoy & Dodd (2008)</p> <p><i>Children and adolescents with ID (severity not defined)</i></p> <p>Considerable variation in convergent validity with the Conners Teacher Rating Scale – Revised ($r = .19 - .73$)</p> <p>Turner, Sloper, & Knussen (1991)</p> <p><i>Children and adolescents with Down Syndrome</i></p> <p>Suggested that the test items yielded a poor fit to the original two-factor AD/IE model and suggested a four factor alternative</p> <p>Strand, Sturmey, & Newton (1990)</p> <p><i>Children and adolescents with severe ID</i></p> <p>Fair to excellent internal consistency using a four-factor structure ($\alpha = .71 - .92$)</p> <p>Moderate concurrent validity with British Ability Scales on attention-distraction factor ($r = .41 - .60$) but not the inhibition-excitation factor (r not reported)</p>

Attention Checklist (AC)

Das & Melnyk (1989)

None to date

Excellent internal consistency ($\alpha = .96$)

High convergent validity with the Conners Rating Scale
($r = -.84$).

There are several other limitations which may have contributed to their lack of uptake by researchers and clinicians. Studies using the ADIECAS (Evans, 1975 in Evans & Hogg, 1984) have focused on children with moderate to severe ID, so its validity for use with children who have mild ID has not been established. The AC (Das, 1986 in Das & Melnyk, 1989) only measures inattentive behaviours with the authors offering no explanation or justification for excluding items measuring hyperactive/impulsive behaviours. Neither scale has developed a parent version, precluding the ability to obtain and contrast behavioural data from multiple informants. Both scales also lack commercial availability and lack age- or gender-based normative data.

4.3 Measures assessing a range of behavioural and emotional problems designed for typically developing children

The measures reviewed in this section assess a broad range of behavioural and emotional problems in typically developing children. Given the focus of this thesis is on behaviours relating to attention, hyperactivity and impulsivity these scales will be reviewed in the context of those subscales that specifically measure these areas.

4.3.1 Behavior Assessment System for Children – Second edition (BASC-2)

The BASC-2 is a set of rating scales for children, adolescents, and young adults aged 2 to 21 years (Reynolds & Kamphaus, 2004) with separate forms for parents (Parent Rating Scale; PRS) and teachers (Teacher Rating Scale; TRS). There is some variation in the number and composition of items depending on the age of the individual being rated: preschool (2 to 5 years), child (6 to 11 years) and adolescent (12 to 21 years). The PRS forms have 134 to 160 items and the TRS forms have 100 to 139 items. Each item is rated on a 4-point scale from *never* to *almost always*. The manual contains separate norms across genders, age ranges, and for general as well as clinical (i.e., learning disability and ADHD) samples.

The BASC-2 contains two subscales relating to ADHD symptomatology: *attention problems* and *hyperactivity*. Markers for ADHD are indicated by scores in the clinical range (a *T* score ≥ 70) on either subscale. These scores are reported separately which allows for different subtypes to be explored. The authors have emphasised that these scores can be used to assist with diagnosis of ADHD but should not be used in isolation (Reynolds & Kamphaus, 2004).

The authors reported that the TRS has good to excellent internal consistency in both general and clinical samples (see Table 4.3; Reynolds & Kamphaus, 2004). They also reported that the BASC-2 has strong test-retest reliability and moderate to strong inter-rater reliability across teachers (Reynolds & Kamphaus, 2004). These properties have been replicated in an independent study (Bergeron, Floyd, McCormack, & Farmer, 2008). Strong convergent validity with the CTRS-R and CBCL TRF has been reported by the authors, but no independent studies have confirmed these findings. The validity of the TRS to discriminate children with ADHD from those who do not have this diagnosis, or to discriminate between ADHD subtypes, has not been examined.

The PRS has good to excellent internal consistency in both general and clinical samples (see Table 4.3; Reynolds & Kamphaus, 2004). The authors also reported that the PRS has strong test-retest reliability and strong inter-rater reliability across parents (Reynolds & Kamphaus, 2004). The convergent validity of the *attention problems* and *hyperactivity* subscales of the BASC-2 PRS with the *attention problems* subscale of the CBCL were found to be strong in a clinically referred kindergarten sample (Myers, Bour, Sidebottom, Murphy, & Hakman, 2010).

Reported advantages of the BASC-2 include its use of validity checks for excessively negative or positive responses (Gladman & Lancaster, 2003), and its inclusion of adaptive

Table 4.3

Psychometric Properties of Measures Assessing a Range of Behavioural and Emotional Problems for Use with Typically Developing Children

Scale	Psychometric properties reported by authors	Independent studies with typically developing children
Behavior Assessment System for Children – Second edition – Parent form (BASC-2 PRS)	Reynolds and Kamphaus (2004) ³ Good to excellent internal consistency across composite scales and the overall BSI for the general ($\alpha = .89 - .95$) and clinical samples ($\alpha = .90 - .96$) Strong test-retest reliability over a period of 9 - 70 days ⁴ ($r = .78 - .92$) Strong inter-rater reliability across mother and father ratings ($r = .65 - .86$) Strong convergent validity with the CBCL on the externalising and internalising subscales, and the total score ($r = .67 - .84$) Strong convergent validity with the Conners PRS-R total score ($r = .65 - .79$) Moderate to strong convergent validity between the attention problems and hyperactivity subscales and the BRIEF working memory and inhibit subscales ($r = .48 - .79$)	Myers et al. (2010) <i>Clinically referred preschool children</i> Moderate to strong convergent validity with corresponding CBCL 1.5 -5 subscales ($r = .44 - .86$) and composite scores ($r = .63 - .90$)
Behavior Assessment System for Children – Second edition – Teacher form (BASC-2 TRS)	Reynolds and Kamphaus (2004) ⁵ Good to excellent internal consistency across composite scales and the overall BSI for the general ($\alpha = .87 - .97$)	Bergeron et al. (2008) <i>Typically developing children attending primary schools</i> Strong test-retest reliability over a period of 8-25 days (r

³ Child and adolescent forms were analysed separately by the authors, but are reported together here⁴ General and clinical samples were combined⁵ Child and adolescent forms were analysed separately by the authors, but are reported together here

	<p>and clinical samples ($\alpha = .87 - .97$)</p> <p>Strong test-retest reliability over a period of 8 - 65 days⁶ ($r = .81 - .93$)</p> <p>Moderate to strong inter-rater reliability across teachers ($r = .48 - .70$)</p> <p>Strong convergent validity with the CBCL TRF on the externalising and internalising subscales, and the total score ($r = .64 - .80$)</p> <p>Strong convergent validity with the CTRS-R total score ($r = .69 - .84$)</p>	<p>$= .83 - .93$)</p> <p>Strong inter-rater reliability across teachers ($r = .72 - .79$)</p> <p>Strong convergent validity across the BASC-2 externalising problems subscale and the CBCL externalising behaviours composite ($r = .89$)⁷</p>
Child Behaviour Checklist - Parent form (CBCL)	<p>Achenbach & Rescorla (2001)</p> <p>Fair to excellent internal consistency ($\alpha = .72 - .97$)</p> <p>Strong test-retest reliability over a mean period of 8 days ($r = .80 - .94$)</p> <p>Strong convergent validity with the ADHD Index and oppositional subscale on the Conners Parent Rating Scale ($r = .71 - .80$)</p>	<p>Hudziak, et al. (2004)</p> <p><i>Children with attention and/or aggression behaviour problems compared with their siblings</i></p> <p>Inadequate sensitivity (.34) but excellent specificity (.99) in diagnosing ADHD</p>
Child Behaviour Checklist - Teacher report form (TRF)	<p>Achenbach & Rescorla (2001)</p> <p>Fair to excellent internal consistency ($\alpha = .72 - .95$)⁸</p> <p>Very weak to moderate inter-rater reliability between teachers and parents ($r = .12 - .44$)</p> <p>Strong test-retest reliability over a mean period of 16 days ($r = .62 - .96$)</p> <p>Strong convergent validity with the Conners Teacher</p>	<p>Bergeron et al. (2008)</p> <p><i>Typically developing children attending primary schools</i></p> <p>Strong test-retest reliability over a period of 8-25 days ($r = .83 - .90$)</p> <p>Strong inter-rater reliability across teachers ($r = .62 - .73$)</p>

⁶ General and clinical samples were combined

⁷ Convergent validity for ADHD subscales were not calculated as only externalising behaviours were examined in this study, precluding a comparison of inattentive behaviours

⁸ Lower alphas corresponded with the somatic complaints and thought problems subscales, which both comprised items that are seldom endorsed by teachers

	Rating Scale ($r = .77 - .89$)	
Children's Behaviour Questionnaire (CBQ)	<p>Rothbart, Ahadi, Hersey, & Fisher (2001) Unacceptable to excellent internal consistency ($\alpha = .64 - .92$) Considerable variability in inter-rater reliability across parents ($r = .28 - .79$)</p>	<p>Kochanska, DeVet, Goldman, Murray, & Putnam (1994) <i>Mother ratings in 2-6 year old children</i> Unacceptable to excellent internal consistency ($\alpha = .68 - .98$)</p> <p>The psychometric properties have also been examined in Chinese (Ahadi, Rothbart, & Ye, 1993) and Japanese (Kusanagi, 1993, in Rothbart, et al., 2001) language adaptations</p>
Strengths and Difficulties Questionnaire (SDQ) – Parent scale	<p>Goodman (2007) Weak to strong inter-rater reliability across parent and teacher ratings ($r = .37 - .62$) Strong convergent validity with corresponding subscales of the Rutter Scales ($r = .78 - .88$)</p> <p>Goodman & Scott (1999) Moderate to strong convergent validity with corresponding subscales of the CBCL ($r = .59 - .87$)</p>	<p>Becker et al. (2006) <i>Children and adolescents with ADHD in 10 European countries</i> Unacceptable to fair internal consistency ($\alpha = .58 - .72$) Weak to moderate convergent validity with corresponding subscales on the ADHD-RS IV ($r = .30 - .54$)</p> <p>Bourdon, Goodman, Rae, Simpson, & Koretz (2005) <i>Typically developing children</i> Unacceptable to fair internal consistency ($\alpha = .46 - .77$)</p> <p>Hawes & Dadds (2004) <i>Typically developing children – Australian study</i> Unacceptable to good internal consistency ($\alpha = .59 - .80$) Weak concurrent validity between SDQ hyperactivity subscale and classroom observation for hyperactivity ($r = .20$)</p>

Strengths and Difficulties Questionnaire (SDQ) – Teacher scale	Goodman (2007) Strong convergent validity with corresponding subscales of the Rutter Scales ($r = .87 - .92$)	Strong test-retest reliability over 12 months ($r = .61 - .77$) Hill & Hughes (2007) <i>Typically developing Grade 1 children with low literacy achievement scores</i> Unacceptable to good internal consistency ($\alpha = .64 - .89$) Weak to moderate inter-rater reliability across parents and teachers ($r = .26 - .47$)
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and maladaptive behaviour scales to provide a balanced perspective of each individual (Tan, 2007). It has been suggested that the use of similar scale and item structures on the parent and teacher forms may increase inter-rater reliability (Gladman & Lancaster, 2003), although others have reported that its reliability across teachers and parents is limited (Tan, 2007). The division of hyperactive and inattentive behaviours into separate subscales is also perceived by some as an advantage (Gladman & Lancaster, 2003) although this could also be disadvantageous as it does not provide an overall score for ADHD.

4.3.2 Child Behaviour Checklist (CBCL)

The CBCL has several parent, teacher and self-rating scales. Separate parent/caregiver and teacher rating scales are available for children aged 1.5 to 5 years (Achenbach & Rescorla, 2000) and 6 to 18 years (Achenbach & Rescorla, 2001). A self-report scale is also available for adolescents aged 11 to 18 years. More recently, multicultural norms were also developed by the author (Achenbach, 2007). The checklist uses a 3-point Likert rating scale of *not true (as far as you know)*, *somewhat/sometimes true*, and *very/often true*.

The parent and teacher rating scales have 118 items relating to specific behavioural and emotional problems. The authors used a wide normative sample with children and adolescents from different ethnic and socio-economic backgrounds, and from urban and rural/remote areas. The CBCL contains syndrome and DSM-oriented subscales relating to ADHD symptomatology: *attention problems* (syndrome) and *attention/deficit hyperactivity* (DSM-oriented) subscales, with a *T* score above 70 considered to be within the clinical range.

The authors reported that the teacher version of this scale (TRF) had strong test-retest reliability but significant variation in internal consistency (fair to excellent) and very weak to moderate inter-rater reliability across parent and teacher ratings. When focusing on the *attention problems* and *attention/deficit hyperactivity* subscales, they have excellent internal consistency ($\alpha = .95$ and $.94$ respectively) and strong test-retest reliability ($r = .95$ for both

subscales). It also has strong convergent validity with corresponding subscales on the CTRS-R (see Table 4.3; Achenbach & Rescorla, 2001). No studies to date have examined the specificity and sensitivity of the TRF for clinical diagnoses, so its diagnostic utility for ADHD is not known. The only independent study examining the psychometric properties of the TRF reported strong test-retest and inter-rater reliability in a sample of typically developing primary school students (Toplak, Bucciarelli, Jain, & Tannock, 2009).

The parent version of this scale (CBCL) is reported to have fair to excellent internal consistency and strong test-retest reliability. When focusing on the *attention problems* and *attention/deficit hyperactivity* subscales, they have good internal consistency ($\alpha = .86$ and $.84$ respectively), strong test-retest reliability ($r = .92$ and $.93$ respectively) and moderate to strong convergent validity with corresponding subscales of the CPRS-R (see Table 4.3; Achenbach & Rescorla, 2001). One study reported that the sensitivity and specificity of diagnosing ADHD improved significantly when using cut-off *T* scores of between 52 and 60 in both community and clinical samples (Hudziak, et al., 2004). Given the authors of this measure would consider these *T* scores to be within the normal range (Achenbach & Rescorla, 2001), it has been suggested that the CBCL may underdiagnose children meeting the criteria for ADHD (Hudziak, et al., 2004). These findings suggested that while the CBCL may be useful for ruling out a diagnosis of ADHD in children and adolescents, its diagnostic utility for identification may be limited when using the author's clinical cutpoints. No other independent studies have examined the psychometric properties of this version of the CBCL.

4.3.3 Children's Behaviour Questionnaire (CBQ)

The Children's Behaviour Questionnaire, initially developed by Mary Rothbart (1981), has 195 items and is completed by the parent/primary caregiver. Initially designed to describe the temperaments of children aged 3 to 7 years, a version has been developed for children aged 7 to 10 years (the Temperament in Middle Children Questionnaire) and a self-

report questionnaire for children and adolescents aged 9 to 15 years (Early Adolescent Temperament Questionnaire). Each item is rated on a 7-point scale from *extremely untrue* to *extremely true*. Short (94 items) and very short (36 items) forms have also been developed (Putnam & Rothbart, 2006).

Although the CBQ was not designed to specifically measure ADHD symptomatology, three of the subscales (*attentional focusing*, *impulsivity* and *inhibitory control*) can provide information to measure attentional difficulties. The instrument has not yet, however, been used among populations of children with ADHD.

The CBQ is reported to have unacceptable to excellent internal consistency (see Table 4.3; Rothbart, et al., 2001). The three subscales measuring attention difficulties all had fair internal consistency ($\alpha = .67 - .78$) a finding which was replicated in an independent study of toddlers and young children ($\alpha = .70 - .72$; Kochanska, et al., 1994). The authors also reported considerable variation in the inter-rater reliability across several samples of parents, ranging from weak for *attentional focusing* ($r = .39 - .41$) to moderate/strong for *impulsivity* ($r = .53 - .72$) and *inhibitory control* ($r = .40 - .72$; Rothbart, et al., 2001). Only one independent study has examined the psychometric properties, which reported variable internal consistency in mother ratings of young children (Kochanska, et al., 1994).

4.3.4 Strengths and Difficulties Questionnaire (SDQ)

The SDQ screens for behavioural difficulties and assesses the impact these behaviours have on the child's life (Goodman, 1997). It contains 25 items: 10 regarded as strengths, 14 regarded as difficulties, and one neutral item. Each item is rated on a 3-point Likert scale of *not true*, *somewhat true* and *certainly true*. Although there are separate forms for parents and teachers across two different age groups (4 to 10 and 11 to 17 years), all contain almost identically worded items. A self-report version is also available for adolescents aged 11 to 17 years. The questionnaires are freely available for download from a

dedicated web site (Goodman, 2004) and normative data from six countries is also available (Goodman, 2007). It is also available in over 30 languages (Goodman & Scott, 1999) making it highly accessible for cross-cultural research. ADHD symptomatology is measured in the *hyperactivity* subscale which contains three items relating to hyperactivity/impulsivity and two items relating to inattention.

The author reported that the SDQ has moderate to strong convergent validity with corresponding subscales of the CBCL and the Rutter Scales, The inter-rater reliability across parents and teachers is variable across subscales (see Table 4.3; Goodman, 2007; Goodman & Scott, 1999), but on the *hyperactivity* subscale it was moderate ($r = .54$). No other psychometric analyses were conducted by the author. An independent study reported strong test-retest reliability over 12 months (Hawes & Dadds, 2004) but other reports of the psychometric properties have been less encouraging. Several studies reported that the SDQ had unacceptable to fair internal consistency in typically developing children (Bourdon, et al., 2005) and children with ADHD (Becker, et al., 2006). Weak to moderate convergent validity has also been reported with corresponding subscales on the ADHD-RS-IV (Becker, et al., 2006).

A strength of the SDQ is its inclusion of items rating the strengths of the child as well as their limitations. While some authors have deemed that the inclusion of positive items lengthens a rating scale unnecessarily (Aman, Singh, Stewart, & Field, 1985), this argument does not hold for this particular scale given the SDQ has just 25 items.

4.3.5 Limitations of measures

A core limitation of both the SDQ (Goodman, 1997) and CBQ (Rothbart, et al., 2001) are their weak psychometric properties. Similar properties have been reported in the limited number of independent studies using these measures (e.g., Becker, et al., 2006; Bourdon, et

al., 2005). The CBQ has not been used in populations of children with ADHD, and therefore its validity as a measure for this clinical group is not known.

A limitation of the BASC-2 (Reynolds & Kamphaus, 2004), CDQ (Rothbart, et al., 2001) and SDQ (Rothbart, et al., 2001) relates to the forms completed by parents and teachers. The CBQ only has a parent/caregiver form, and therefore it cannot provide information or comparisons about the child's behaviour across different environments. The BASC-2 and SDQ, while offering separate forms, contain almost identical items, suggesting that ADHD symptoms do not present differently across settings despite research suggesting otherwise (Barkley, 2006c; Wolraich et al., 2004). Further, the authors of the BASC-2 did not report inter-rater reliability across parents and teachers, which do little to support their choice of developing similar rating scale items across scales.

Another limitation of the SDQ (Goodman, 1997) is that each subscale contains five items, and therefore its ability to measure hyperactive and inattentive behaviours is restricted. Compared with other measures, Goodman (1997) stated the SDQ provided a "better coverage of inattention" (p. 581) but with only two items, it is unclear how he drew this conclusion. Given the SDQ is intended for use as a screening tool, this clearly poses limitations on its ability to screen for ADHD symptoms.

4.3.6 Use with children and adolescents with ID

The authors of the BASC-2 included children with mental retardation /developmental delay as a clinical group (2.2%, $n = 142$) in their standardisation study and subscale norms were calculated (Reynolds & Kamphaus, 2004). The manual does not state, however, how this group was defined or how individuals were selected for inclusion in this group. No independent studies to date have examined the psychometric properties of the BASC-2 in children and adolescents with ID.

The psychometric properties of the CBQ and SDQ have been reported in several studies of children and adolescents with Down Syndrome (Nygaard, et al., 2002) and idiopathic ID (Emerson, 2005; Kaptein, Jansen, Vogels, & Reijneveld, 2008). The internal consistency of the SDQ *hyperactivity* subscale was fair ($\alpha = .73$) while the three subscales measuring attention difficulties in the CBQ ranged from unacceptable to fair ($\alpha = .49 - .76$). The inter-rater reliability of the SDQ across parents and teachers was weak to moderate and therefore low for clinical purposes. While none of these properties were dissimilar from those reported for typically developing samples (e.g., Becker, et al., 2006; Kochanska, et al., 1994), it would suggest that findings from these scales needed to be interpreted with caution when used with children and adolescents with ID, and may not be an accurate reflection of their behaviour profile.

Only two studies have examined the psychometric properties of the most recent version of the CBCL, with both studies being conducted on children with ASD (Pandolfi, Magyar, & Dill, 2009, 2012). The findings of the CBCL 6-18 reported fair to excellent internal consistency ($\alpha = .76 - .94$). Similar to Achenbach and Rescorla (2001), the *attention problems* subscale had good internal consistency at .83. The internal consistency was unacceptable on four of the six factors of the CBCL 1.5-5 including the *attention problems* subscale ($\alpha = .68$). Confirmatory factor analyses on both versions of the CBCL supported the existing factor structure suggested by the authors (Achenbach & Rescorla, 2000) and the scale's acceptability for use among children with ASD. Pandolfi and colleagues (2009, 2012) recommended the CBCL be used in conjunction with other scales when examining comorbid psychopathology.

When evaluating the suitability of the CBCL for children with ID, reviews have again been restricted to earlier versions (Koskentausta, Iivanainen, & Almqvist, 2004; Pueschel, Bernier, & Pezzullo, 1991; Turk, 1998). It is noteworthy, however, that qualitative feedback

based on the earlier edition remains relevant to the item set in the more recent release. Koskentausta and colleagues (2004), for example, believed that the item *Acts too young* referred to the child's intellectual disability rather than being symptomatic of a behaviour disorder. In another study, parents and teachers found some items irrelevant to the child being rated, and omitted one or more items when completing it (Turk, 1998). Unfortunately the author of this study did not provide any further detail of the items deemed irrelevant.

4.4 Measures assessing a range of emotional functioning and behaviour disorders developed for children with intellectual or developmental disabilities

4.4.1 Aberrant Behaviour Checklist – Community (ABC-C)

The Aberrant Behaviour Checklist has 58 items and was originally developed to measure treatment efficacy in adults with moderate to profound ID in residential settings (ABC - R; Aman, et al., 1985). Since then it has been modified to measure challenging behaviours in children (Marshburn & Aman, 1992). In 1994, the ABC was revised to reduce language suggestive of an institutional environment thus creating two checklists: one for residential settings (ABC-R) and one for the community (ABC-C; Aman & Singh, 1994). The items are completed by a person well-known to the child (e.g., parent, teacher, carer) with each item ranked on a 4-point scale from *not at all a problem* to *the problem is severe in degree*. The ABC-C contains one subscale relating to ADHD symptomatology named *hyperactivity/noncompliance* with normative data generated for children and adolescents in the study conducted by Marshburn and Aman (1992).

While the ABC-C was developed to be a valid tool in measuring challenging behaviours in individuals with ID, the original study drew on “medical judgement” to estimate degrees of ID. By omitting to use findings from standardised instruments to classify degree of ID in study participants, the author's conclusions about behavioural differences based on severity of ID could be called into question. Earlier studies also excluded

individuals with an estimated mild degree of ID (Aman, Richmond, Stewart, Bell, & Kissel, 1987; Aman, et al., 1985) although subsequent studies have since supported the reliability and validity of this instrument across all degrees of ID (E. C. Brown, Aman, & Haverkamp, 2002; Marshburn & Aman, 1992).

The authors of the ABC-C have reported the psychometric properties of this scale in several studies. Good to excellent internal consistency was reported in studies of children and adolescents using parent (see Table 4.4; E. C. Brown, et al., 2002; Kaat, et al., 2013) and teacher ratings (Marshburn & Aman, 1992). The internal consistency of the *hyperactivity/noncompliance* subscale was good ($\alpha = .89$) for parent ratings of a sample of toddlers and young children, although it ranged from unacceptable to excellent for the other subscales (Karabekiroglu & Aman, 2009). Significant variation in convergent validity was reported with corresponding subscales of the CBCL 1.5-5, although there was moderate to strong correlation between the ABC-C *hyperactivity/noncompliance* subscale and the internalising and externalising indices of the CBCL ($r = .42 - .77$; Karabekiroglu & Aman, 2009).

Several other studies have examined the subscale structure of the ABC-C among children and adolescents with ASD (Brinkley et al., 2007; Kaat, et al., 2013; Karabekiroglu & Aman, 2009), and a variety of other developmental disabilities and clinical disorders (Karabekiroglu & Aman, 2009). The findings from these studies generally indicated a good fit with the ABC-C subscales described by Marshburn and Aman (1992).

4.4.1 Developmental Behaviour Checklist (DBC)

The DBC is a 96-item checklist designed to assess a broad range of behavioural and emotional problems in children and adolescents with ID. Two versions of the checklist have been developed, with one completed by parents or caregivers (DBC-P) and the other by teachers or teacher's aides (DBC-T; Einfeld & Tonge, 2002). The DBC-P was derived from

Table 4.4

Psychometric Properties of Measures Assessing a Range of Behavioural and Emotional Problems for Use with Children with Intellectual Disability

Scale	Psychometric properties reported by authors	Independent studies with children with ID
Aberrant Behaviour Checklist – Community (ABC-C)	<p>Brown et al. (2002) <i>Parent ratings only</i> Good to excellent internal consistency ($\alpha = .84 - .95$)</p> <p>Marshburn & Aman (1992) <i>Teacher ratings only. Included children with borderline intellectual functioning (IQ = 70-80)</i> Excellent internal consistency ($\alpha = .90 - .96$)</p>	<p>Kaat, Lecavalier & Aman (2013) <i>Parent ratings of children with autistic disorder and high functioning autism</i> Good to excellent internal consistency ($\alpha = .85 - .94$) Strong concurrent validity between ABC hyperactivity subscale and CBCL attention problems subscale ($r = .56$)</p> <p>Karabekiroglu & Aman (2009) <i>Parent ratings of toddlers</i> Unacceptable to excellent internal consistency ($\alpha = .68 - .90$) Moderate to strong concurrent validity between ABC hyperactivity subscale and CBCL 1.5-5 internalising and externalising indices ($r = .42 - .77$)</p> <p>Miller, Fee & Netterville (2004) <i>Teacher and teacher assistant ratings in children and adolescents with ID</i> Fair to excellent internal consistency ($\alpha = .76 - .94$) Strong test-retest reliability over 2 weeks for teachers ($r = .68 - .85$) and teaching assistants ($r = .74 - 1.00$) Strong inter-rater reliability across teachers and teaching assistants ($r = .72 - .80$)</p>

	<p>Miller, Fee & Jones (2004)</p> <p>Strong concurrent validity with corresponding subscales of the ACTeRS ($r = -.51 - .52$), CBCL - Teacher Report Form ($r = .67$), Conners Teacher Rating Scale ($r = .63$) and SNAP-III ($r = .81$)</p> <p>Weak concurrent validity between ABC hyperactivity subscale and classroom observation for off-task behaviour for teachers ($r = .31$) and teaching assistants ($r = -.07$)</p>
	<p>Paclawskyj et al. (1997)</p> <p><i>Staff ratings of children, adolescents and adults with severe to profound ID</i></p> <p>Fair to excellent internal consistency ($\alpha = .79 - .94$)</p>
Developmental Behaviour Checklist - Parent/caregiver scale (DBC-P)	<p>Einfeld & Tonge (2002)</p> <p>Unacceptable to excellent internal consistency ($\alpha = .66 - .91$)</p> <p>Strong inter-rater reliability between parents (ICC = .80) and nurses (ICC = .83) of adolescents in residential settings</p> <p>Weak inter-rater reliability across parents and teachers (ICC = .30)</p> <p>Strong test-retest reliability over 2 weeks (ICC = .83)</p> <p>Strong concurrent validity between parent ratings on DBC and psychiatrist/psychologist ratings on three scales of behavioural/emotional disturbance ($r = .81$)</p> <p>Strong convergent validity with the maladaptive behaviour subscale of the Adaptive Behavior Scale School edition ($r = .86$) and the problem behaviour subscale on the Scales of Independent Behaviors ($r =$</p>
	<p>Hastings et al. (2001)</p> <p><i>Children and adolescents with mild to profound ID</i></p> <p>Unacceptable to excellent internal consistency ($\alpha = .66 - .91$)⁹</p>
	<p>Dekker, et al. (2002)</p> <p><i>Children with mild to profound ID as well as children with borderline intelligence</i></p> <p>Unacceptable to excellent internal consistency ($\alpha = .66 - .91$)</p> <p>Strong test-retest reliability over 17 days ($r = .76 - .89$)</p> <p>Moderate to strong inter-rater reliability between mothers and fathers ($r = .52 - .67$)</p> <p>Moderate to strong convergent validity on disruptive/antisocial, anxiety and social relating subscales compared with corresponding subscales on the</p>

⁹ Parent and teacher rating scales were analysed together

	.72) Excellent sensitivity (.83) and specificity (.85) in distinguishing children with severe psychopathology from “non-cases”	CBCL ($r = .47 - .85$)
Developmental Behaviour Checklist - Teacher scale (DBC-T)	Einfeld & Tonge (2002) Unacceptable to excellent internal consistency ($\alpha = .62 - .91$) Moderate inter-rater reliability between teachers and teacher’s aides (ICC = .60) Strong test-retest reliability over 2 weeks (ICC = .73) Strong concurrent validity between teacher ratings on DBC and psychiatrist/psychologist ratings on three scales of behavioural/emotional disturbance ($r = .66$)	Dekker et al. (2002) <i>Children with mild to profound ID as well as children with borderline intelligence</i> Unacceptable to excellent internal consistency ($\alpha = .67 - .91$) Strong test-retest reliability over 19 days ($r = .69 - .91$) Weak to moderate inter-rater reliability between parents and teachers ($r = .27 - .57$) Moderate to strong convergent validity on disruptive/antisocial, anxiety and social relating subscales compared with corresponding subscales on the CBCL ($r = .43 - .87$)
Nisonger Child Behaviour Rating Form (NCBRF) – Parent form	Aman et al. (1996) Fair to excellent internal consistency ($\alpha = .77 - .93$) Weak to moderate inter-rater reliability across parents and teachers ($r = .37 - .54$) Moderate to strong convergent validity with corresponding subscales of the Aberrant Behaviour Checklist ($r = .49 - .80$) Lecavalier, Aman, Hammer, Stoica & Mathews (2004) <i>Children and adolescents with autism</i> Fair to excellent internal consistency ($\alpha = .71 - .92$) Construct validity of subscales supported in children with autism Lecavalier, Leone & Wiltz (2006)	None to date

Children and adolescents with autism
Weak to moderate inter-rater reliability across parents and teachers (ICC = .16 – .57)

Rojahn et al. (2010)
Children and adolescents with mild to profound ID
Fair to excellent internal consistency
($\alpha = .72 - .92$)
Weak inter-rater reliability across teachers and parents (ICC = .01 - .25)

Norris & Lecavalier (2011)
Children and adolescents with borderline functioning to profound ID
Fair to excellent internal consistency
($\alpha = .77 - .94$)
Confirmatory factor analysis yielded a fair model fit (RMSEA = .08) for a five-factor solution of the problem behaviour subscales
Weak to very strong convergent validity with corresponding subscales of the DBC – P ($r = .37 - .85$)

The psychometric properties have also been examined in French (Tasse, Morin & Girouard, 2000 in Tasse & Lecavalier, 2000) and Romanian (Mircea, Rojahn, & Esbensen, 2010) language adaptations

Nisonger Child Behaviour Rating Form (NCBRF) – Teacher form

Aman et al. (1996)
Good to excellent internal consistency
($\alpha = .81 - .91$)
Moderate to strong convergent validity with corresponding subscales of the Aberrant Behaviour Checklist ($r = .55 - .85$)

None to date

Lecavalier et al. (2004)
Children and adolescents with autism
Fair to excellent internal consistency for problem
behaviours ($\alpha = .77 - .92$)
Construct validity of subscales supported in children
with autism

Rojahn et al. (2010)
Children and adolescents with mild to profound ID
Poor fit between factor analysis findings and factor
structure of the NCBRF
Strong inter-rater reliability across teachers
(ICC = .66 – .85)
Strong test-retest reliability for teachers
(ICC = .66 – .92)

The psychometric properties have also been examined in
a Romanian language adaptation (Mircea, et al., 2010)

an examination of the behavioural and emotional symptoms described in a large sample (more than 7000) of case notes of children and adolescents with ID. The DBC-T contains almost identical items, excluding the three items relating to sleep disturbance, and including an additional item relating to popularity with peers. Each item is ranked on a 3-point Likert scale from *not true as far as you know* to *very true or often true*. Although not specifically developed to measure ADHD symptomatology, the DBC contains a subscale to measure *hyperactivity* which was derived by pooling six items from the checklist that had face validity for these behaviours. The authors conceptualised hyperactivity as a spectrum rather than a categorical disorder (Hay, et al., 2007), and therefore did not provide a clinical cut-off score. Instead, they suggested that higher scores related to greater severity of ADHD symptoms (Einfeld & Tonge, 2002).

The authors have done an extensive examination of the psychometric properties of the DBC-P. The internal consistency is variable, being good to excellent on the self-absorbed and disruptive/antisocial subscales ($\alpha = .89 - .91$), unacceptable on the anxiety subscale ($\alpha = .66$) and fair on the remaining two subscales (see Table 4.4; Einfeld & Tonge, 2002). Inter-rater reliability is varied, being strong across parents and nurses of adolescents in residential settings but weaker across parents and teachers. Other psychometric properties of the DBC-P are strong, including test-retest reliability, concurrent validity and excellent sensitivity and specificity in distinguishing children with severe psychopathology from “non-cases”. Two independent studies reported similar psychometric properties in terms of internal consistency, test-retest and inter-rater reliability (Dekker, et al., 2002; Hastings, et al., 2001).

The psychometric properties of the *hyperactivity* subscale were assessed with a group of children aged 4 to 13 years ($n = 57$; Einfeld & Tonge, 2002). Using the DBC-P, the subscale was found to have excellent internal consistency and convergent validity with the hyperactivity subscale on the CPRS-R. The authors also reported that the DBC-P had

significant discriminant ability in detecting the presence or absence of hyperactivity using the DSM-III-R criteria.

Similar to the DBC-P, the DBC-T has variable internal consistency, being excellent on the self-absorbed and disruptive/antisocial subscales ($\alpha = .90 - .91$), unacceptable on the anxiety subscale ($\alpha = .62$) and fair on the remaining two subscales. It has strong test-test reliability, moderate inter-rater reliability across teacher and teacher's aide ratings, and strong concurrent validity with psychologist/psychiatrist ratings on three scales of behavioural/emotional disturbance (see Table 2.4; Einfeld & Tonge, 2002). An independent study has reported similar psychometric properties relating to the internal consistency and test-retest reliability, although their sample included children with borderline intelligence (Dekker, et al., 2002). The reliability and validity of the *hyperactivity* subscale on the DBC-T have not yet been examined.

The reported advantages of the DBC include ease of administration and its ability to assess a broad range of emotional and behavioural problems in children and adolescents with ID (Dekker, et al., 2002; Hastings, et al., 2001). The robust psychometric properties have been confirmed by independent studies using both the parent and teacher versions (Dekker, et al., 2002; Hastings, et al., 2001). The face validity of the behaviours in the DBC are also high, given they were drawn from case notes of children with ID presenting at clinics.

4.4.2 Nisonger Child Behaviour Rating Form (NCBRF)

The NCBRF was derived from an existing child psychopathology rating scale, the Child Behavior Rating Form (Edelbrock, 1985), and was developed to assess behavioural and emotional problems in children and adolescents with ID (Aman, et al., 1996; Tasse, Aman, Hammer, & Rojahn, 1996). For the problem behaviour items, each is ranked on a 4-point Likert scale from *not a problem* to *a severe problem*. It contains six subscales, with the *hyperactive* subscale measuring ADHD symptomatology. The NCBRF has teacher/teacher's

aide and parent versions (although the authors stipulate that it could also be completed by a caregiver or mature sibling; Tasse, et al., 1996). The items and wording are identical on both forms, although factor analyses extracted different items within the subscales across the two versions (Aman, et al., 1996). The NCBRF forms are freely available to download (Research Unit on Pediatric Psychopharmacology, 2010), although the authors have stipulated that only qualified professionals should use and administer these forms.

The internal consistency of the teacher version is good to excellent among children with ID (see Table 4.4; Aman, et al., 1996) and fair to excellent among children with ASD (Lecavalier, et al., 2004). Moderate to strong convergent validity with corresponding subscales of the ABC-C (Aman, et al., 1996), strong inter-rater reliability across teachers (Rojahn, et al., 2010), and strong test-retest reliability (Rojahn, et al., 2010) were also reported. No independent studies have examined the psychometric properties of the NCBRF teacher form.

The parent version of this scale has fair to excellent internal consistency among children with ID (Aman, et al., 1996; Rojahn, et al., 2010) or ASD (Lecavalier, et al., 2004). Weak to moderate inter-rater reliability has been reported across parents and teachers (Aman, et al., 1996; Lecavalier, et al., 2006; Rojahn, et al., 2010), but moderate to strong convergent validity with corresponding subscales of the ABC-C (Aman, et al., 1996). No independent studies have examined the psychometric properties of the NCBRF parent form.

One of the reported advantages of the NCBRF is its inclusion of positively-worded items (Aman, et al., 1996; Hastings, et al., 2001), which others have suggested may improve the response rates from parents and teachers when reporting on a child's behaviours (Goodman, 1997).

4.4.3 Limitations of these measures

A limitation common to all of these scales is the use of a rating system that places an emphasis on deficits in attention. For example, symptom severity may be rated on a scale from *not at all* to *very often or always*. The use of such rating systems may result in a skewed representation of attention (Hay, et al., 2007), with all individuals who do not have ADHD being assigned low or zero scores. This system implies that ADHD occurs as a categorisation rather than recognising that it may exist on a continuum (Hay, et al., 2007; Levy, Hay, McStephen, Wood, & Waldman, 1997; Waschbusch & Sparkes, 2003), with some individuals performing better than average in their ability to pay attention or inhibit activity. While this limitation has been addressed in the development of the SWAN (Swanson, et al., 2005), this scale has been used in relatively few studies to date, none of which included children with ID.

Despite a favorable review of the ABC-C (Aman & Singh, 1994) by Miller and colleagues (2004), their conclusions are limited by their lack of generalisability to the wider population due to the small sample size ($n = 48$), exclusion of children with severe or profound ID, lack of generalisability to the wider population due to the high proportion (85.4%) of African Americans in their sample, and comparing the ABC-C with older versions of ADHD rating scales that have since been revised. Another weakness of the ABC-C is that it has not been revised since its development over 20 years ago. Our understanding of inattention and hyperactivity has changed greatly in this time (Cornish & Wilding, 2010). These developments suggest that this scale may be somewhat outdated in its behavioural descriptors of ADHD symptoms.

The score on the *hyperactivity/noncompliance* subscale of the ABC-C (Aman & Singh, 1994) may also be difficult to interpret at face value given the composition of the items within it. The subscale contains items relating to hyperactivity, impulsivity, noncompliance and inattention. It would be therefore possible that a child may be rated

highly only on the items relating to noncompliance and inattention, and yet without examining the items individually one might draw the conclusion that the child had difficulties with hyperactivity (based on the subscale name) even though few or none of those items were endorsed. Even if examined at an item level, this subscale contains only two items relating to inattention (*Pays no attention when spoken to* and *Does not pay attention to instructions*), thus limiting both its ability to identify behaviours relating to inattentive symptoms and its use as a screening tool.

The DBC (Einfeld & Tonge, 1995, 2002) was not specifically designed to assess ADHD symptomatology but does contain a subset of six items that have face validity for hyperactive and inattentive behaviours within the existing item set. This subset of items forms part of a broader *disruptive/antisocial* subscale which describe behaviours that can be disruptive to self or others. Although the *hyperactivity* subscale has demonstrated internal consistency, further psychometric analyses have been limited to the parent version of the rating scale (Einfeld & Tonge, 2002). Given the majority of children in the sample examining the *hyperactivity* subscale had mild ID (86%), its validity for measuring hyperactivity in children with moderate, severe, or profound ID is not clear at the present time. The small number of hyperactive and inattentive behaviours within this scale, while being useful markers, are not sufficiently broad enough to understand the range of behaviours related to ADHD symptomatology that may exist across children with ID.

4.5 Summary

Rating scales are often used to assist with screening for and diagnosing ADHD (Barkley & Edwards, 2006), and for identifying ADHD symptomatology in clinical research. The utility of existing rating scales, however, reveal significant shortcomings when used among populations with ID. These limitations can be seen both when considering scales designed for typically developing children and those for children with ID.

When examining the rating scales designed for typically developing children, the psychometric properties of four of the measures have not been examined in children or adolescents with ID, namely the ADD-H Comprehensive Teacher Rating Scale - Second edition (Ullman, et al., 2000); the ADHD Rating Scale IV (DuPaul, et al., 1998); the Swanson, Nolan & Pelham Checklist – Fourth edition (Swanson, 1992); and the Strengths and Weaknesses of ADHD Symptoms and Normal Behaviour Scale (SWAN; Swanson, et al., 2005). The psychometric properties of the Behaviour Assessment System for Children – Second edition (Reynolds & Kamphaus, 2004) have not been replicated in independent studies. Studies using the Children’s Behaviour Questionnaire (Rothbart, 1981) and the Strength and Difficulties Questionnaire (Goodman, 1997) have examined the psychometric properties in children with ID, although the findings from both measures concluded that the internal consistency was unacceptable to fair.

The Conners Rating Scales – Revised (Conners, 1997) have frequently been used in studies of children with ID even though their validity for use within this population is questionable (Guerin, et al., 2009). Two studies have reported limitations with its psychometric properties, including its inter-rater reliability across parents and teachers (Deb, et al., 2008; M. L. Miller, Fee, & Netterville, 2004). It was also noted that 13 items (46.4%) on the teacher version were dependent upon the child being verbal, thus invalidating the measure for a significant proportion of children with severe and profound intellectual disabilities who are non-verbal (Deb, et al., 2008).

The Child Behaviour Checklist (CBCL; Achenbach & Rescorla, 2001) has also been used in a number of studies of children with ID. An examination of the psychometric properties is limited to two studies which reported the internal consistency for children with autism was highly variable (Pandolfi, et al., 2009, 2012) and no further analyses of psychometrics were conducted. Further examination of the psychometric properties would be

needed to establish whether the CBCL has reliability and validity within this population.

Several authors have questioned the validity of some of the rating scale items, citing that they were developmentally inappropriate (Koskentausta, et al., 2004) or irrelevant (Turk, 1998) to the child being rated, particularly for children with moderate, severe or profound ID.

Shortcomings also exist that are specific to those rating scales developed for children with ID. A lack of independent studies has validated the psychometric properties of the Nisonger Child Behaviour Rating Form (NCBRF; Aman, et al., 1996) and the Attention Checklist (AC; Das, 1986 in Das & Melnyk, 1989). The NCBRF is restricted to only measuring hyperactive behaviours and the AC only inattentive behaviours. The Attention-Distracton, Inhibition-Excitation Classroom Assessment Scale (Evans, 1975 in Evans & Hogg, 1984) lacks age- and gender-based normative data and a parent version of the form, and independent studies report variable psychometric properties (Guerin, et al., 2009; Strand, et al., 1990). It has not been validated for use in children with mild ID. Limitations of the Aberrant Behaviour Checklist – Community (Aman & Singh, 1994) include the lack of updated versions since its development 20 years ago, the difficult interpretability of the *hyperactivity* subscale given items relating to noncompliance also loaded on this factor, and the limited number of items relating to inattention. The items making up the *hyperactivity* subscale of the Developmental Behaviour Checklist (Einfeld & Tonge, 2002) contain items relating to both hyperactivity and inattention, although it is likely to be limited in its ability to provide a complete picture of ADHD symptomatology given this subscale contains just six items. Its ability to assess hyperactive symptoms in children with moderate to profound ID, or older adolescents, is also yet to be evaluated.

CHAPTER 5 THE FOCUS OF THE PRESENT STUDY

The review of rating scales in the previous chapter suggests that most of the measures are used infrequently among children and adolescents with ID, and few of the scales developed for typically developing children demonstrated sound psychometric properties when they are used with these populations. In the case of the Conners Third edition (Conners, 2008), the review drew upon results of studies using the previous edition (Conners, 1997) which may not reflect their reliability or validity in the current version. The decrease in the number of studies utilising these scales may also reflect the realisation that they are less appropriate for use with children and adolescents who have ID, or the slow but growing availability of clinically reliable and valid scales developed specifically for this population.

5.1 Aims of the present study

The need to develop a rating scale to measure attention and hyperactivity among children with ID has been recognised (Deb, et al., 2008) but not yet adequately addressed. This is particularly important given that the prevalence of ADHD is at least as common, if not more so, in children with ID as it is among children who are typically developing (Neece, et al., 2011). The administration of rating scales is useful when conducting a clinical evaluation of ADHD in an individual (Barkley & Edwards, 2006), and is supported by a recent study indicating that they are utilised by two-thirds of clinicians when using formal criteria to make this diagnosis (Chan, et al., 2005).

Cross-syndrome studies have suggested that differences in inattention and hyperactivity exist across known causes of ID (Cornish, Steele, et al., 2012; Hastings, et al., 2005; Papaïiou, et al., 2012). In the absence of any alternatives, these studies have had to utilise rating scales included in the review in Chapter 4 above, all of which have shortcomings in their ability to measure ADHD symptomatology within this population. The inclusion of a measure that has been validated for children with ID would assist researchers

in gaining a greater understanding of these differences. Therefore, it is clear that a reliable and valid rating scale for children within this population is needed.

The aims of the present study are:

- to develop a reliable and valid rating scale that is more sensitive to exploring the range and severity of ADHD symptoms in school-aged children with intellectual disability
- that the scores on the new rating scale will have good convergent validity with existing measures of ADHD
- to describe and compare the profiles of ADHD symptoms in children with known causes of ID

5.2 Hypotheses

It is hypothesised that:

1. there will be a positive relationship between hyperactivity/impulsivity and level of intellectual disability.
2. there will be lower levels of inattentive and hyperactive/impulsive behaviours in the Down Syndrome group.
3. there will be higher levels of hyperactive/impulsive behaviours in the ASD group.

CHAPTER 6 METHOD

6.1 Phase 1a: Item Development for Rating Scale

The guidelines as defined by DeVellis (2003) were used as a framework to inform all phases of rating scale development. In the first phase, a variety of methods were drawn upon to determine the behaviours related to attention difficulties in children and adolescents with intellectual disability (ID) that were salient to teachers. In the first stage, all items from the rating scales reviewed previously that were related to attention difficulties were listed in a table under the headings of hyperactivity, impulsivity, inattention and working memory. Behaviours were also recorded from observational and descriptive data provided in published studies examining attention difficulties among children with ID.

These items and behaviours were categorised onto concept maps under these four headings, with subcategories reflecting the criteria described in the DSM-IV-TR (American Psychiatric Association, 2000), ICD-10 (World Health Organization, 1992), DC-LD (Royal College of Psychiatrists, 2001) and DM-ID (P. Lee & Friedlander, 2007). The use of concept maps allowed for consideration of many possible behaviours representing these four areas.

Two members of the research team experienced in the field of attention difficulties among young people with known causes of ID (Professor Kim Cornish and Associate Professor Kylie Gray), along with the author, evaluated the concept maps to determine whether they reflected behaviours that would be observed in young people with an intellectual disability. Many behaviours were discarded as they were not considered representative of the behaviours of children with ID (e.g., *Puts off projects until the last minute*). Some behaviours were modified to better reflect the abilities expected of a young person with ID (e.g., *Crosses the road independently* was modified to *Stops and waits when they get to the road* to take into account those children with greater degrees of ID for whom asking them to independently cross the road would not be considered possible and/or appropriate).

Those behaviours that were retained were converted into lay language that would be readily understood by teachers and teacher's aides. Examples followed some items to help define or illustrate the behaviour they were being asked to rate. All items were worded positively as it has been proposed that this may help to improve response rates of parents and teachers when reporting on children's behaviours (Goodman, 1997). Prior to distributing the questionnaire to participants in the study, the T-SAID was subjected to the Flesch-Kincaid test (Bond & Fox, 2007; Pallant & Tennant, 2007). This test uses two formulae to calculate reading ease and grade level based on sentence and word length and was calculated using Flesch 2.0 software (Frink, 2007). The findings indicated that the rating scale has a readability index of 56 and a reading grade level of 8.54, making it appropriate for distribution among teachers.

Following these procedures, the list of attention difficulties encompassing the four headings listed above were organised as a rating scale. The response set consisted of a 4-point scale where each item is scored from *never* to *often*. Once the rating scale items and response set had been developed, the rating scale was presented to groups of health professionals and teachers via focus group discussions as described in Phase 1b below.

6.2 Phase 1b: Focus Group Discussions

6.2.1 Participants

Nine health professionals consisting of 6 psychologists (all females; mean years of work experience = 10.4 years, range = 2.5 – 25 years) and 3 paediatricians (2 males and 1 female; mean years of work experience = 27.3 years, range = 15 – 37 years), and 9 teachers (2 males and 7 females; mean years of teaching experience = 11.2 years, range = 6 months – 20 years) were recruited for the focus group discussions. Teachers and health professionals were employed in the metropolitan area of Melbourne, Australia.

6.2.2 Procedure

The process of selecting participants for the focus groups was through two stages. For the school teachers, approval to recruit participants for the focus group was first sought from the school principals of their respective schools via a letter or phone call informing them about the study and the questions to be used.

Subject recruitment at schools that consented to participate was through announcements made at staff meetings by the school principal. The teachers were told that the study was investigating the attention profiles of children with different causes of ID, and that they would be asked to comment on items written that would potentially be included in a new rating scale developed by the research team, the Scale of Attention in Intellectual Disability (SAID). All teachers were invited to take an explanatory statement providing details of the study and a consent form. Interested teachers returned the consent form by reply-paid envelope. The letter informed teachers that they could withdraw from the study at any time.

Health professionals were individuals known to the research team and were approached individually or in small groups either via a face-to-face conversation or telephone call. They were given the same information about the focus group discussion as the teacher groups (outlined above).

Each focus group met for approximately 90 minutes in a quiet room at a convenient location for participants (e.g., school staff room, meeting room at a workplace). The author led each group, serving as the group facilitator. The participants were reminded that the discussion would be recorded on Minidisk and that they could leave the focus group at any time. Light refreshments were provided at each focus group discussion, but no other tangible incentives were given for participation.

The focus group discussions began with introductions from the facilitator and the participants. The facilitator proceeded with an overview of the study and the purpose of the focus group discussion. The focus group discussion commenced with an activity that had the participants divide into groups to promote engagement and facilitate communication between members (see Appendix A for the procedure used). This activity used the freelist technique (Borgatti, 1999) where each group was given a sheet of paper and were instructed to think about the children they had seen in their practice or classroom who had ID and attention difficulties. They were asked to list the behaviours they had observed in these children, including difficulties with hyperactivity, impulsivity, inattention and working memory. During this exercise, the facilitator observed the participants and monitored their progress but did not participate in the discussions. After 10 minutes, the facilitator asked the groups to share their ideas, which were listed on a whiteboard or poster paper. The facilitator then led a brief discussion about the similarities and differences between the lists.

Following this activity, the facilitator proceeded with the focus group questions. Each participant was given a draft copy of the SAID rating scale and asked to read the items silently. Following this, the participants were invited to comment on the rating scale items. They were also given some guiding issues to consider such as the clarity and expression of the wording, whether they understood the behaviour they would be asked to rate for each item, the usefulness of each item in the scale, and whether there was any redundancy in the items. The participants were also asked if they felt there were any behaviours missing on the rating scale that warranted inclusion, which included a consideration of the behaviours listed in the brainstorming exercise.

After the discussion, a brief summary of the issues that had been raised was given by the facilitator, and the participants were given the opportunity to ask any questions or to

discuss the experience of being in the focus group. Participants were thanked by the facilitator for participating in the discussion.

6.2.3 Analysis

The focus group discussions were transcribed from the Minidisk into word processed documents. These discussions were subjected to thematic analysis, using the method described by Braun and Clarke (2006). The behaviours relating to attention difficulties from the freelist activity were coded using a theory-driven (a priori) approach, in that only particular behaviours discussed were analysed into codes. Codes are defined as a unit of information extracted from a focus group discussion, and refer to “the most basic segment, or element, of raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, pg. 63). Discussions that diverted away from the central theme were excluded from the analysis.

Codes from the freelist were then organised into potential themes using mind maps. These themes were then subjected to review and refinement. The homogeneity of themes was assessed and resulted in some themes being collapsed, and others were broken down further into separate themes. The importance of each code was also calculated across focus group interviews. This was determined by the proportion of individuals to whom the code was applied, rather than the absolute number of times a theme is expressed and coded (which could be expressed many times by one participant emphasising his/her perceived importance of this theme, but not at all by other participants; Guest, Bunce, & Johnson, 2006). Some codes were discarded from the thematic analysis but were considered of interest and therefore retained to be discussed separately.

Comments made about the rating scale were coded separately using a theory-driven approach, and related to the central issues that participants had been asked to consider. Namely, these issues pertained to: the response set used, clarity and expression of the

wording, whether they understood the behaviour described in each item, the usefulness of each item in the scale, redundancy in the items, and any behaviours missing on the rating scale that warranted inclusion. Coding for the rating scale review was organised into themes consistent with these issues.

6.3 Phase 2: Community Survey

6.3.1 Participants

A total of 215 consent forms were returned by families of children attending a special, special developmental, autism specialist, or mainstream school in the Melbourne metropolitan area and across regional Victoria. A small number of children were on a split placement (spending part of their school week in a mainstream school and the rest of their time in a special school) or were located in a support centre for children with ID on a mainstream school site. A flowchart illustrating recruitment in the study is illustrated in Figure 1.

Children were eligible to participate in the study if: (i) they were aged between 5 and 13 years; and (ii) their most recent cognitive assessment placed their functioning in the intellectually disabled range (i.e., their cognitive and/or adaptive living skills assessment total score was less than 70). Children with a diagnosis of ASD were only included in the sample if they scored above the recommended cutoff for autism (i.e., 15 or more) on the lifetime version of the Social Communication Questionnaire (Rutter, Bailey, & Lord, 2003). A total of 176 students were eligible to be included in the analyses (114 males and 62 females).

Socioeconomic status was determined via parental completion of the Hollingshead (Hollingshead, 1975) Four Factor Index. This measure has been found to yield comparable information to more recently developed SES measures (Cirino et al., 2002) but has the advantages of being simple to complete and less time-consuming. The scale gives a rating for each parent based on the highest level of education completed and their current occupation.

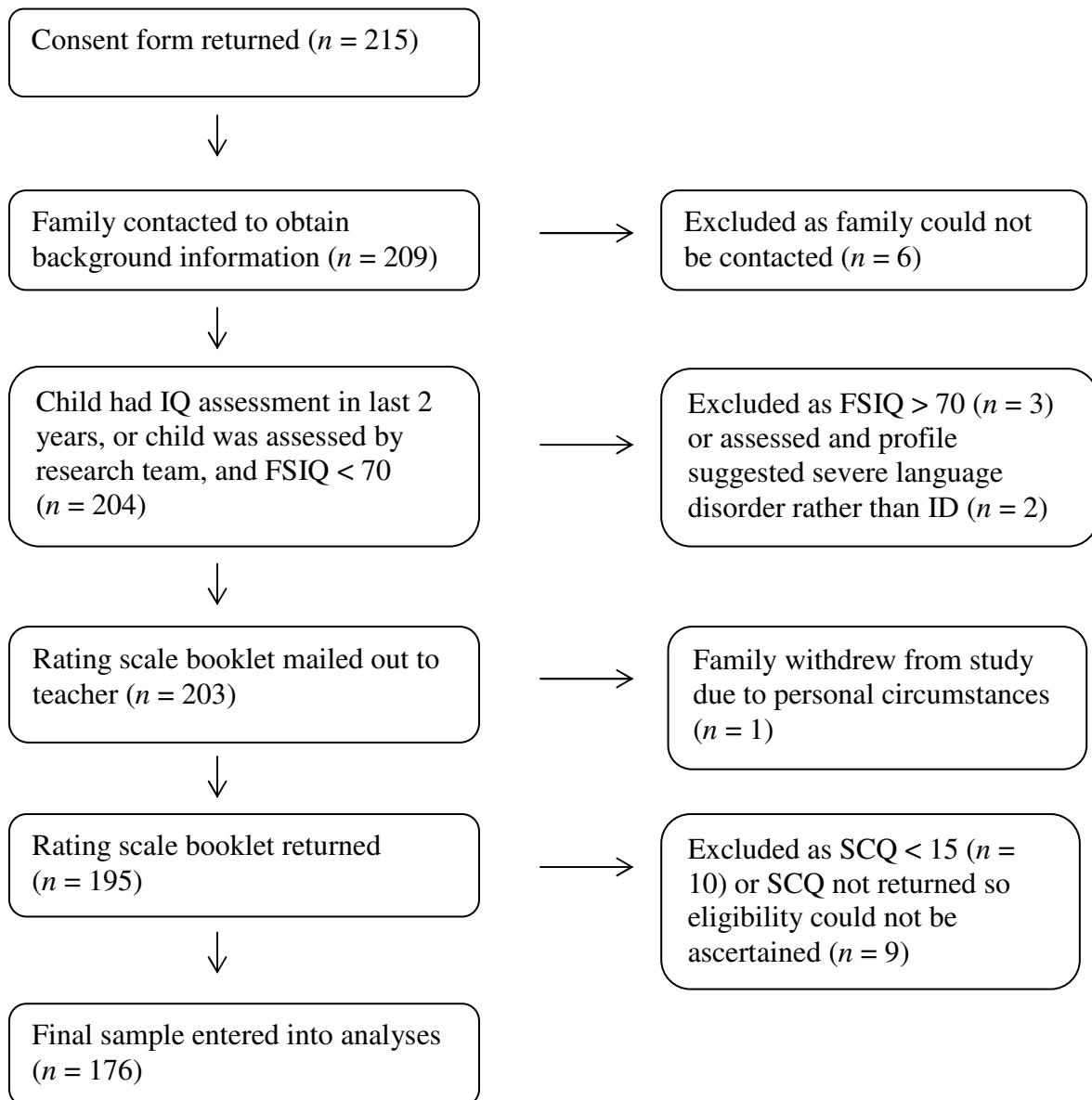


Figure 1. Recruitment flowchart for the study.

Scores are averaged across ratings for each parent and an overall score is calculated. For those families where there was only one parent or caregiver, only the ratings for that person were used. For those families where one parent was unemployed or was a full-time carer, the ratings were averaged for level of education but only the rating for the employed parent was used for current occupation. Hollingshead SES scores range from 8 to 66, with a higher score indicating a higher level of socioeconomic status.

6.3.1.1 Test-retest sample

The test-retest reliability of the new rating scale was assessed by asking a random sample of classroom teachers to complete a second rating scale. The mean interval between the first and second rating scales being completed was 28 days ($SD = 10.41$). Teachers who took longer than 50 days to return the second rating scale ($n = 12$) were excluded from the analyses.

6.3.2 Measures

6.3.2.1 *Wechsler Preschool and Primary Scale of Intelligence – Third edition/Wechsler Intelligence Scale for Children – Fourth edition* (WPPSI-III/WISC-IV; Wechsler, 2002; Wechsler, 2003). The WPPSI-III and WISC-IV are standardised cognitive assessments which measure the thinking and reasoning skills of children and adolescents. The WPPSI-III is used with children aged 2 years 6 months to 7 years 3 months, and the WISC-IV is used with children and adolescents aged 6 years 0 months to 16 years 11 months. The WPPSI-III yields three index scores (*verbal, performance and processing speed*) as well as a full scale score. The WISC-IV yields four index scores (*verbal comprehension, perceptual reasoning, working memory and processing speed*) as well as a full scale score. The WPPSI-III and WISC-IV index and full scale scores have moderate to excellent internal consistency ($\alpha = .85 - .95$) and the WISC-IV has very strong test-retest reliability over a mean interval of 27 days ($r = .80 - .95$)¹⁰. The WPPSI-III and WISC-IV were used in this study to determine each child's current cognitive functioning.

6.3.2.2 *Vineland Adaptive Behaviour Scales, Second edition – Teacher Rating Form* (VABS-II; Sparrow, Cicchetti, & Balla, 2005). The VABS-II is a standardised instrument that measures the adaptive living skills of children and adolescents. It consists of 9 subscales categorised into three composite scores: *communication, socialisation and daily*

¹⁰ Test-retest reliability not reported for the WPPSI-III.

living skills. In young children (5-6 years), there is also a fourth composite score (motor skills) comprising fine and gross motor skill subscales. The scores are added together to yield the adaptive behaviour composite. The VABS-II has low to excellent internal consistency for children aged 5 to 18 years ($\alpha = .74 - .98$). Test-retest reliability was measured over an average period of 3 weeks and was found to be moderate to very strong ($r = .43 - .97$). The inter-rater reliability (across two teachers or a teacher and a teacher's aide) had significant variation, from unacceptably low to strong ($r = .04 - .79$). The VABS-II-T was used in this study to determine the current adaptive functioning of children whose cognitive abilities could not be measured with the WPPSI-III or WISC-IV.

6.3.2.3 *Conners Rating Scales – Third edition, Teacher Short form* (Conners 3; Conners, 2008). The Conners 3 consists of 39 items and provides a means of screening for symptoms of ADHD and related disorders. It has five subscales: *inattention*, *hyperactivity/impulsivity*, *learning problems/executive functioning*, *aggression* and *peer relations*. It has moderate to excellent internal consistency across subscales ($\alpha = .87 - .94$), strong test-retest reliability over two to four weeks ($r = .70 - .81$), and strong inter-rater reliability across teachers ($r = .72 - .83$). The subscales of the Conners 3 have very strong correlations with ratings on the full-length version for both general population and clinical samples ($r = .93 - .98$), suggesting that scores on the short form are a sufficient proxy for those obtained on the long form (Conners, 2008). The Conners 3 was completed by the child's current classroom teacher to determine convergent validity with the author's new attention scale.

6.3.2.4 *Developmental Behaviour Checklist – Second edition, Teacher version* (DBC-T; Einfeld & Tonge, 2002). The DBC-T is a 93-item checklist designed to assess a broad range of behavioural and emotional problems in children and adolescents with an ID. The DBC-T has low to excellent internal consistency across the five subscales ($\alpha = .62 - .91$),

strong test-retest reliability over 2 weeks ($ICC = .73$) and moderate inter-rater reliability across teachers and teacher's aides ($ICC = .60$). The DBC-T was completed by the child's current classroom teacher to determine convergent validity with the author's new attention scale.

6.3.2.5 *Social Communication Questionnaire* (SCQ; Rutter, Bailey, et al., 2003). The SCQ, previously known as the Autism Screening Questionnaire (ASQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999), is a 40-item questionnaire completed by the parent/primary caregiver that examines the areas of communication, socialisation and restricted and repetitive behaviours and interests. It is used as a screener for autism spectrum disorder and is based on the Autism Diagnostic Interview (ADI; le Couteur et al., 1989), an earlier version of the Autism Diagnostic Interview – Revised (ADI - R; Rutter, le Couteur, & Lord, 2003). The authors reported moderate to excellent internal consistency for the SCQ total score ($\alpha = .84 - .93$) and strong convergent validity with the ADI - R ($r = .71$). The SCQ has the ability to differentiate between individuals with pervasive developmental disorders (including autism) and those without, with moderate sensitivity (.85) and specificity (.75). The lifetime version of the SCQ was completed by families of children with a diagnosis of autism and was used to determine eligibility to participate in the study.

6.3.2.6 *Scale of Attention in Intellectual Disability* (SAID). This rating scale consists of 46 items and was developed for the purpose of this study. It incorporates four areas of attention difficulty: hyperactivity, impulsivity, inattention and aspects of working memory. The teacher version (T-SAID) was examined for validation in this study (see Appendix B) and was completed by the child's current teacher (provided they have known the child for a minimum of 6 months). A parent version (P-SAID) is under development. Participants respond to each statement on a 4-point scale (*never, rarely, sometimes, or often*). All items are worded positively as it has been proposed that this may help to improve

response rates when reporting on children's behaviours (Goodman, 1997). Higher scores relate to fewer difficulties. The T-SAID was completed by the child's teacher to determine attention difficulties in the classroom.

6.3.3 Procedure

Participant selection was through a three-stage process. In the first stage, children were recruited from several sources. Following ethics clearance from the Department of Education and Early Childhood Development (DEECD) and the Catholic Education Office Melbourne (CEOM), principals at special schools ($n = 22$), special developmental schools ($n = 8$), and autism specialist schools ($n = 2$) were invited to assist with recruitment for the study (see Appendix C). Nineteen schools agreed to assist in subject recruitment resulting in a participation rate of 59.4%. Support groups and community organisations specific to the diagnostic groups of interest were also approached (e.g., Autism Victoria, Williams Syndrome Support Group of Victoria), asking them to advertise the study in their newsletter, on their Internet forum, on their web site.

The majority of schools ($n = 16$; 84.2%) who agreed to assist with recruitment consented to the research team sending home an envelope containing a poster, explanatory statement and consent form (see Appendices D and E) to all eligible students at their school aged between 5 and 12 years, either in the student's diary, communication book or through the mail. One school (5.3%) allowed the team to only send home information to children in selected year levels. Two schools (10.5%) consented to a notice about the study being put in the newsletter for two consecutive weeks. These families contacted the research team directly either by phone or email, and information was mailed out to them as described above. The explanatory statement described the study in detail and encouraged families to contact the research team if they had any questions. Families were informed that they or their child could withdraw from the study within 6 weeks of the assessment phase of the study, as per

the ethical guidelines of Monash University. Families who consented to participate in the study returned the consent form to the research team in a reply-paid envelope.

Support groups and community organisations who agreed to assist with advertising the study displayed posters, included an article in their newsletter, and/or posted the information on an Internet forum or web site. Interested families contacted the research team directly by phone or email, and information was mailed out as described above. This information was also available on a web site for families to download.

Two organisations (Down Syndrome Victoria and the Association of Genetic Support of Australasia) allowed the research team to mail out the information to all member families with a child aged between 5 and 12 years, following approval from their respective Committees. Families who consented to participate in the study returned the consent form to the research team in a reply-paid envelope.

In the second stage, a member of the research team telephoned each consenting family to determine their child's eligibility to participate in the study. Basic demographic (parent's occupation and highest level of schooling) and information about their child's school (i.e., current school attended and classroom teacher) was obtained, as well as clinical information including their child's primary diagnosis, comorbid diagnoses, and any medication they were currently prescribed. They were asked whether their child had received a cognitive and/or adaptive living skills assessment in the past and, if this had taken place, were asked for the date and results of these assessments (if available).

Children across all groups were administered a cognitive assessment, the WPPSI-III or WISC-IV, depending on their chronological age. If the child had been administered a cognitive assessment in the last 18 months (WPPSI-III) or 2 years (WISC-IV) then the previous test results were used and another assessment was not administered. Assessments were conducted either in a quiet room at the child's school during school hours or at the

Centre for Developmental Psychiatry and Psychology, Monash Medical Centre. If a child was deemed untestable using the WPPSI-III or WISC-IV, then the VABS-II total Adaptive Behaviour Composite score (ABC) was used to determine the severity of impairment.

The families of all children who received an assessment were given a written report and verbal feedback by the main investigator (a registered psychologist) explaining the results. If the family consented, a copy of the report was also provided to the school. The child needed a FSIQ of 70 or below to be eligible to participate in the study. Children who received a FSIQ above 70 were excluded from the study.

In the third stage, the classroom teacher of each eligible child was mailed a booklet of questionnaires explaining that the research team had informed consent to approach them and explaining the nature of the study. Although teachers were encouraged to participate, they were under no obligation to do so and were told that they could withdraw from the study at any time. For families who consented to participate in the study via a community group or support organisation, the principal of the school their child attended was contacted informing them about the study and requesting permission to mail out a booklet to the child's classroom teacher. All principals ($n = 36$) contacted gave consent to assist with the study. It was a requirement that each teacher who completed the questionnaires had known the child for a minimum of 6 months. They were asked to complete the Conners 3 (Conners, 2008), the DBC-T (Einfeld & Tonge, 2002) and the T-SAID.

The questionnaires were completed in the teacher's own time and took approximately 30 minutes to complete. Questionnaires were returned to the research team in a reply-paid envelope. Reminder letters or emails were sent to teachers if questionnaires had not been returned within 4 weeks, and a second reminder was sent if they had not been returned within 6 weeks.

Parents of children with ASD were asked to complete the SCQ (Rutter, Bailey, et al., 2003). This questionnaire was mailed to families to complete in their own time and was returned via a reply-paid envelope. This questionnaire took approximately 10 minutes for parents to complete. A reminder phone call was made to families if the SCQ had not been returned within 4 weeks, and a second SCQ was mailed out if it had not been returned within 6 weeks.

6.3.4 Analysis

At the time of its development, the Hollingshead Four Factor Index (Hollingshead, 1975) did not account for single parents who were unemployed or families where both parents were unemployed. Given that a significant number of families in this study fell into these categories, the authors recoded the occupational status so that the range from 1 to 9 (service worker to senior manager) was altered and ranged from 1 to 10 (unemployed to senior manager). Therefore, the total score could range from 8 to 71.

The grouping for level of ID was determined by using the child's FSIQ from the WPPSI-III or WISC-IV, or the ABC from the VABS-II for children who were untestable on the cognitive assessment. Level of ID was defined using the criteria in Sattler (2001): mild ID (55 – 70), moderate ID (40 – 54), and severe/profound (< 40). Eight children for whom severity of ID could not be determined were excluded from the regression analyses.

As the response set of the T-SAID offered little distinction between the *rarely* and *never* ratings, it was decided to collapse these two ratings into a single category. Scores on the T-SAID were then reversed for analysis so that higher scores were indicative of greater difficulties.

The total score was calculated by taking the mean of all the items (known as the Mean Item Score, or MIS). This method has a number of advantages over calculating the sum of all item scores (Taffe, Tonge, Gray, & Einfeld, 2008). One advantage is that the MIS may be

deconstructed to measure the breadth of behaviours an individual exhibits (the Proportion of Items Checked, or PIC) and the intensity at which the items are checked for that person (the Intensity Index, or II). PIC is the proportion of recoded items receiving codes of 1 or 2, indicating that the corresponding items indicated problematic behaviours. The II is the proportion of items scored 2 among the 1 or 2 coded items.

Regression analyses were conducted to examine the T-SAID total score across degree of ID, controlling for age, gender, and SES, with idiopathic ID as the comparison group.

6.3.4.1 Reliability

Internal consistency of the T-SAID was assessed using Cronbach's alpha (Cronbach, 1951). This assesses the degree to which each item on the T-SAID measures the same construct based upon all possible correlations between two sets of items within the scale. The range of the statistic is from 0 to 1. The accepted minimal standard to claim internal consistency is .70 when evaluating the psychometrics of an instrument. The total score for the T-SAID from all participants were used to compute Cronbach's alpha.

Test-retest reliability was measured using inter-class correlations. This assesses the extent to which a scale can reproduce the same score for the same individual at different times.

6.3.4.2 Validity

Convergent validity measured the relationship between the T-SAID and other scales thought to measure the same construct. In this study, convergent validity was assessed using Pearson's correlation coefficient across the following measures: the *hyperactivity/impulsivity* and *inattention* subscale scores from the Conners 3 (Conners, 2008), the *hyperactivity* subscale score from the DBC-T (Einfeld & Tonge, 2002), and the T-SAID total score.

Divergent validity measured the relationship between the T-SAID and other scales thought to measure a different construct. In this study, divergent validity was assessed using

Pearson's correlation coefficient between the adaptive behaviour composite on the VABS-II-T (Sparrow, et al., 2005) and the total score on the T-SAID.

A number of factor analytic solutions were considered when examining the T-SAID data. Oblique rotation was chosen given the assumption that there was a correlation across factors (Tabachnick & Fidell, 2001). Given the sample size in this study, loadings at or above .50 were selected for inclusion of an item in interpreting each factor (Hair, Anderson, Tatham, & Black, 1998).

CHAPTER 7 RESULTS FROM PHASE 1: QUESTIONNAIRE DEVELOPMENT

The focus groups were analysed in two parts: the freelist activity and the review of the rating scale. A total of 52 behaviours related to attention difficulties experienced by children and adolescents with ID were extracted from the transcript. Comments from the participants relating to the composition of the rating scale items were also recorded.

7.1 Behaviours describing attention difficulties in children with ID

7.1.1 Talking

The majority of teachers who raised the issue of talking mainly focused on the speed of speech: “On some days he talks so fast I can’t even understand him and I’ll just think ‘Boy, he’s got a bad case of the yaps today’” (F3, P7). Other teachers also spoke about students with attention difficulties having poor topic maintenance and talking louder than other students.

7.1.2 Sitting still

A number of teachers raised the issue of children with attention difficulties being unable to sit still. They described the challenge and ongoing process of helping them to be able to sit still, or to even stay in their seat:

At the start of the year he couldn’t even sit still on a chair. He would bang the table...but we’ve got him to a point now where he can sit still in a chair for 30 seconds. He can sit longer than that, but for 30 seconds he can sit still (F3, P2).

Others said that a child’s inability to sit still serving a functional purpose as an avoidance strategy: “like [he says] he needs paper or a pencil sharpened...he’ll just say he needs something so as not to sit down and work” (F3, P6), while others said it depended on the type of activity they were being asked to do:

Like they can be on the move all the time when you're asking them to do some arithmetic or a writing task but when you give them a hands on activity they are much more engaged and focused (F3, P2).

7.1.3 Attention/concentration

Behaviours relating to inattention were discussed less frequently. When the issue was raised, however, children with attention difficulties were reported to find it significantly more difficult to maintain concentration during classroom activities:

He'll have his head down as if he's reading, but he does this head movement and his eyes...I know that he's not working, he's looking at what others are doing. He needs 1:1 supervision to get anything done (F3, P2).

Some teachers and psychologists, however, elaborated on this observation and said that it depended on the task a child was being asked to do, and that they had a greater capacity to focus on tasks that were more practical and hands on, as opposed to academic tasks. Some psychologists also discussed the difficulties that some children experienced in returning to a task after they have been distracted, and that shifting attention back to a task can be as challenging as getting a student to initiate the task in the first place.

7.1.4 Impulsive

A number of teachers within the focus groups spoke about the impulsivity of children, and several related it specifically to the issue of their desire for instant gratification:

Kids are getting on the computers so much at home, they've become like 'clickerati' and kids just want things at the click of a button like what they get when they're on the computers (F3, P7).

Others agreed that they had observed this behaviour, but questioned whether this was specific to children with ID: "I don't think that's specific to ID though. That's any kid with ADHD" (F3, P8).

Some psychologists discussed the variety of behaviours that could relate to taking things that belong to other children. One psychologist suggested that the age of the child needed to be taken into account when considering this behaviour: "A lot of kids in the junior years of primary school...grab things without asking. I don't think this is specific to ID" (F2, P4). Another psychologist suggested that taking other people's belongings was too specific, as they engage in other, related behaviours as well:

Often kids don't take, but they do muck around with....they touch, they play with....They might not be taking things but they're mucking up other people's stuff. Touching it, or pushing it over, or smudging it...[they're] interfering. Getting in the way (F4, P1).

7.1.5 Executive functioning

Several teachers in the focus groups talked about the difficulties of children with ID organising their materials in class, or bringing things to and from school. There was some difference of opinion regarding whether these behaviours were specific to ADHD, or whether they reflected many children with ID more generally: "When you're talking about planning

and organisation...these are really big issues for these kids. They need step by step; it has to be broken down” (F3, P1).

Teachers also discussed how many children with attention difficulties have limited working memory. Specifically, they detailed that these children have significant difficulties with remembering instructions, or that they can only recall the first or last instruction given. This was also observed out in the yard when asking these children about an incident:

...they can only remember the last event...like they’ll be teasing another kid, teasing them and teasing them, but if that kid lashes out and hits them, then all they can remember is “Such and such hit me”. Never mind that they were teasing the other kid for half an hour. It’s like nothing happened before that. Nothing happened before they got hit (F3, P9).

7.2 Other issues of interest raised

7.2.1 Specificity of behaviours

Teachers within the focus groups sometimes had difficulty distinguishing behaviours that were specific to children with ID and attention difficulties, and those that were more consistent presentations of children with ID generally:

F3, P1: I think you need [some items] on fine and gross motor skills as well. Cos these kids have trouble in those areas.

F3, P7: [Name], that’s all kids with ID.

F3, P1: No, but I think these kids have even more difficulties. Cos their attention difficulties make it more difficult for them to learn, and stuff like fine motor skills...it takes them even longer.

7.2.2 Medication

Some teachers discussed the impact that medication could have on behaviour. They made references to the positive impact that medication could have, such as the student “seem[ing] like a different child” (F3, P5) or being able to understand the child’s speech more easily when taking medication.

Other teachers discussed their beliefs about medication, such as its efficacy in the long-term, dosage and medication compliance. Compliance related directly to parental decision about ceasing medication; the issue of student refusal to take the medication was not raised.

7.3 Rating scale evaluation

Comments or concerns that arose from any rating scale item were taken into consideration, which resulted in some changes being made to the rating scale. In total, 58.5% of the rating scale items were modified in some way. Twenty-three items were reworded, generally to add clarity to the behaviour being rated. Eight items were deleted to eliminate unnecessary duplication. Three of these eight items relating to a child’s ability to concentrate and were deleted for several reasons. Firstly, these items had asked about the child’s ability to concentrate over two different periods of time: “The rating scale should be able to capture whether a child exhibits this behaviour...two different time limits do not add additional information.” (F5, P2). Secondly, it was reported that the items might cause confusion as they asked whether the child could concentrate independently or under supervision when no other items made this distinction. One psychologist also felt that these items would raise a scoring issue when summing the ratings:

Would items 14 and 15, which talk about 5 minutes, somehow get a higher or better score than 12 and 13 which only talk about 1 minute? Do you see what I mean? It's sort of like a scale within a scale... I don't quite know how you [would] deal with that (F4, P1).

Concerns were raised in focus group discussions for a further three items but the decision was made to retain the original wording. These related to small concerns such as using a different example, or a rewording suggestion: "Avoids making a new mistake when corrected once... I don't know if this item is worded positively. The item is fine but maybe you could reword it." (F2, P2). Nineteen items had no concerns raised in any of the focus groups, and also remained unchanged.

Concerns regarding the validity of behaviour as a symptom of attention difficulties were raised for a single item. Item 2 on the rating scale, which asks whether the student speaks at a reasonable volume, was not considered valid by one health professional: "I don't think volume of speech is necessarily a hyperactivity symptom" (F1 P1). This professional noted that talking loudly may be distracting to other students, and may present a challenge to teachers in terms of classroom management, but believed that this behaviour was not specific to, or characteristic of, children with attention difficulties. The decision was made to retain this item, however, due to the number of teachers who referred to this behaviour in their freelist observations, and as only one professional raised this issue.

While several suggestions were made by focus group participants about possible items that could be added to the scale, the majority of these suggestions were outside the scope of the current scale being developed. These included suggestions for items relating to

tics, food fads, sleeping patterns¹¹, social skills and academic achievement. One item was added to the rating scale based on a suggestion made by a health professional and related to shifting attention.

The majority of participants felt that the response set selected by the authors was appropriate. One participant, however, felt that the wording of the response set needed to be reviewed:

I'm not so much quibbling with the 5 points but I've got real trouble with that word 'always'. I mean, how many kids are going to walk from room to room when indoors always?...Keeps legs and feet still while performing a classroom task or when listening to a story. I don't think they *make* a child who always does those things...I just don't think it's happened in the life of the planet (F4, P1).

The author felt that this participant made a valid point about the response set and its relationship with the rating scale items. Based on this observation it was decided to change the response set from a 5-point to a 4-point scale, retaining the initial 4 responses (never, rarely, sometimes, often) and removing the 'always' response option.

The general consensus from the focus groups were that the rating scale was easy to understand and complete, and was not too time consuming. They also commented favourably on the use of positive wording in the items, with teachers in particular appreciating this feature. They reported that in psychological assessments and evaluations (particularly for funding applications) they generally have to focus on the difficulties of the child. Several teachers commented that this rating scale represented a significant, positive shift from the

¹¹ Items on sleep were developed for the parent scale, but the authors believed that teachers would not be appropriate informants for this behaviour. This is consistent with other rating scales that have been developed for teachers and parents, such as the CBCL (Achenbach & Rescorla, 2001) and DBC (Einfeld & Tonge, 2002), which also include items on sleep only in the parent scale.

deficit model: “I like the way the items are written in a positive way. It makes you feel less judgemental” (F3 P7).

Following the scale revisions, the T-SAID was once again subjected to the Flesch-Kincaid test using Flesch 2.0 software (Frink, 2007). The findings indicated a slight improvement in readability with an index of 61 and a reading grade level of 8.16, confirming that it was appropriate for distribution among teachers.

**CHAPTER 8 DEVELOPMENT OF A NEW ATTENTION
RATING SCALE FOR CHILDREN WITH INTELLECTUAL
DISABILITIES: THE SCALE OF ATTENTION IN
INTELLECTUAL DISABILITY (SAID)**

8.1 Declaration

In the case of Chapter 8, contributions to the work involved the following:



Name	% contribution	Nature of contribution
Nerelie Freeman	70%	Formulation of project design, data collection, data analysis, and writing manuscript.
A/Prof Kylie Gray	12.5%	Contribution to development of project design, discussion of ideas expressed in manuscript, and critical review of manuscript.
Prof Kim Cornish	12.5%	Contribution to development of project design, discussion of ideas expressed in manuscript, and critical review of manuscript.
Dr John Taffe	5%	Consultation in data analysis and critical review of manuscript

Declaration by co-authors:

- (1) they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;
- (2) they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
- (3) there are no other authors of the publication according to these criteria;
- (4) potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit; and
- (5) the original data are stored at the following location(s) and will be held for at least five years from the date indicated below:

Location: Centre for Developmental Psychiatry and Psychology, Department of Psychiatry, Southern Clinical School, Monash University, Clayton Campus

Date

Signature 1		
Signature 2		
Signature 3		
Signature 4		

8.2 Paper commentary

Chapter 8 presents a paper that has been submitted for publication in the *American Journal on Intellectual and Developmental Disabilities*. This paper has been formatted to the specific requirements of the journal. Pages have been re-numbered to provide consistency throughout the thesis.

Paper 1 is a study examining the psychometric properties of a new teacher rating scale developed to measure hyperactivity, impulsivity and inattention in children with intellectual disability (ID). Teachers of 176 children aged five to thirteen years with idiopathic ID, Down Syndrome or autism spectrum disorder completed this rating scale. This study addresses an important gap in the literature as there are currently no reliable or valid rating scales that measure these behaviours among children with ID.

DEVELOPMENT OF A NEW ATTENTION RATING SCALE FOR CHILDREN WITH INTELLECTUAL DISABILITIES: THE SCALE OF ATTENTION IN INTELLECTUAL DISABILITY (SAID)

Abstract

Difficulties with attention, impulsivity, and hyperactivity are thought to be as common among children with intellectual disability (ID) as they are in typically developing populations. Despite this, there is a lack of assessment scales to specifically assess ADHD symptomatology in children and adolescents with ID. This paper describes the development and evaluation of a teacher completed measure; the Scale of Attention in Intellectual Disability (T-SAID). A community survey of 176 teachers of children aged 5 to 13 years, with mild-severe/profound ID, indicated that the T-SAID is a reliable and valid measure. Integrating this scale with neuropsychological and clinical research holds exciting promise for enhancing our understanding of the nature of attention difficulties within the ID population.

Key words: intellectual disability, attention, rating scale, children

Attention-deficit/hyperactivity disorder (ADHD) is a pervasive psychiatric condition which affects approximately 11% of primary aged school children (Willcutt, 2012). ADHD is characterised by a pattern of inattention, impulsivity and/or hyperactivity that impairs an individual's functioning across different environments, for example, at home and at school (American Psychiatric Association, 2000). Inattentive behaviour, as observed in the classroom, has an insidious impact on academic attainment (Spira & Fischel, 2005). For example, inattentive behaviour in kindergarten children, but not hyperactive behaviour, predicts poor reading outcomes in Grade 1 and also in Grade 5, independent of kindergarten reading-related skills and concurrent levels of hyperactivity (Dally, 2006; Rabiner & Coie, 2000). This would suggest that if inattention is not treated in early years, deficits in academic performance will become more pronounced with time. To date, the majority of published research has focused on typically developing populations yet pervasive inattention, impulsivity and hyperactivity characterise many children with developmental delay and intellectual disability (Cornish & Wilding, 2010).

Historically, it was maintained that attention difficulties were part of the presentation of intellectual disability (ID) (Antshel, et al., 2006; Guerin, et al., 2009) which may in part have been due to *diagnostic overshadowing bias*. This term refers to the tendency of clinicians, in the presence of ID, to regard accompanying mental health issues as less salient and specific than they would if the child were typically developing (Jopp & Keys, 2001; Mason & Scior, 2004). A recent and growing body of literature, however, suggests that children with comorbid ID and ADHD form a distinct subgroup, and that some children who have ID display few or no difficulties with attention (Hastings, et al., 2005). There is also suggestion that inattention difficulties may vary depending upon factors such as the uneven developmental trajectory in children with ID, and differences in presentation across developmental disorders e.g., Fragile X Syndrome (Cornish, Turk, & Levitas, 2007; Turk,

2011), Down Syndrome (Cornish, et al., 2010; Cornish, Scerif, et al., 2007); Williams Syndrome (Rhodes, et al., 2011; Rhodes, et al., 2010; Scerif, et al., 2004); and autism (Ghaziuddin, et al., 2010; Witwer & Lecavalier, 2010).

Current Clinical Scales

Two diagnostic classificatory tools have been published to assist clinicians in making diagnoses among individuals with ID: the Diagnostic Criteria for Psychiatric Disorders for use with adults with Learning Disabilities/Mental Retardation (DC-LD; Royal College of Psychiatrists, 2001) and the Diagnostic Manual – Intellectual Disability (DM-ID; P. Lee & Friedlander, 2007). Both recognise the limitations of the ICD-10 (World Health Organization, 1992) and DSM-IV-TR (American Psychiatric Association, 2000) in making diagnostic decisions when a person has ID, and appreciate that psychiatric conditions may present differently among adults within this group. These two tools contain differences in their criteria for ADHD, namely whether all three behaviours (impulsivity, hyperactivity and inattention) need to be present to make a diagnosis, and the exclusionary criteria used. For example, the DC-LD allows comorbid diagnoses of autism and ADHD (consistent with the DSM-5; American Psychiatric Association, 2013) whereas the DM-ID does not (consistent with DSM-IV-TR criteria, which the DM-ID was based upon). Despite these inconsistencies, both publications represent a positive step in recognising differences in the clinical presentation of people with ID.

While rating scales are often used to assist with making a diagnosis of ADHD in the absence of ID (Barkley & Edwards, 2006), their usefulness in diagnosing ADHD symptoms reveals significant shortcomings when used among populations with ID.

The Conners Rating Scales – Revised (Conners, 1997) have frequently been used in studies of children with ID even though their validity for use within this population is questionable (Guerin, et al., 2009). Two research groups have examined the psychometric

properties of the Conners Parent Rating Scales-Revised (CPRS-R) and the Conners Teacher Rating Scales-Revised (CTRS-R) among children with either borderline intelligence or ID ranging from mild to severe (Deb, et al., 2008; M. L. Miller, Fee, & Jones, 2004; M. L. Miller, Fee, & Netterville, 2004). The findings suggested that the CPRS-R may be able to indicate the presence of ADHD in children with borderline intelligence or ID, but the CTRS-R was unable to do so (Deb, et al., 2008). Both studies reported limitations with its psychometric properties, including its inter-rater reliability across parents and teachers (Deb, et al., 2008; M. L. Miller, Fee, & Netterville, 2004). It was also noted that 13 items (46.4%) on the CTRS-R were dependent upon the child being verbal, thus invalidating the measure for a significant proportion of children with severe and profound intellectual disabilities who are non-verbal (Deb, et al., 2008).

Shortcomings also exist in rating scales that have been developed for use within the ID population. The Aberrant Behaviour Checklist – Community (ABC-C; Aman & Singh, 1994) measures a broad range of behavioural and emotional problems. In a review of seven rating scales among children with ID, it was concluded that the ABC-C was the most reliable and valid scale for measuring ADHD symptoms in children with ID (M. L. Miller, Fee, & Jones, 2004; M. L. Miller, Fee, & Netterville, 2004). This was perhaps not surprising, however, given that the ABC-C was the only measure included in the review that had been developed for the ID population. Their conclusions are also limited by their lack of generalisability to the wider population due to the small sample size, exclusion of children with severe or profound ID, and the high proportion of African Americans in their sample.

A widely used rating scale that measures a broad range of behavioural and emotional problems in children and adolescents with ID is the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1995, 2002). While the DBC was not specifically designed to assess ADHD symptomatology, it does contain a subset of six items that have face validity for these

behaviours within the existing item set. Although this subset of items has demonstrated internal consistency, further psychometric analyses have been limited to the parent version of the rating scale and not the teacher version (Einfeld & Tonge, 2002).

Another, lesser-known scale is the Attention-Distraction, Inhibition-Excitation Classroom Assessment Scale (ADIECAS; Evans, 1975, in Evans & Hogg, 1984) that measures difficulties across two dimensions: inattention/excitation (IE) and attentiveness/distractibility (AD). While it has been used in several independent studies (Buckley, et al., 2008; Guerin, et al., 2009), it presents with a number of shortcomings. Limited replication of the psychometric properties, inconsistent findings regarding the scale's factor structure (Evans & Hogg, 1984; Strand, et al., 1990; Turner, et al., 1991), lack of commercial availability and no normative data may have contributed to its restricted use and lack of uptake by researchers and clinicians.

Although the prevalence of ADHD symptomology is at least as common in children with ID as without (Dekker & Koot, 2003; Feinstein & Reiss, 1996; Hastings, et al., 2005; Lindblad, et al., 2011), the profile of attention difficulties across known causes of ID is only starting to be identified and described. The need to develop a rating scale to measure attention difficulties in these populations has been recognised (Deb, et al., 2008) but not yet adequately addressed.

The limitations inherent in most commercially available attention scales fail to capture subtle attention profiles in ID and yet attention difficulties represent core and pervasive concerns in many children with ID. Therefore, the overarching aim of the present study was to develop and evaluate the psychometric properties of a novel attention rating scale to explore the range and severity of everyday inattention, hyperactivity, impulsivity, and working memory difficulties in children with ID.

Method

Phase 1a: Development of the New Rating Scale

Behaviours related to attention difficulties in children with ID that are salient to parents and teachers were identified through a review of the content of existing rating scales, descriptive behaviours reported in published studies, and an examination of the diagnostic criteria in the DSM-IV-TR (American Psychiatric Association, 2000), ICD-10 (World Health Organization, 1992), DC-LD (Royal College of Psychiatrists, 2001) and DM-ID (P. Lee & Friedlander, 2007). These behaviours were categorised onto concept maps under four headings of hyperactivity, impulsivity, inattention and working memory.

The research team evaluated the concept maps to determine the difficulties that would be observed in young people with ID. Those behaviours retained were converted into checklist items in lay language that would be readily understood by parents and teachers. All items were worded positively as it has been proposed that this improves response rates when reporting on children's behaviours (Goodman, 1997).

Following these procedures, the list of attention difficulties encompassing the four headings listed above were organised as a rating scale. The response set consisted of a 4-point scale where each item is scored using ratings of *never*, *rarely*, *sometimes* and *often*, with higher scores indicating fewer difficulties.

Phase 1b: Focus Group Discussions

The new rating scale, the Scale of Attention in Intellectual Disability – Teacher version (T-SAID), was presented to nine health professionals (three paediatricians and six psychologists) and nine teachers from special schools via focus group discussions. An initial activity using the freelist technique (Borgatti, 1999) required participants to think about the children with ID they had seen in their practice or classroom and to list the behaviours they had observed in these children that related to hyperactivity, impulsivity, inattention and working memory. This enabled the research team to gather further behaviours for potential

inclusion in the rating scale that had not already been identified using the methods described above. Participants were then asked to evaluate the items in the T-SAID, including the clarity and expression of the wording, and any behaviours omitted that they believed warranted inclusion.

Phase 2: Community Survey

Participants

Two hundred and fifteen consent forms were returned by families of children attending schools in the Melbourne metropolitan area and across regional Victoria, Australia. Children were eligible to participate in the study if: (1) they were aged between 5 and 13 years; and (2) their most recent cognitive assessment placed their functioning in the intellectually disabled range (i.e., their cognitive and/or adaptive living skills assessment total score was 70 or below).

Socioeconomic status (SES) was determined via parental completion of the Hollingshead Four Factor Index (Hollingshead, 1975). This measure has been found to yield comparable information to more recently developed SES measures (Cirino, et al., 2002) but has the advantages of being simple to complete and less time-consuming. The scale gives a rating for each parent based on the highest level of education completed and their current occupation. Scores are averaged across ratings for both parents and an overall score is calculated. A higher score indicates a higher level of socioeconomic status.

Measures

Wechsler Preschool and Primary Scale of Intelligence – Third edition/Wechsler Intelligence Scale for Children – Fourth edition (WPPSI-III/WISC-IV; Wechsler, 2002; Wechsler, 2003). The WPPSI-III and WISC-IV are established, reliable and valid measures of intellectual ability with good to excellent internal consistency ($\alpha = .85 - .95$) and strong

test-retest reliability ($r = .80 - .95$). They were used in this study to determine each child's current cognitive functioning.

Vineland Adaptive Behaviour Scales, Second edition – Teacher Rating Form (VABS-II-T; Sparrow, et al., 2005). The VABS-II-T is a reliable and valid measure of adaptive behaviour with acceptable to excellent internal consistency ($\alpha = .74 - .98$) and moderate to very strong test-retest reliability ($r = .43 - .97$). It was used in this study to determine the current adaptive functioning of children whose intellectual ability could not be measured with the WPPSI-III or WISC-IV.

Conners Rating Scales – Third edition, Teacher Short form (Conners 3; Conners, 2008). The Conners 3 has 39 items and screens for symptoms of ADHD and related disorders. It has five subscales: *inattention*, *hyperactivity/impulsivity*, *learning problems/executive functioning*, *aggression* and *peer relations*. It was developed for use with typically developing children and has not been validated for children with ID (Conners, 2008). The Conners 3 was completed by each child's current teacher to determine convergent validity with the T-SAID.

Developmental Behaviour Checklist – Teacher version (DBC-T; Einfeld & Tonge, 2002). The DBC-T is a 93-item checklist designed to assess a broad range of behavioural and emotional problems in children and adolescents with ID. It has five subscales: *disruptive/antisocial*, *communication disturbance*, *self-absorbed*, *social relating* and *anxiety*. A subset of items measure hyperactivity which was generated based on the face validity of items that appeared consistent with hyperactive behaviour (Einfeld & Tonge, 2002). The DBC-T was scored by calculating the mean of the six hyperactivity item ratings, with higher scores indicating greater difficulties. It was completed by each child's current teacher to determine convergent validity with the T-SAID (M. L. Miller, Fee, & Netterville, 2004).

Scale of Attention in Intellectual Disability (SAID). The proposed rating scale developed in Phase 1 of the study consists of 46 items that taps hyperactivity/impulsivity, inattention, and aspects of working memory. The teacher version (T-SAID) was completed by the child's current teacher (provided they had known the child for a minimum of 6 months). A parent version (P-SAID) is under development. Teachers responded to each statement on a 4-point scale of *never*, *rarely*, *sometimes* and *often*, with lower scores on the T-SAID relating to greater difficulties.

Procedure

Ethics approval was obtained from the Monash University Standing Committee on Ethics in Research Involving Humans, the Victorian Department of Education and Early Childhood Development, and the Catholic Education Office Melbourne, Australia.

School principals at special schools ($n = 22$), special developmental schools ($n = 8$), and autism specialist schools ($n = 2$) were invited to assist with recruitment for the study. Of the 32 schools, 19 agreed to assist in recruitment resulting in a school participation rate of 59.4%. Support groups and community organisations were also approached, asking them to advertise the study on their web site and seeking permission to contact member families with a child aged 5 –13 years. Families were sent home an envelope containing a poster, explanatory statement and consent form. Those who consented to participate returned the form in a reply-paid envelope. Principals of the schools attended by children recruited via a support group or community organisation ($n = 36$) were also contacted, and all consented to assist with the study. A member of the research team telephoned each consenting family to determine their child's eligibility to participate in the study, and to collect demographic and clinical data.

If a child had been administered a cognitive and/or adaptive living skills assessment in the past they were asked to provide these results to the research team. A cognitive

assessment was conducted if they had not been administered one in the last 18 months (WPPSI-III) or two years (WISC-IV). If the child's FSIQ could not be calculated, then the VABS-II-T Adaptive Behaviour Composite (ABC) was used as a proxy for their IQ score. Concurrent validity between the ABC and FSIQ has suggested a strong positive relationship for children with severe and profound ID ($r = .65$; de Bildt, Kraijer, Sytema, & Minderaa, 2005).

The child's classroom teacher was mailed a booklet of rating scales. It was a requirement that each teacher who completed the questionnaires had known the child for a minimum of six months. Teachers were asked to complete the DBC-T (Einfeld & Tonge, 2002), the Conners 3 (Conners, 2008) and the T-SAID. Questionnaires were returned to the research team in a reply-paid envelope. Reminder letters or emails were sent to teachers if questionnaires had not been returned within four weeks, and a second reminder was sent if they had not been returned within six weeks.

Test-retest reliability was assessed by mailing a second copy of the T-SAID to a random sample of classroom teachers 2 weeks after the first one was returned. The mean interval between the first and second rating scales being completed was 28 days ($SD = 10.41$). Teachers who took longer than 50 days to return the second rating scale ($n = 12$) were excluded from the analyses, leaving a total sample of 19 for analyses.

Analysis

As the response set offered little distinction between the *rarely* and *never* ratings, it was decided to collapse these two ratings into a single category. Scores on the T-SAID were then reversed for analysis so that higher scores were indicative of greater difficulties.

The total score was calculated by taking the mean of all the items (known as the Mean Item Score, or MIS). This method has a number of advantages over calculating the sum of all item scores (Taffe, et al., 2008). One advantage is that the MIS may be deconstructed to

measure the breadth of behaviours an individual exhibits (the Proportion of Items Checked, or PIC) and the intensity at which the items are checked for that person (the Intensity Index, or II). PIC is the proportion of recoded items receiving codes of 1 or 2, indicating that the corresponding items indicated problematic behaviours. The II is the proportion of items scored 2 among the 1 or 2 coded items.

Results

Phase 1: Development of the T-SAID Rating Scale

The focus groups were analysed in two parts: the freelist activity and the review of the rating scale. A total of 52 behaviours related to attention difficulties experienced by children with ID were extracted from the transcript. Five main themes were extracted: (1) talking (speed; volume; amount; poor topic maintenance); (2) inability to sit still; (3) limited attention span/concentration; (4) impulsivity; and (5) executive function difficulties (working memory; organisation of materials).

A total of thirty-one items (58.5%) were modified following comments in the focus group discussions. The reading ease and grade level of the T-SAID was analysed using the Flesch-Kincaid test (Flesh 2.0 software; Frink, 2007). The T-SAID received a reading ease score of 61 and a grade level score of 8.16, suggesting an appropriate level of readability. Example items from the T-SAID are provided in Table 1.

[Insert Table 1 about here]

Phase 2: Community Survey

Study Sample

Of the 181 children deemed eligible to participate in the study, rating scales were returned for 176; a return rate of 97.2%. The demographic characteristics of the sample are

described in Table 2. Almost half the sample ($n = 76$; 43.2%) had idiopathic ID, 33.5% ($n = 59$) autism spectrum disorder, and 23.3% ($n = 41$) Down Syndrome. Results from the cognitive and adaptive living skills assessments, broken down by degree of ID, are described in Table 3.

[Insert Table 2 about here]

[Insert Table 3 about here]

Comorbid Diagnoses

Across the sample, 31 parents (17.6%) reported their child as having at least one comorbid diagnosis, the most common being ADHD ($n = 20$; 11.4%). Of the 20 children, 13 were currently taking medication e.g., Ritalin (65.0%), four had never been prescribed medication (20.0%), and three had taken medication in the past but were not doing so at the present time (15.0%). Other reported comorbid diagnoses included epilepsy ($n = 18$; 10.2%) and anxiety ($n = 6$; 3.4%).

Reliability of the T-SAID

Item-total and inter-item correlations were calculated for all 46 items of the T-SAID. Item-total correlations ranged from .16 – .78 and inter-item correlations ranged from .01 – .88. Two items (item 38 *Understands instructions presented non-verbally* and item 39 *Understands instructions better if they include non-verbal prompts*) were found to have poor item-total (.45 and .16 respectively) and inter-item correlations (.19 – .47 and .01 – .47). The decision was made to remove these two items from the rating scale, leaving 44 items.

The Cronbach's alpha for the T-SAID total score indicated it has excellent internal consistency according to Cohen's (1988) criteria, as shown in Table 4. The test-retest reliability, assessed by intra-class correlations, was also strong.

Validity of the T-SAID

The content validity of the rating scale items was established via the method of item derivation and use of focus group discussions to evaluate the scale as described above. The general consensus from the focus group discussions suggested that the T-SAID was easy to understand and complete, and was not too time consuming. Participants commented on the usefulness of the examples that accompanied some of the items as it enhanced their understanding of the behaviour they were being asked to rate. They also spoke favourably of the use of positive wording in the items, with teachers in particular appreciating this feature. Several teachers commented that this rating scale represented a significant, positive shift from the deficit model: *“I like the way the items are written in a positive way. It makes you feel less judgemental”*.

Convergent validity was measured by examining the raw scores for the hyperactivity items on the DBC-T ($n = 173$) and the Conners 3 inattention and hyperactivity subscales. To establish the appropriateness of using the Conners 3 as a measure to examine convergent validity, the internal consistency of the hyperactivity and inattention subscales with the current sample was calculated. It was found to be good to excellent ($\alpha = .88 - .90$) and therefore deemed to work reasonably well in an ID population. The T-SAID had strong convergent validity with both the DBC-T and the Conners 3 suggesting that these different scales measured the same construct, as shown in Table 4. The divergent validity of the T-SAID was measured by comparing it with the total score on the VABS-II-T ($n = 109$). The T-SAID had moderate divergent validity with the ABC, suggesting a lack of association between these measures and that they measured different constructs. Higher adaptive functioning was associated with fewer problems with attention, hyperactivity, impulsivity and aspects of working memory.

Although it is beyond the scope of this study to evaluate the properties of the T-SAID as a screening tool for ADHD, the discriminant validity was examined by comparing those children with a comorbid ADHD diagnosis ($n = 20$) and those without ($n = 156$). A significant difference in the total score was found across groups ($t_{174} = 2.56, p < .01$) with children who had an ADHD diagnosis having significantly higher scores.

[Insert Table 4 about here]

ADHD Symptoms Across Degree of Intellectual Disability

Regression analyses were conducted to examine the T-SAID total score across degree of ID, controlling for age, gender, and SES. As shown in Table 5, the mean item score (MIS) on the T-SAID (possible range 0-2) was greater by .49 for those with severe or profound ID than for those with mild ID, but only by .06 for those with moderate ID. A similar pattern was evident in the regressions of the proportion of items checked (PIC) and intensity index (II; both on a 0-1 scale), indicating that the two possible reasons for higher MIS (i.e., a greater breadth of behaviours exhibited and these behaviours being noticeably more severe) are both in evidence among those with severe or profound ID. On average, 25% ($p < .001$) more items were marked *sometimes* or *rarely/never* for those with severe or profound ID than for those with mild ID, and of these ‘checked’ items, 24% ($p < .001$) more were marked at the more intense *rarely/never* level for those with severe or profound ID than for those with mild ID. There was also a significant negative effect for age, with the MIS decreasing by .07 with every year of aging. This suggests that as children age their attention improves, with fewer behaviours exhibited and these behaviours being less severe.

[Insert Table 5 about here]

Discussion

The findings of the present study suggest that the 44 item T-SAID is a reliable and valid scale measuring attention, hyperactivity, and impulsivity in children with ID. The advantages of this new measure over existing measures include: (1) no assumption of academic competence in the scale items (e.g., items relating to literacy or numeracy) which is appropriate given children with ID may not have the skills to do such tasks even with assistance; (2) the use of positively worded items which are thought to improve response rates when reporting on children's behaviours (Goodman, 1997); and (3) the inclusion of items related to aspects of working memory given its strong association with attention (Scerif, 2010; Steele, et al., 2012). Previously, capturing attention profiles or 'signatures' in children with ID was dependent either upon rating scales that were standardised on children from non-ID populations but who had ADHD-like symptoms e.g., Conners Rating Scales, or on more generalised rating scales of atypical behaviours but not especially focused on inattentive, hyperactive or impulsive behaviours in children with ID.

Preliminary results suggest that the T-SAID may have the ability to discriminate between children who have ADHD and those who do not, although its efficacy as a screening tool is yet to be evaluated. It should be noted, however, that in this study the ADHD diagnosis was determined via parent report only. As the majority of clinicians use rating scales when considering a diagnosis of ADHD (Chan, et al., 2005), the availability of a reliable and valid tool like the T-SAID may increase clinician confidence in making this diagnosis when working with children who have ID. Its strong convergent validity with existing rating scales i.e., the DBC-T and Conners 3, further suggests that the T-SAID measures the intended constructs of hyperactivity, impulsivity and inattention.

Regression analyses suggested that children with severe or profound ID had greater difficulties with attention, hyperactivity and impulsivity, with a broader range of behaviours and greater intensity being exhibited (accounting for 16.3 – 19.3% of the variance). This is consistent with the findings of Rojahn and colleagues (2010), who reported that children and adolescents with severe and profound ID had higher levels of hyperactivity. Given the significant challenges already faced by educators of children with ID – particularly severe and profound ID – in terms of maximising their learning potential and vocational options (Einfeld et al., 2006), additional difficulties with attention would further compromise their capacity to realise these long-term outcomes. This finding therefore has implications for teachers as it may result in the need for more complex behaviour management plans to assist children with severe or profound ID in the classroom. The analyses also suggested that as children get older they have fewer difficulties with attention, hyperactivity and impulsivity, a finding consistent with research into typically developing children (Faraone, et al., 2006).

When asking teachers and health professionals to identify behaviours relating to attention difficulties in children with ID, more externalising behaviours were raised and fewer behaviours relating to inattention. This is consistent with research which suggests that teachers are less likely than parents to report and/or identify inattentive behaviours (Murray et al., 2007). It highlights the importance of making teachers more aware of the problem of inattention in the classroom – both through improved identification and greater understanding of the impact it has on students. Even though these behaviours may not be as readily observable or disruptive to others, they can still have a significant impact on individual student outcomes and achievement.

It is important to consider the findings of this study in the context of methodological limitations and directions for future research. Participants in the focus group discussions consisted of teachers from schools for children with mild ID but not those working in schools

for children with moderate, severe or profound ID. Given that these teachers are likely to have had experience working across settings, however, this is unlikely to have had an impact on the representativeness of the items for children with moderate, severe or profound ID. Convergent validity was measured by asking teachers to complete several rating scales that measures ADHD symptomatology, but future studies could incorporate additional information from a structured diagnostic interview or behavioural observations. While the test-retest reliability was strong, it was conducted on a small sample, necessitating replication. Finally, future research is needed to determine the psychometric properties of the parent version (P-SAID) and the validity of the SAID in adolescent populations.

A strength of the current study is the high return rate of the T-SAID from teachers. The return rates from teachers in the area of child psychopathology are often low (Bishop, Laws, Adams, & Norbury, 2006; Lecavalier, et al., 2006; J. R. Sullivan & Riccio, 2007). The high return rate suggests acceptability of the scale itself given the teachers were given no incentive to return the booklet. A second strength is the rigorous development of the items in the T-SAID. The integrated approach of reviewing the content of existing rating scales and diagnostic manuals, gathering data from behaviour observations, reviewing relevant research papers, and using focus group discussions during the drafting process all ensured sound content validity for the items chosen. A third strength is that the T-SAID was developed specifically for the population of interest. Researchers and clinicians may consider using this measure as it focused on the particular attention difficulties experienced by children with ID, as opposed to existing measures designed for typically developing children which may contain items that are developmentally inappropriate.

The Scale of Attention in Intellectual Disability – Teacher version (T-SAID) is the first measure developed specifically for children with ID, facilitating reliable and valid measurement of attention, impulsivity and hyperactivity for research and clinical purposes.

Potential applications of the T-SAID include use in research examining ADHD symptomatology, and by clinicians to assist with assessment and diagnosis. It is anticipated that the development of this disability specific measure will enhance identification, diagnosis and subsequent access to treatment, along with improvements in the development and evaluation of interventions for children with ID and ADHD.

Word count: 4793

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Table 1

Examples of Items from the Scale of Attention in Intellectual Disability – Teacher Version

(T-SAID)

Problem behaviour	Examples of items
Hyperactivity/impulsivity	<p>Item 6: Stays in own seat when expected to</p> <p>Item 27: Takes turns when playing with others</p> <p>Item 33: Waits until called on by the teacher before giving an answer (avoids calling out)</p>
Inattention	<p>Item 12: Persists with a task for 2 minutes even if they find it difficult (avoids giving up)</p> <p>Item 15: Can easily give his/her attention to start a new task</p> <p>Item 21: Returns attention to task after being distracted by another student</p>

Table 2

Sample Demographics

	Total sample (<i>n</i> = 176)	Mild ID (<i>n</i> = 62)	Moderate ID (<i>n</i> = 79)	Severe/profound ID (<i>n</i> = 27)
Gender <i>n</i> (% male)	114 (64.8)	43 (69.4)	51 (64.6)	15 (55.6)
Age				
<i>M</i> (SD)	9.15 (2.13)	9.08 (2.13)	9.09 (1.92)	10.07 (2.34)
Range	5 – 13	5 – 12	5 – 12	5 – 13
SES ^a				
<i>M</i> (SD)	35.44 (15.97)	33.42 (15.32)	35.62 (16.91)	38.65 (15.43)
Range	8 – 69	11 – 67	8 – 69	14 – 67
School attended <i>n</i> (%)				
Mainstream	27 (15.3)	8 (12.9)	13 (16.5)	2 (7.4)
Special/Special developmental	131 (74.4)	49 (79.1)	58 (73.4)	21 (77.7)
Split placement ^b	11 (6.3)	5 (8.1)	5 (6.3)	1 (3.7)
Autism specialist	2 (1.1)	*	*	1 (3.7)
school				
Support centre in mainstream school	5 (2.8)	*	3 (3.8)	2 (7.4)

Note. Degree of ID could not be determined for eight students.

^aHollingshead scores range from 8 to 71. ^bChildren who spend part of their week in a mainstream school and part of their week in a special school.

Table 3

Scores from the Cognitive and Adaptive Living Skills Assessments by Degree of ID

		Mild (<i>n</i> = 62)	Moderate (<i>n</i> = 79)	Severe/ profound (<i>n</i> = 27)
WISC-IV /WPPSI-III	<i>M</i> (SD)	63.71 (4.71)	47.50 (4.02)	40.00 (0.00)
FSIQ				
	Range	56 – 70	40 – 54	40
WISC-IV				
VCI	<i>M</i> (SD)	64.64 (7.12)	53.18 (7.25)	45.44 (0.88)
	Range	53 – 75	45 – 71	45 – 47
PRI	<i>M</i> (SD)	72.43 (7.38)	55.44 (7.93)	47.83 (4.13)
	Range	63 – 86	45 – 75	45 – 59
WMI	<i>M</i> (SD)	66.72 (9.24)	56.53 (5.81)	50.22 (0.67)
	Range	52 – 88	50 – 74	50 – 52
PSI	<i>M</i> (SD)	75.25 (10.83)	59.09 (8.25)	50.75 (1.39)
	Range	50 – 94	50 – 78	50 – 53
WPPSI-III				
Verbal	<i>M</i> (SD)	63.92 (8.87)	54.58 (3.85)	*
	Range	53 – 77	48 – 61	*
Performance	<i>M</i> (SD)	68.23 (9.03)	51.50 (4.60)	*
	Range	53 – 81	47 – 61	*

VABS-II-T

ABC	<i>M</i> (SD)	59.55 (6.71)	54.19 (9.18)	41.78 (13.17)
	Range	42 – 70	26 – 74	20 – 64
Communication	<i>M</i> (SD)	61.66 (5.11)	56.50 (8.11)	45.78 (10.15)
	Range	54 – 74	42 – 74	25 – 60
Socialisation	<i>M</i> (SD)	67.49 (8.26)	62.56 (10.17)	54.00 (12.60)
	Range	49 – 84	37 – 89	32 – 76
Daily Living Skills	<i>M</i> (SD)	60.63 (8.65)	55.27 (9.62)	42.14 (11.23)
	Range	38 – 78	36 – 80	21 – 62

Note. WISC-IV = Wechsler Intelligence Scale for Children – Fourth edition; WPPSI-III = Wechsler Preschool and Primary Scale of Intelligence – Third edition; VABS-II-T = Vineland Adaptive Behaviour Scales, Second edition – Teacher Rating Form.

Table 4

Reliability and Convergent Validity of the T-SAID

	Reliability		Validity			
	Internal consistency (α)	Test-retest ICC (95% CI)	Convergent		Divergent	
			Conners 3 inattention (r)	Conners 3 hyperactivity (r)	DBC-T hyperactivity (r)	VABS-II-T (r)
T-SAID total	.98	.96* (.90 – .99)	.66*	.69*	.67*	-.43*

Note. ICC = Intra-class correlation; CI = confidence interval.

* $p < .001$.

Table 5

Beta Coefficients of Regressions of the Mean Item Score (MIS), the Proportion of Items Checked (PIC) and the Intensity Index (II) of the Teacher Version of the Scale of Attention in Intellectual Disability (T-SAID) on Degree of ID

	MIS	PIC	II
Age	-0.07*	-0.03*	-0.04*
Gender	-0.14	-0.08	-0.05
SES (ref: low)			
Average	0.02	-0.02	0.02
High	-0.05	-0.07	-0.01
Level of ID (ref: mild)			
Moderate	0.06	0.01	0.04
Severe/profound	0.49*	0.25*	0.24*
Constant	1.56*	0.99*	0.69*
% variance	19.3	18.3	16.3

* $p < .001$.

**CHAPTER 9 THE SCALE OF ATTENTION IN
INTELLECTUAL DISABILITY (SAID): FACTOR ANALYSIS
OF A NEW RATING SCALE FOR USE WITH CHILDREN
WITH AN INTELLECTUAL DISABILITY**

9.1 Declaration

In the case of Chapter 9, contributions to the work involved the following:

Name	% contribution	Nature of contribution
Nerelie Freeman	70%	Formulation of project design, data collection, data analysis, and writing manuscript.
A/Prof Kylie Gray	12.5%	Contribution to development of project design, discussion of ideas expressed in manuscript, and critical review of manuscript.
Prof Kim Cornish	12.5%	Contribution to development of project design, discussion of ideas expressed in manuscript, and critical review of manuscript.
Dr John Taffe	5%	Consultation in data analysis and critical review of manuscript

Declaration by co-authors:

- (1) they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;
- (2) they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
- (3) there are no other authors of the publication according to these criteria;
- (4) potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit; and
- (5) the original data are stored at the following location(s) and will be held for at least five years from the date indicated below:

Location: Centre for Developmental Psychiatry and Psychology, Department of Psychiatry, Southern Clinical School, Monash University, Clayton Campus

Date

Signature 1	
Signature 2	
Signature 3	
Signature 4	

9.2 Paper commentary

Chapter 9 presents a paper that has been submitted for publication in the *American Journal on Intellectual and Developmental Disabilities*. This paper has been formatted to the specific requirements of the journal. Pages have been re-numbered to provide consistency throughout the thesis.

Paper 2 is a companion to the previous paper and examines the factor structure of the new teacher rating scale that has been developed: the Scale of Attention in Intellectual Disability (SAID). Studies that have measured ADHD symptoms within children with ID have often used measures that were designed for children who were typically developing in the absence of any reliable or valid alternatives. Shortcomings of these rating scales when used with children with ID include inconsistencies in the factor structure and the inappropriateness of some of the rating scale items. A factor analysis of the SAID was needed to determine whether the rating scale items grouped together into constructs that could provide meaningful information about ADHD symptoms in children with ID.

THE SCALE OF ATTENTION IN INTELLECTUAL DISABILITY (SAID): FACTOR ANALYSIS OF A NEW RATING SCALE FOR CHILDREN WITH INTELLECTUAL DISABILITIES

Abstract

Attention-Deficit/Hyperactivity Disorder (ADHD) is a well-documented childhood psychiatric condition but one that is inconsistently identified in the context of intellectual disabilities (ID). Although ADHD ratings scales exist, few if any can reliably measure the range and severity of behaviours within the ID population. Limitations of these scales include the inappropriateness of some items and the lack of replicability of the factor structure. In an attempt to remedy this problem, a novel scale measuring attention and hyperactivity specific to ID – the Scale of Attention in Intellectual Disability (SAID) – has been developed. An exploratory factor analysis of the teacher version (T-SAID) yielded a four factor solution. The results indicate that the T-SAID is a valid tool for use with children with ID.

Key words: intellectual disability, rating scale, factor analysis, children

The past 20 years has seen considerable progress in understanding difficulties with attention and hyperactivity among children with intellectual disability (ID). Some earlier studies suggested that ADHD symptoms (e.g., high levels of inattentive and hyperactive/impulsive behaviours) were related to cognitive deficits rather than being a comorbid psychiatric diagnosis (Burack, et al., 2001; Handen, et al., 1997). Conversely, other studies argued that mental health issues were underdiagnosed due to the complexity of diagnosing additional disorders in the presence of ID, a concept known as diagnostic overshadowing (Jopp & Keys, 2001; Mason & Scior, 2004). These conflicting views culminated in a comprehensive review by Antshel and colleagues (2006), who concluded that ADHD was a valid disorder in ID but emphasised that more studies were needed to further identify the complexities of these comorbid diagnoses across the areas of treatment, assessment, behavioural and experimental studies.

Research from the neuropsychological field has led the way in demonstrating not only that ADHD symptomatology is present in children with ID, but that at the cognitive level there are disorder-specific profiles of attention functioning that differentiate one group from another for example autism spectrum disorder (e.g., Christ, et al., 2011; Landry & Bryson, 2004), Fragile X Syndrome (e.g., Cornish, et al., 2013; Cornish, Scerif, et al., 2007), Williams Syndrome (e.g., Breckenridge, et al., 2013; Rhodes, et al., 2011), and Down Syndrome (e.g., Breckenridge, et al., 2013; Cornish, Steele, et al., 2012). Furthermore, recent parent surveys suggest that ADHD symptomatology in these groups is at least as common as that reported in children with ADHD with no intellectual impairment (Neece, et al., 2011). Indeed, in the case of autism spectrum disorder, Fragile X Syndrome and Williams Syndrome, it would appear that ADHD symptoms are markedly greater with prevalence rates as high as 59% (Goldstein & Schwebach, 2004), 62% (Bailey, et al., 2008) and 100%

(Rhodes, et al., 2011) respectively within these ID populations, compared with 6-7% of typically developing children and adolescents (Willcutt, 2012).

Although there is now accruing consensus that ADHD behaviours have a significant and long lasting impact in children with ID, there is currently no one measure that can capture different severity and profiles of inattentive and hyperactive behaviours in children specifically with ID. The Conners Rating Scales (CRS; Conners, 1989, 1997, 2008) and the Child Behaviour Checklist (CBCL; Achenbach, 1991; Achenbach & Rescorla, 2001) are amongst the most commonly used both clinically and in the research literature. The parent version of these scales have been used to examine ADHD symptoms in studies of children with idiopathic ID (Deb, et al., 2008; M. L. Miller, Fee, & Jones, 2004; M. L. Miller, Fee, & Netterville, 2004), Fragile X Syndrome (Cornish, et al., 2013; Farzin et al., 2006), autism spectrum disorder (Hartley, et al., 2008), and Williams Syndrome (Rhodes, et al., 2011). Few studies have used the teacher version of these scales (Buckley, et al., 2008; M. L. Miller, Fee, & Netterville, 2004) and all used samples of children with idiopathic ID.

One of the core disadvantages of both the CRS and CBCL scales is that they were developed for children who function within normal range of IQ; they were not specifically developed with the intention of being used to rate the behaviours of children with ID. One of the key issues, therefore, is the appropriateness of the items for this population. Literacy and numeracy skills cannot be assumed among children with ID, and yet both the CRS and the CBCL contain several items on their attention subscales that relate to these skills such as *Not reading up to par* or *Has difficulty learning*. Further, such items offer poor discriminant validity as limited academic achievement can be observed in many children with ID, irrespective of whether they have attention difficulties.

A second key issue to consider when evaluating a rating scale is the replicability of the factor structure in independent studies. This is particularly important when using them in

a population for which they were not originally designed or validated. A study by Deb and colleagues (2008) examined the factor structure of the CRS - R (Conners, 1997) among children with either borderline intelligence (i.e., an IQ of 70 – 79) or mild to severe ID. While the same factors were extracted for the parent version (i.e., inattention, hyperactivity and conduct problems), the teacher version extracted less distinct factors with four items having cross loadings, and five items with face validity for ADHD symptomatology loading on the conduct problems factor. The authors concluded that the teacher version was not recommended as a screening tool for ADHD symptomatology among children with ID. Two studies by Pandolfi and colleagues (2009, 2012) examined the factor structure of the CBCL among toddlers and children with autism spectrum disorder, although it should be noted that over one third of the sample were high functioning and therefore the conclusions that can be drawn on the validity of this structure within the ID population can only be viewed as tentative. Further, these studies were restricted to the parent version of the CBCL and did not examine teacher ratings.

Therefore, the inappropriateness of some rating scale items and limited replicability of the factor structure suggest that both the CRS and CBCL have significant limitations in their ability to reliably identify ADHD symptoms within the ID population. Despite these issues, these scales continue to be used with children who have ID in the absence of any reliable or valid alternatives. In an attempt to capture profiles of inattentive behaviours in children with ID and across different syndrome aetiologies, we have developed a new rating scale – the Scale of Attention in Intellectual Disability (SAID) – which, for the first time, has items related to ADHD symptomatology that specifically relate to the ID population. The reliability and validity of this measure have been described in Paper 1 (this volume). In this paper we focus on evaluating the factor structure of the Scale of Attention in Intellectual Disability - Teacher version (T-SAID).

Method

Participants

Two hundred and fifteen consent forms were returned by families of children aged 5 to 13 years attending schools in the Melbourne metropolitan area and across regional Victoria, Australia. Further details about the sample and recruitment into the study are described in Paper 1 (this volume).

Measures

Scale of Attention in Intellectual Disability (SAID). This newly developed rating scale consists of 44 items that tap three core domains: hyperactivity/impulsivity, inattention, and aspects of working memory. The teacher version (T-SAID) was completed by the child's current teacher (provided they have known the child for a minimum of 6 months). A parent version (P-SAID) is under development. Teachers responded to each statement on a 4-point scale of *never*, *rarely*, *sometimes* and *often*, with lower scores on the T-SAID relating to greater difficulties.

Procedure

Ethics approval was obtained from the Monash University Standing Committee on Ethics in Research Involving Humans, the Victorian Department of Education and Early Childhood Development, and the Catholic Education Office Melbourne, Australia.

The rating scale was developed firstly by identifying behaviours salient to children with ID through a combination of reviewing items from existing rating scales, drawing on descriptive behaviours reported in published studies, and an examination of the diagnostic criteria in the DSM-IV-TR (American Psychiatric Association, 2000), ICD-10 (World Health Organization, 1992), DC-LD (Royal College of Psychiatrists, 2001) and DM-ID (P. Lee & Friedlander, 2007). Items were then developed by the research team and presented to focus groups of health professionals and teachers for their comment and feedback.

A community survey followed development of the new rating scale. Participant selection was via a three-stage process described in greater detail in Paper 1 (this volume). Briefly, families were approached to participate in the study via mail outs from schools (following permission from the school principal). Support groups and community organisations were also approached, asking them to advertise the study on their web site and seeking permission to contact member families with a child aged between 5 and 13 years. Families who consented to participate in the study returned a consent form to the research team in a reply-paid envelope.

Eligibility to participate was determined via a telephone interview with the family which included collection of demographic and clinical data, and assessment results. Children were eligible to participate in the study if: (1) they were aged between 5 and 13 years; and (2) their most recent cognitive assessment placed their functioning in the intellectually disabled range (i.e., their cognitive and/or adaptive living skills assessment total score was 70 or below).

For those children eligible to participate in the study, their classroom teacher was then mailed a booklet of rating scales to complete which included the T-SAID. It was a requirement that each teacher who completed the questionnaires had known the child for a minimum of 6 months. Rating scales were mailed back to the research team in a reply-paid envelope after completion.

Analysis

A number of factor analytic solutions were considered when examining the T-SAID data. A principal components factor analysis was used, with oblique rotation chosen given the assumption that there was a correlation across factors (Tabachnick & Fidell, 2001). The number of factors to be extracted was determined by a number of considerations: examination of the scree plot (Cattell, 1966), interpretability of the factors, the preference for

a simple structure, the generation of discrete factors with little overlap, and the rejection of analyses that only had a few items loading onto a factor. Given the sample size in this study, loadings at or above .50 were selected for inclusion of an item in interpreting each factor (Hair, et al., 1998).

Results

Of the 181 children deemed eligible to participate in the study, rating scales were returned for 176 yielding a return rate of 97.2%. Of these, 114 were male and 62 were female with a mean age of 9.15 years. The children included in the sample had a diagnosis of autism spectrum disorder ($n = 59$; 33.5%), Down Syndrome ($n = 41$; 23.3%) or idiopathic intellectual disability ($n = 76$; 43.2%). The majority of children had either a mild ($n = 62$; 35.2%) or moderate intellectual disability ($n = 79$; 44.9%), with a smaller proportion being in the severe/profound range ($n = 27$; 15.3%)¹². Further details about the sample, including demographic characteristics, cognitive ability and comorbid behavioural and emotional problems are described in Paper 1 (this volume).

Communalities for the 33 items loaded on the four factors were all at or above .50. The Kaiser-Meyer-Olkin measure of sampling adequacy was high at .95, and the Bartlett's test of sphericity was significant ($\chi^2(946) = 6541.26, p < .001$). Taken together, these results suggest that the data satisfied the assumptions for factor analysis. The results of this analysis are shown in Table 1.

[Insert Table 1 about here]

¹² Degree of ID based on cognitive ability was unable to be obtained for 8 children

Thirty-three of the items retained for analysis loaded onto one of the four factors, with loadings from .50 to .87 accounting for 62.8% of the variance. There were no significant cross loadings on any of the factors, suggesting a low shared variance across the variables. Factor 1 accounted for 49.7% of the variance and consisted of items related to hyperactive and impulsive behaviours. This subscale was therefore labelled Hyperactivity/Impulsivity. Factor 2 accounted for 4.1% of the variance and consisted of behaviours related to sustained and selective attention. This subscale was therefore labelled Inattention. Factor 3 accounted for 5.6% of the variance and consisted of behaviours relating to language. This subscale was therefore labelled Verbal Communication. Factor 4 accounted for 3.4% of the variance and consisted of behaviours related to following instructions and compliance to rules. This subscale was therefore labelled Following Instructions. The internal consistency of these subscales was excellent for the *hyperactivity/impulsivity* and *inattention* subscales ($\alpha = .91 - .94$), and good for the *verbal communication* and subscales ($\alpha = .79 - .82$).

Discussion

The current study examined the factor structure of a new rating scale for use among children with intellectual disability: the Scale of Attention in Intellectual Disability – Teacher version (T-SAID). Four factors were extracted using exploratory factor analysis in this study. As expected, *Hyperactivity/Impulsivity* and *Inattention* were extracted, being the two core dimensions of ADHD symptomatology (American Psychiatric Association, 2013). A third subscale, labelled *Verbal Communication*, consisted of items relating to language such as volume and pace of speech, making requests and retaining information. The fourth subscale, labelled *Following Instructions*, contained items relating to instructions and compliance to rules.

While the extracted *Hyperactivity/Impulsivity* and *Inattention* factors support the two dimensional model of ADHD (American Psychiatric Association, 2013), there are few factor

analytic studies that we can compare these findings to, as most of the available rating scales designed for or used with children with ID have only a hyperactivity subscale. It has similarities with validation studies using the CBCL (Pandolfi, et al., 2009, 2012) and the CRS – R (Deb, et al., 2008) which both have attention and hyperactivity subscales. The four factor structure of the T-SAID, however, suggests that there are other elements which may also need to be considered. Given these children may present with additional complexities, such as limited or no language or a physical disability, the nature of ADHD symptoms may present quite differently within children with ID.

The rating scale items generated for the T-SAID were based on diagnostic classificatory tools, descriptive behaviours reported in published studies, and focus group feedback suggesting that they were representative of hyperactive, impulsive and inattentive behaviours observed in children with ID. An item such as *Stays within the school grounds during the day* was therefore expected to load onto the *Hyperactivity/Impulsivity* factor, consistent with the notion that a child who is impulsive might forget about school rules or safety and abscond from the school grounds. In the current analysis, however, the item loaded together with a group of items about understanding and carrying out instructions (*Following Instructions*) therefore suggesting that among children with ID this behaviour might relate to something else such as compliance around obeying the rules, and perhaps understanding the rules. Qualitatively, some teachers from schools for children with moderate, severe or profound ID commented that this item did not apply to the child they were rating as their school had high fences and/or required a security code to exit. The child was therefore not given the opportunity to demonstrate this behaviour as there was no way they could leave or abscond. So it is also possible that this item could be interpreted differently depending on the school setting attended by the child.

The extraction of an *Inattention* factor represents an exciting development in the study of ADHD symptoms among children with ID. Recent research integrating attentional processes in boys with Fragile X Syndrome (Cornish, Cole, Longhi, Karmiloff-Smith, & Scerif, 2012; Cornish, et al., 2013) highlighted the importance of understanding both the cognitive markers of inattention and the ways they map across into classroom behaviours. Our understanding of this complex interplay, particularly when examining different neurodevelopmental disorders, can only be enriched by using rating scales that are standardised and validated for the population of interest. For the first time, the T-SAID will enable researchers to supplement their observational laboratory data on inattention with rating scale data that captures behaviours salient to the ID population.

Using the T-SAID to identify inattentive behaviours in young children with ID also has important implications for academic achievement. While recent research has shed some light on the different developmental trajectory in literacy acquisition for children with Down and Williams Syndromes (Steele, Scerif, Cornish, & Karmiloff-Smith, 2013), research into the mediating role of attention on academic achievement among children with ID is still wanting. By identifying the specific behaviours impacting on the child's ability to attend to tasks, the T-SAID can help guide behaviour management plans and interventions that are weaknesses for that child. In turn, this will enable the scaffolding of strategies that can be used by the child to more rapidly acquire literacy and numeracy skills in the classroom.

The *Verbal Communication* factor contained items that *a priori* were believed to have face validity across behaviours reflecting ADHD symptomatology and aspects of working memory. It is logical that these items grouped together, however, as all the items inferred the need for verbal ability in order to exhibit the behaviour. This recognises that verbal skills cannot be assumed among children with ID, as children with certain neurodevelopmental disorders (e.g., autism spectrum disorder) and/or severe/profound ID may be nonverbal. The

T-SAID therefore overcomes the scoring dilemma posed by rating scales such as the CRS (Conners, 1989, 1997, 2008) and CBCL (Achenbach, 1991; Achenbach & Rescorla, 2001) where items related to verbal ADHD symptoms such as *Talks too much or too fast* cannot be scored and thus subscale scores cannot be calculated. Children who are nonverbal would simply receive a score of 0 as they would not have the ability to demonstrate any of the skills in this subscale, an approach used by other disability specific measures such as the Developmental Behaviour Checklist (Einfeld & Tonge, 1995).

A core strength of the current study is that analysis of the T-SAID extracted factors that are consistent with ADHD symptomatology. Preliminary analyses in Paper 1 (this volume) suggested that the T-SAID total score has discriminant validity across children who have ADHD and those who do not, although its efficacy as a screening tool is yet to be evaluated. Another strength is that the factor analysis extracted a *Verbal Communication* factor, thus recognising the importance of considering children who are nonverbal; a shortcoming identified in the CRS – R (Deb, et al., 2008) that was not addressed in the more recently released Conners 3 (Conners, 2008).

It should be noted that the participants-to-items ratio for factor analysis is adequate in the current study. While the 10:1 ratio of participants-to-items was recommended in the past (Tabachnick & Fidell, 2001), there is agreement in the literature that this is no longer required. This is supported by recent published studies in the field of developmental psychopathology that have used similar ratios in their factor analyses. A study by Deb, Dhaliwal and Roy (2008) which drew upon a sample of children with ID or borderline intelligence conducted a factor analysis using the Conners and had a 5:1 ratio (151 children: 27 items). A study by Norris and Lecavalier (2011) which factor analysed the NCBRF using a sample of children with autism also had a 5:1 ratio (399 children: 76 items). Another recent

study conducted by Pandolfi and colleagues (2012) drew upon a sample of children with autism using the CBCL had a 1:1 ratio (122 children: 118 items).

Future studies need to look at the stability of this factor structure across different neurodevelopmental disorders given that ADHD symptomatology can present differently across diagnoses (Cornish, Scerif, et al., 2007). It may be, as with the Aberrant Behaviour Checklist – Community (Aman & Singh, 1994), that different factor structures exist across neurodevelopmental disorders (Brinkley, et al., 2007; Sansone et al., 2012), or the factor structure may remain constant irrespective of diagnosis. The modest sample size of this study also necessitates replication with a larger sample to further support the findings from this factor analysis. An examination of the P-SAID is also needed to determine whether the factor structure is similar in the parent version of this scale.

The findings of this study suggest that the T-SAID is a valid scale for measuring hyperactivity/impulsivity and inattention among children with ID. The findings lend support to the notion that DSM-5 ADHD subtypes (American Psychiatric Association, 2013) are valid among children with ID, although the clinical behaviours observed may be different within this population. Some items that relate to ADHD symptomatology in typically developing children loaded onto different factors in the present study. This reinforces the value of developing rating scales specific to children with ID as the items give an accurate representation of behaviours likely to be observed within this population. The development of the T-SAID may assist clinicians and researchers to more reliably identify these behaviours, which may aid with assessment and diagnosis within this population.

Word count: 3120

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Table 1
Principal Components Factor Solution for T-SAID Items

Factor I		Factor II		Factor III		Factor IV	
Hyperactivity/impulsivity	Loading	Inattention	Loading	Verbal communication	Loading	Following instructions	Loading
1 Plays quietly inside	.65	21 Returns to task after distracted	.85	44 Verbally repeat 1 part instruction	.87	41 Carry out one part instruction	.70
13 Keeps legs to self	.62	19 Maintains attention without rewards	.82	45 Verbally repeat 2 part instruction	.82	40 Understands instructions <10 words	.65
4 Walks rather than runs	.56	12 Persists for 2 minutes	.79	46 Recall main points of story	.76	37 Stays in school grounds	.61
33 Waits until called on	.56	23 Timely completion of work	.75	3 Speaks reasonable pace	.73	42 Carry out two part instruction	.59
10 Keeps hands to self	.55	11 Concentrates for 2 minutes	.73	16 Stays on topic	.67		
25 Waits in line	.55	24 Does not get distracted	.71	2 Speaks reasonable volume	.65		
6 Stays in own seat	.54	15 Gives attention	.65	28 Asks before joining in	.60		
26 Waits his/her turn	.52	22 Completes work accurately	.64	29 Asking before taking	.58		
27 Takes turns playing	.50	20 Maintains attention when interested	.59	34 Does not interrupt	.54		
		18 Completes an activity	.54				
		8 Keeps legs still	.50				

**CHAPTER 10 EVALUATION OF A NEW ATTENTION
RATING SCALE ACROSS NEURODEVELOPMENTAL
DISORDERS: THE SCALE OF ATTENTION IN
INTELLECTUAL DISABILITY**

10.1 Declaration

In the case of Chapter 10, contributions to the work involved the following:

Name	% contribution	Nature of contribution
Nerelie Freeman	70%	Formulation of project design, data collection, data analysis, and writing manuscript.
A/Prof Kylie Gray	15%	Contribution to development of project design, discussion of ideas expressed in manuscript, and critical review of manuscript.
Prof Kim Cornish	15%	Contribution to development of project design, discussion of ideas expressed in manuscript, and critical review of manuscript.

Declaration by co-authors:

- (1) they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;
- (2) they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
- (3) there are no other authors of the publication according to these criteria;
- (4) potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit; and
- (5) the original data are stored at the following location(s) and will be held for at least five years from the date indicated below:

Location: Centre for Developmental Psychiatry and Psychology, Department of Psychiatry, Southern Clinical School, Monash University, Clayton Campus

Date	
Signature 1	
Signature 2 	
Signature 3	

10.2 Paper commentary

Chapter 10 presents a paper that has been submitted for publication in the *Journal of Autism and Developmental Disorders*. This paper has been formatted to the specific requirements of the journal. Pages have been re-numbered to provide consistency throughout the thesis.

Paper 3 contrasted the hyperactive, impulsive and inattentive behaviours of 59 children with autism spectrum disorder, 41 children with Down Syndrome and 76 children with idiopathic intellectual disability using data from the psychometric and factor analytic studies (Papers 1 and 2). While neuropsychological research has helped enhance our understanding of the cognitive phenotype of attention across neurodevelopmental disorders, less is known about the behavioural phenotype due to limited research, inconsistent findings, and the use of rating scales that were not appropriate for the population. More research was needed to investigate the behavioural phenotype of ADHD symptoms across children with different neurodevelopmental disorders using a reliable and valid rating scale.

EVALUATION OF A NEW ATTENTION RATING SCALE ACROSS NEURODEVELOPMENTAL DISORDERS: THE SCALE OF ATTENTION IN INTELLECTUAL DISABILITY

Abstract

Whilst neuropsychological research has enhanced our understanding of inattentive and hyperactive behaviours among children with neurodevelopmental disorders, the absence of rating scales developed for those who have intellectual disability continues to be a gap in knowledge. This study examined these behaviours in 176 children with autism spectrum disorder (ASD), Down Syndrome, or idiopathic ID using a newly developed teacher rating scale, the Scale of Attention in Intellectual Disability. Findings suggested that children with ASD had a significantly greater breadth of hyperactive/impulsive behaviours than those with Down Syndrome or ID. These findings support existing research suggesting differing profiles of attention and activity across neurodevelopmental disorders. Understanding disorder-specific profiles has implications for developing strategies to support students with ID in the classroom.

Key words: autism spectrum disorder, attention-deficit hyperactivity symptoms, rating scale, teacher ratings, children, Down Syndrome, intellectual disability

The acquisition of skills such as the ability to sustain attention on a task, inhibit impulsive actions and outbursts, and maintain attention in the presence of distractors are all important developmental milestones and help predict academic outcomes (Metcalf, Harvey, & Laws, 2013). Children with significant deficits in these areas may be diagnosed with attention-deficit hyperactivity disorder (ADHD) which is associated with adverse long term outcomes such as lower academic achievement (Barkley, et al., 2006; Polderman, et al., 2010), friendship difficulties (Normand, et al., 2007) and lower socioeconomic status (Joseph Biederman et al., 2012). Considerable research has focused on identification, treatment, and interventions for children with ADHD in an effort to ameliorate these outcomes, at least among typically developing children.

Comparatively less research has examined the impacts of this disorder in children with intellectual disability (ID). This may be due to the mistaken belief that attention difficulties were part of the presentation of ID (Antshel, et al., 2006; Guerin, et al., 2009), a phenomenon known as *diagnostic overshadowing bias*. This term refers to the tendency of clinicians, in the presence of ID, to regard accompanying mental health issues as less salient and specific than they would if the child were typically developing (Jopp & Keys, 2001; Mason & Scior, 2004). Another contributing factor may be the exclusion criteria in the DSM-IV-TR (American Psychiatric Association, 2000) which did not allow clinicians to diagnose ADHD in the presence of some neurodevelopmental disorders.

The beginning of this century saw momentum starting to gather in the field of developmental psychology through greater recognition and identification of the impact of ADHD symptoms among individuals with ID (e.g., Antshel, et al., 2006; Chadwick, et al., 2005). Neuropsychological research has also made a significant contribution to our understanding in this area by challenging the notion that children with ID and attention

difficulties formed a homogenous group, and have since suggested that there are divergent trajectories in the development of these behaviours across neurodevelopmental disorders (e.g., Cornish, Scerif, et al., 2007; Scerif, et al., 2012). Further, this research has revealed that while rating scales and structured interviews may present behavioural symptoms of inattention as being similar across disorders, these may not necessarily translate into identical cognitive attention mechanisms (see Cornish & Wilding, 2010 for a comprehensive review). An examination of the subcomponents of attention (including sustained, divided and selective attention; Petersen & Posner, 2012) has provided us with an even richer understanding of these differences to help us further understand the unique challenges faced by children across neurodevelopmental disorders.

The current study focuses on children with two neurodevelopmental disorders that have contrasting profiles of hyperactivity and inattention: Down Syndrome and autism spectrum disorder. The selection of these two groups was guided by the high prevalence of ADHD symptomatology in children with these disorders (e.g., Cornish, Steele, et al., 2012; Ekstein, et al., 2011; Rommelse, et al., 2010; Witwer & Lecavalier, 2010). Down Syndrome (DS) is the most common genetic syndrome causing ID due to a third copy of chromosome 21 (trisomy 21; McInerney, et al., 2009). Autism spectrum disorder (ASD) is a childhood-onset developmental disability characterised by deficits in social communication and restricted, repetitive patterns of behaviour (American Psychiatric Association, 2013). Approximately 70-80% have severe cognitive delays, many functioning in the moderate to severe ID range (Fombonne, 2005).

At the behavioural level, recent studies have suggested a high proportion of children in both groups have ADHD symptoms (Ekstein, et al., 2011; Mahan & Matson, 2011; Witwer & Lecavalier, 2010). Children with ASD and DS have both been identified as having difficulties with inattention (Cornish, Steele, et al., 2012; Estes, et al., 2007; Papaeliou, et al.,

2012; Sinzig, et al., 2009; van Gasteren-Oosterom, et al., 2011), but difficulties with hyperactivity have only been reported in children with ASD (Estes, et al., 2007; D. O. Lee & Ousley, 2006; Sinzig, et al., 2009). Within the ASD group, some studies have suggested ADHD symptoms of similar severity across the spectrum (Kaat, et al., 2013; Mahan & Matson, 2011; Witwer & Lecavalier, 2010). Others have suggested that these symptoms are more severe in children with ASD and ID than those who are high functioning (Holtmann, Bolte, & Poustka, 2007; Sinzig, et al., 2009).

At the cognitive level, sustained attention has been identified as an area of strength in both groups (Breckenridge, et al., 2013; Cornish, Scerif, et al., 2007; Johnson, et al., 2007). In the area of selective attention, children with ASD have been reported to perform comparable to (Iarocci & Burack, 2004) or better than (Jarrold, et al., 2005; Joseph, et al., 2009) their typically developing peers. In contrast, Cornish and colleagues (2007) suggested a developmental trajectory for individuals with DS where toddlers perform similarly to their typically developing peers (matched for mental age), but that this skill deteriorates in childhood before improving again as they move into adulthood.

As demonstrated above, while research at the cognitive level has broadened our understanding of this phenotype of attention and activity across neurodevelopmental disorders, the behavioural phenotype has shown less evidence of progressing forward. This has been compounded by limited and inconsistent findings across studies which may be due to the lack of appropriate measures to examine ADHD symptoms. Neuropsychological studies have often used measures developed specifically for children with ID (although see Hooper, et al., 2008 who reported that even when using simple tasks the floor effects precluded skills from being measured in some children with severe or profound ID) whereas the majority of behavioural studies have used rating scales designed for typically developing children such as the Conners Rating Scales (Conners, 1989, 1997, 2008) or the Child

Behaviour Checklist (Achenbach, 1991; Achenbach & Rescorla, 2001). Few of the studies cited above (i.e., Estes, et al., 2007; Kaat, et al., 2013; Witwer & Lecavalier, 2010) utilised a rating scale that has been developed for children with ID such as the Aberrant Behaviour Checklist (Aman & Singh, 1994). Given that children with ID may present with ADHD symptoms at the behavioural level that are quite different to those who are typically developing (Freeman, Gray, Taffe, & Cornish, 2013a), the sensitivity of rating scales used to capture ADHD symptoms in many of the studies cited above therefore need to be called into question. This was also noted by Witwer and Lecavalier (2010), who reported that the behaviours *Interrupts others* and *Pushes their way into groups* were frequently endorsed by parents of children with ASD and ID but questioned whether these behaviours were a function of the children's deficits in social skills, rather than being ADHD symptoms *per se*. This highlights the importance of using rating scales containing items appropriate to the ID population.

Collectively, while recognition of ADHD symptoms among children with ID represented a step forward, our understanding of these symptoms at the behavioural level has been clouded by limited research, inconsistent findings and use of rating scales that are not appropriate for the population. In the present study, we aimed to compare the range of ADHD symptoms in children with ASD, DS and idiopathic ID ranging from mild to profound impairment using a new attention rating scale, the Scale of Attention in Intellectual Disability (SAID; Freeman, et al., 2013a). It was hypothesized that different attention and activity profiles could be identified across groups using this new scale. It was also hypothesized that the SAID would be significantly better at identifying profiles of attention and activity across groups compared with the Conners 3 (Conners, 2008).

Method

Participants

Two hundred and fifteen consent forms were returned by families of children attending special ($n = 156$), mainstream ($n = 32$) or autism specific ($n = 2$) schools in the Melbourne metropolitan area or across regional Victoria (Australia). A small number of children were on a split placement (spending part of their school week in a mainstream school and part of their time in a special school; $n = 12$) or were located in a support centre for children with intellectual disabilities on a mainstream school site ($n = 7$). Children were eligible to participate in the study if: (i) they were aged between 5 and 13 years; and (ii) their most recent cognitive assessment placed their functioning in the intellectually disabled range (i.e., their cognitive and/or adaptive living skills assessment total score was less than 70). Children with a diagnosis of ASD were only included in the sample if they scored above the recommended cutoff for autism (i.e., 15 or more) on the lifetime version of the Social Communication Questionnaire (Rutter, Bailey, et al., 2003). A total of 181 students were deemed eligible to participate in the study (117 males and 64 females).

Socioeconomic status was determined via parental completion of the Hollingshead Four Factor Index (Hollingshead, 1975). This measure has been found to yield comparable information to more recently developed SES measures (Cirino, et al., 2002) but has the advantages of being simple to complete and less time-consuming. Scores are averaged across ratings for both parents and an overall score is calculated. A higher score indicates a higher level of socioeconomic status.

Measures

Wechsler Preschool and Primary Scale of Intelligence – Third edition/Wechsler Intelligence Scale for Children – Fourth edition (WPPSI-III/WISC-IV; Wechsler, 2002; Wechsler, 2003). The WPPSI-III and WISC-IV are established, reliable and valid measures of intellectual ability with good to excellent internal consistency ($\alpha = .85 - .95$) and strong

test-retest reliability ($r = .80 - .95$). They were used in this study to determine each child's current cognitive functioning.

Vineland Adaptive Behaviour Scales, Second edition – Teacher Rating Form (VABS-II-T; Sparrow, et al., 2005). The VABS-II-T is a reliable and valid measure of adaptive behaviour with acceptable to excellent internal consistency ($\alpha = .74 - .98$) and moderate to very strong test-retest reliability ($r = .43 - .97$). It was used in this study to determine the current adaptive functioning of children who were unable to complete the WPPSI-III or WISC-IV.

Social Communication Questionnaire – Lifetime version (SCQ; Rutter, Bailey, et al., 2003). The SCQ, previously known as the Autism Screening Questionnaire (ASQ; Berument, et al., 1999), is a 40-item questionnaire completed by the parent/primary caregiver that examines the areas of communication, socialization, and restricted and repetitive behaviour and interests. The SCQ was completed by families of children with a diagnosis of ASD and was used to determine eligibility to participate in the study.

Conners Rating Scales – Third edition, Teacher Short form (Conners 3; Conners, 2008). The Conners 3 has 39 items and screens for symptoms of ADHD and related disorders. It has five subscales: *inattention*, *hyperactivity/impulsivity*, *learning problems/executive functioning*, *aggression* and *peer relations*. It was developed for use with typically developing children and was not developed for use with children who have ID (Conners, 2008). The Conners 3 was completed by each child's current teacher. It was used to examine its ability to detect differences in ADHD symptoms across groups compared with the author's new rating scale described below.

Scale of Attention in Intellectual Disability (Teacher version) (T-SAID; Freeman, et al., 2013a; Freeman, Gray, Taffe, & Cornish, 2013b). This newly developed rating scale for teachers consists of 44 items with four subscales: *hyperactivity/impulsivity*, *inattention*,

verbal communication and *following instructions*. These items were developed with specific consideration for behaviours that would be observed in children with ID. The items were generated through behaviour observations, consultation with teachers and health professionals, and a review of existing rating scales. Teachers respond to each statement on a 3-point scale of *never/rarely*, *sometimes* and *often*. All items are worded positively as it has been proposed that this may help to improve response rates of parents and teachers when reporting on children's behaviours (Goodman, 1997). Lower scores on the T-SAID relate to greater difficulties. The subscales have good to excellent internal consistency ($\alpha = .79 - .94$) and strong test-test reliability over 30 days ($ICC = .86 - .96$; Freeman, et al., 2013a, 2013b). Strong convergent validity with corresponding subscales on the Conners Rating Scales – Third edition, Teacher Short form ($r = .66 - .69$) and the Developmental Behaviour Checklist ($r = .67$) have also been reported (Freeman, et al., 2013a). The T-SAID was completed by each child's current teacher.

Procedure

Ethics approval was obtained from the Monash University Standing Committee on Ethics in Research Involving Humans, the Victorian Department of Education and Early Childhood Development, and the Catholic Education Office Melbourne.

Participants were selected through a three-stage process. In the first stage, children were recruited from several sources. School principals were invited to assist with recruitment for the study. Families at consenting schools were sent home an envelope containing a poster, explanatory statement and consent form. Families who consented to participate returned the consent form in a reply-paid envelope. Support groups and community organisations were also approached to assist with recruitment and they advertised the study on their web site. Interested families contacted the research team directly by phone or email, and information was mailed out as described above.

In the second stage, a member of the research team telephoned each consenting family to determine their child's eligibility to participate in the study. Basic demographic information was obtained, as well as clinical information including their child's primary diagnostic status, comorbid diagnoses, and any medication they were currently prescribed.

If their child had received a cognitive and/or adaptive behaviour assessment in the past they were asked to provide these results to the research team. A cognitive assessment was conducted if the child had not been administered one in the last 18 months (WPPSI-III) or 2 years (WISC-IV). If a child was deemed untestable using the WPPSI-III or WISC-IV, then the VABS-II total Adaptive Behaviour Composite score (ABC) was used to determine the severity of impairment.

In the third stage, the classroom teacher was mailed a booklet of rating scales. It was a requirement that each teacher who completed them had known the child for a minimum of 6 months. They were asked to complete a number of rating scales including the Conners 3 (Conners, 2008) and the T-SAID (Freeman, et al., 2013a, 2013b). Questionnaires were returned to the research team in a reply-paid envelope. Reminder letters or emails were sent to teachers if questionnaires had not been returned within four weeks, and a second reminder was sent if they had not been returned within six weeks.

Parents of children with ASD were asked to complete the lifetime version of the SCQ (Rutter, Bailey, et al., 2003). This questionnaire was mailed to families to complete in their own time and was returned via a reply-paid envelope.

Analysis

The grouping for level of ID was determined by using the child's FSIQ from the WPPSI-III or WISC-IV, or the ABC from the VABS-II for children who were untestable on the cognitive assessment. Severity of ID was defined using the criteria in Sattler (2001): mild

ID (55 – 70), moderate ID (40 – 54), and severe/profound (< 40). Eight children for whom severity of ID could not be determined were excluded from the regression analyses.

Scores on the T-SAID were reversed for analysis so that higher scores were indicative of greater difficulties. The total score was calculated by taking the mean of all the items (known as the Mean Item Score, or MIS). This method has a number of advantages over calculating the sum of all item scores (Taffe, et al., 2008). One advantage is that the MIS may be deconstructed to measure the breadth of behaviours an individual exhibits (the Proportion of Items Checked, or PIC) and the intensity at which the items are checked for that person (the Intensity Index, or II). PIC is the proportion of recoded items receiving codes of 1 or 2, indicating that the corresponding items indicated problematic behaviours. The II is the proportion of items scored 2 among the 1 or 2 coded items.

Correlates of ADHD symptomatology on T-SAID scores were entered into a multiple regression analysis including gender, chronological age, SES, level of ID and diagnostic group. For level of ID, mild ID was used as the comparison group and for diagnostic group, idiopathic ID was used as the comparison group.

Results

Of the 79 students in the idiopathic ID group (hereafter referred to as the ID group), 76 classroom teachers returned the rating scale booklet yielding a return rate of 96.2%. Of the 61 students with ASD, rating scales were returned for 59 students (96.7%). Rating scales were returned for all 41 students in the DS group. This yielded a total sample of 176 students (114 males, 62 females) with a mean age of 9.15 years. The demographic characteristics of the sample are described in Table 1. There were no significant differences in age ($p = .71$) or SES ($p = .46$) across diagnostic groups. There was a higher proportion of males in the ASD group compared with the other two groups ($\chi^2 = 10.91, p < .01$). A higher proportion of

children in the ASD group were nonverbal compared with the other two groups ($\chi^2 = 24.12$, $p < .001$).

[Insert Table 1 about here]

Across groups, there was no significant difference in gender ($p = .82$), age ($p = .77$), or SES ($p = .42$) for the students whose teachers returned the rating scales and those who did not.

Comorbid psychopathology

Across the total sample, 31 parents (17.1%) reported their child as having at least one comorbid diagnosis. The most common comorbid diagnosis was ADHD, with 20 children having this diagnosis (12 from the ASD group, 8 from the ID group; 11.4%). Thirteen children were currently taking medication for ADHD (65.0%), of which nine were taking methylphenidate, two were taking dexamphetamine, one was taking clonidine, and one was taking atomoxetine. Three had never been prescribed medication (16.7%), and 3 had taken medication in the past but were not doing so at the present time (16.7%). Other commonly reported comorbid diagnoses included epilepsy ($n = 17$; 9.4%) and anxiety ($n = 6$; 3.3%).

Cognitive ability

One hundred and twenty-three children (69.9%) were able to complete at least part of a cognitive assessment. The means, standard deviations and ranges for the assessment broken down by group are described in Table 2. For those children for whom a Full Scale Score (FSIQ) could be derived ($n = 107$), their mean FSIQ was 53.37, placing them in the moderately intellectually disabled range. Across groups, the children with DS had a significantly lower FSIQ than the other 2 groups ($F_{2,104} = 19.05$, $p < .001$). For those children

administered the WISC-IV ($n = 95$), the children with DS had significantly lower scores on all four Indices: Verbal Comprehension ($F_{2,83} = 5.89, p < .01$), Perceptual Reasoning ($F_{2,89} = 18.15, p < .001$), Working Memory ($F_{2,84} = 6.10, p < .01$) and Processing Speed ($F_{2,79} = 12.24, p < .001$). In the younger students administered the WPPSI-III ($n = 28$), there was no difference across groups for the Performance Scale ($p = .12$), but children with DS had a significantly lower Verbal Score ($F_{2,21} = 3.65, p < .05$).

One hundred and nine students had the Vineland Adaptive Behaviour Scales completed by their teacher. The means, standard deviations and ranges for the assessment broken down by group are described in Table 2. Their mean Adaptive Behaviour Composite (ABC) was 54.66 placing them in the moderately intellectually disabled range. Children in the ID group had a significantly higher ABC than the other two groups ($F_{2,106} = 3.98, p < .05$). There were no significant differences across diagnostic groups on the Communication Scale ($p = .47$). Children in the DS group had a significantly lower Daily Living Skills Score ($F_{2,104} = 4.72, p < .01$) than the other two groups. Children in the ASD group had a significantly lower score on the Socialisation Scale than the other two groups ($F_{2,104} = 8.32, p < .001$). The overall scores for both assessments broken down by diagnosis are described in Table 2.

[Insert Table 2 about here]

Internal consistency

The internal consistency of the T-SAID was examined to determine whether it had adequate reliability across neurodevelopmental disorders. As shown in Table 3 below, the T-SAID had good to excellent internal consistency on the *hyperactivity/impulsivity*, *inattention* and *verbal communication* subscales ($\alpha = .87 - .95$). It had fair internal consistency on the

following instructions subscale ($\alpha = .74 - .81$). Given that these results are similar to the internal consistency reported for the combined sample (Freeman, et al., 2013b), the T-SAID subscales were deemed appropriate as a method of comparison across neurodevelopmental disorders.

[Insert Table 3 about here]

T-SAID scores across groups

Regression analyses were conducted to examine the T-SAID total score across groups, controlling for age, gender, SES, and severity of ID. As shown in Table 4, the proportion of items checked (PIC) on the hyperactivity/impulsivity subscale of the T-SAID (possible range 0-2) was significantly greater for children with ASD. On average, 11% ($p < .05$) more items were marked *sometimes* or *rarely/never* for those with ASD than for those with ID. There were no differences across groups on this subscale for the mean item score (MIS) or intensity index (II). This suggests that while the children with ASD exhibited a greater breadth of hyperactive/impulsive behaviours, these were not noticeably more severe than children in the other groups.

The MIS on the verbal communication subscale was greater by .21 for those with ASD than for those with mild ID, but only by .09 for those with DS. A similar pattern was evident in the regressions of the II (on a 0-1 scale), but there were no differences in the PIC. This suggests that the higher MIS was due to verbal communication skills being noticeably more limited among children with ASD. There were no differences across groups on the inattention or following instructions subscales.

[Insert Table 4 about here]

The Conners 3 scores revealed no significant differences across groups for the hyperactivity or inattention subscales. When examining the proportion of children within the clinical range for ADHD symptomatology, again there were no differences across diagnostic groups for the hyperactive, inattentive, or combined subtypes.

Discussion

The findings of this study suggest that children with ASD display a significantly greater breadth of hyperactive/impulsive behaviours than children with ID or DS, which is consistent with the findings of a previous study with adolescents (Bradley & Isaacs, 2006). These difficulties were independent of gender, age and severity of ID. The findings also suggest that hyperactive/impulsive symptoms significantly decrease with age in children with ID, similar to the trend noted in children who are typically developing (Biederman, et al., 2000; Biederman, et al., 2006). Children with severe/profound ID were also found to have a significantly greater breadth and intensity of hyperactive/impulsive behaviours, a finding which has been discussed previously by the authors (Freeman, et al., 2013a).

The suggestion that children with ASD have a significantly greater breadth of hyperactive/impulsive behaviours compared with other neurodevelopmental disorders provides support for the removal of the current exclusionary criteria in the ICD-10 that does not permit dual diagnoses of ASD and ADHD (World Health Organization, 1992). Further, it supports the DSM-5 (American Psychiatric Association, 2013) and the Diagnostic Criteria for Psychiatric Disorders for use with adults with Learning Disabilities/Mental Retardation (DC-LD; Royal College of Psychiatrists, 2001) which do allow for these comorbid diagnoses to be made.

The case for removing such exclusionary criteria would appear even more convincing when looking at our sample which included children with other types of ID who had *lower* levels of hyperactivity than the ASD group, even though paradoxically no exclusionary criteria exist that preclude a comorbid diagnosis of ADHD in these groups. With twelve children in our sample being diagnosed with both ASD and ADHD, clearly some clinicians have made this dual diagnosis, and two-thirds of these children are taking medication to manage these symptoms. Given this exclusionary criteria has been removed in the DSM-5 (American Psychiatric Association, 2013), it is hoped that this will give other clinicians “permission” to make a dual diagnosis if they feel that it is warranted. This may in turn enable more children to access treatments to help manage these symptoms.

This study also found that children with ASD had significantly greater difficulties with behaviours that make up the *Verbal Communication* subscale than children with DS or ID, and that the intensity of these behaviours was also significantly greater. This subscale includes behaviours such as *Can verbally repeat back an instruction that has one step* and *Asks before joining in a game*. This is likely to be a reflection of language ability, given that children with ASD often have impairments in verbal language skills (Luyster, Seery, Talbott, & Tager-Flusberg, 2011; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). While children with DS are also known to experience language difficulties (Luyster, et al., 2011), the findings from the present study would suggest their inattentive and impulsive behaviours as they manifest in verbal communication may be comparatively stronger than those with ASD. Further, the intensity of difficulty would naturally be greater in the ASD group given a higher proportion of these children were non-verbal and would be unable to demonstrate their skills on these items.

While differences across groups for hyperactivity/impulsivity were found using the T-SAID (Freeman, Cornish, & Gray, 2012), the Conners 3 (Conners, 2008) did not detect such

differences. This finding is not surprising given that the Conners 3 (Conners, 2008)– or indeed previous versions of the Conners (Conners, 1989, 1997) – was not developed for children within the intellectually disabled range. Items on existing rating scales describe behaviours related to hyperactivity, impulsivity and inattention that are not often observed in children with ID such as *Dislikes it when phone is engaged when trying to call someone*. Other items relate to behaviours that have limited relevance such as *Puts off homework/projects to the last minute* as such activities are rarely, if ever, asked of children with ID. The assumption that a child is able to speak or verbalise also compromises the validity of many rating scales, which often include items such as *Talks too much or too fast*. Such items could not be rated in a significant proportion of people with severe and profound ID who are non-verbal (Deb, et al., 2008). The T-SAID contains items that are more developmentally appropriate and readily observable in children functioning within the ID range, and avoids the use of vague terms such as *Excitable, impulsive* or *Restless, overactive*. The inclusion of clarifiers and examples in the T-SAID further illustrate the behaviours of interest and aim to minimise the degree of subjectivity when rating each item (Reid & Maag, 1994). Findings of this study emphasise the need for the development and use of measures developed specifically for children with ID. Use of measures designed for typically developing children may result in misleading or potentially inaccurate findings and conclusions.

Many studies continue to use instruments such as the Child Behaviour Checklist (CBCL; Achenbach & Rescorla, 2001) or the Conners (Conners, 1989, 1997, 2008) that have limited or questionable validity when examining inattention and hyperactivity among the ID population (Koskentausta, et al., 2004; Turk, 1998), with the shortcomings being reportedly even more marked when using teacher ratings (Deb, et al., 2008). Therefore, the findings of this study reinforce the importance and utility of using instruments that are clinically valid for

the population of interest. Using tools developed for typically developing children may mask important differences in symptom presentation and behaviour that exist in children who have ID.

It should be noted that while the results of this study suggest differences across neurodevelopmental disorders in the area of hyperactivity/impulsivity, a rating scale alone is insufficient to identify difficulties or to formulate a diagnosis, particularly when only collected from one source. Irrespective of whether a rating scale can identify behavioural phenotypes, it is best practice to use this information in conjunction with developmental history, parent ratings, behavioural observations and results from neuropsychological tests (e.g., Wilding Monster Card Sorting task; Wilding, Munir, & Cornish, 2001) which would provide a more complete profile of these differences across disorders.

The findings of the present study suggest that the new rating scale developed by the authors, the T-SAID (Freeman, et al., 2013a), has the ability to detect differences in ADHD symptomatology in children with ID. Given the lack of reliable and valid rating scales that have normative data to measure ADHD symptoms among children within the intellectually disabled range (Deb, et al., 2008), the T-SAID has the potential to become a valuable tool that can be used by clinicians and researchers not only to detect difficulties within this population, but also to detect differences across neurodevelopmental disorders.

The value of using a teacher rating scale to measure inattention and hyperactivity is that teachers, unlike parents, have the opportunity to observe large groups of children engaging in goal-directed tasks. They can draw on behaviours they have observed both in the present cohort of students being taught and past students, and can use this information to make inferences about what behaviours deviate from the norm (Gadow, et al., 2006). Teachers potentially have a wider exposure to children's behaviour compared with parents who may only know the behaviours of their own children and may consider unusual or

challenging behaviours to be “normal” because they have no basis of comparison (K. Sullivan, et al., 2006). Children’s behaviour in school can also be markedly different from at home due to the expectation of following instructions from a teacher and engaging in prescribed activities where an outcome is expected, unlike at home where some children may engage in fewer goal-directed activities and/or more free play where such difficulties are less likely to be observed (Murray, et al., 2007; Tandon, et al., 2009).

One of the limitations of this study is that teachers of the children with a diagnosis of ADHD were not naïve when completing the rating scales. This may have led them to rate the student differently compared with those teachers whose students had similar difficulties but had not undergone a professional evaluation. Another limitation is that medication use was not formally collected or monitored among children with an ADHD diagnosis, and was dependent upon parent report. For those children who were reported to be on medication, this study did not control for dosage, length of time child had been on the medication, or whether it was used continuously or sporadically. Assuming that the medication taken managed the frequency and intensity of ADHD symptoms (Antshel, et al., 2006), the behaviours of these children may have been qualitatively different from those in the study with hyperactivity or inattention who did not take medication to manage these symptoms. A third limitation is that while the T-SAID subscales were found to have adequate internal consistency across neurodevelopmental disorders, it drew upon relatively small samples of children in each group. Future studies need to look at the larger samples to confirm the stability of this factor structure across neurodevelopmental disorders given that ADHD symptomatology can present differently across diagnoses (Cornish, Scerif, et al., 2007).

Overall, the pattern of results reported in this paper supports research suggesting that attention and activity levels are not homogenous in children with ID. Different trajectories may exist across neurodevelopmental disorders and across development (Cornish & Wilding,

2010; Karmiloff-Smith, 2009). While this study suggests differences in hyperactive and impulsive behaviours across children with ASD, DS and ID, further longitudinal and cross-sectional studies are needed to yield more conclusive findings regarding inattention, hyperactivity, and the differences across known and idiopathic causes of ID. An understanding of these differences would also be beneficial for teachers and school settings as it will enable them to develop strategies and implement interventions to improve learning of students experiencing these difficulties in the classroom, which in turn will enhance long-term outcomes.

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Table 1

Sample Demographics

	Autism (<i>n</i> = 59)	ID (<i>n</i> = 76)	Down Syndrome (<i>n</i> = 41)
Gender <i>n</i> (% male)	48 (81.4)	44 (57.9)	22 (53.7)
Age			
<i>M</i> (SD)	8.98 (2.22)	9.19 (1.94)	9.33 (2.36)
Range	5 – 12	5 – 12	5 – 13
Ethnicity <i>n</i> (% Australian)	40 (67.8)	60 (78.9)	31 (75.6)
Language skills <i>n</i> (%)			
Nonverbal	11 (18.6)	7 (9.2)	6 (14.6)
Short sentences	42 (71.2)	45 (59.2)	29 (70.8)
Fluent	6 (10.2)	24 (31.6)	6 (14.6)
SES ^a			
<i>M</i> (SD)	33.24 (15.32)	33.75 (15.28)	41.65 (16.85)
Range	11 – 69	8 – 69	14 – 69
School attended <i>n</i> (%)			
Mainstream	2 (3.4)	13 (17.1)	12 (29.3)
Special/Special developmental	50 (84.7)	55 (72.4)	26 (63.4)

Split placement ^b	1 (1.7)	7 (9.2)	3 (7.3)
Autism specialist school	2 (3.4)	*	*
Support centre in mainstream school	4 (6.8)	1 (1.3)	*

^aHollingshead scores range from 8 to 71. ^bChildren who spend part of their week in a mainstream school and part of their week in a special school.

Table 2

Scores From Cognitive and Adaptive Living Skills Assessments by Group

		Autism	ID	Down Syndrome
		Mean (SD)	Mean (SD)	Mean (SD)
		Range	Range	Range
WISC-IV	FSIQ	54.43 (8.69)	56.40 (9.05)	43.00 (3.14)†
/WPPSI-III		40 – 70	41 – 70	40 – 49
WISC-IV	VCI	56.35 (10.01)	58.52 (9.16)	50.21 (5.99)**
		45 – 75	45 – 75	45 – 63
	PRI	64.59 (11.28)	62.26 (10.71)	47.95 (3.85)†
		45 – 84	45 – 86	45 – 59
	WMI	58.83 (8.94)	61.67 (9.04)	53.41 (4.74)**
		50 – 77	50 – 88	50 – 65
	PSI	68.17 (11.79)	66.22 (12.17)	52.67 (4.92)†
		50 – 91	50 – 94	50 – 68
WPPSI-III	Verbal	57.23 (7.05)	64.75 (8.39)	53.33 (5.51)*
		49 – 75	53 – 77	48 – 59
	Performance	59.46 (11.11)	64.78 (10.78)	49.67 (3.06)
		47 – 79	49 – 81	47 – 53
VABS-II-T	ABC	52.55 (11.22)	57.93 (9.71)**	51.89 (8.49)
		20 – 70	30 – 74	31 – 63
	Communication	56.27 (10.19)	58.34 (8.25)	56.00 (7.05)
		25 – 74	40 – 74	46 – 72

Socialisation	58.68 (11.59)†	67.14 (9.13)	65.26 (7.49)
	32 – 83	50 – 89	50 – 84
Daily Living	54.45 (11.04)	59.00 (11.01)	50.42 (8.81)**
Skills	21 – 72	30 – 80	36 – 69

Note. WISC-IV = Wechsler Intelligence Scale for Children – Fourth edition; WPPSI-III =

Wechsler Preschool and Primary Scale of Intelligence – Third edition; VABS-II-T =

Vineland Adaptive Behaviour Scales, Second edition – Teacher Rating Form.

* $p < .05$. ** $p < .01$. † $p < .001$.

Table 3.

Internal Consistency of T-SAID Subscales and Total Score Across Diagnostic Groups

	Autism	Down Syndrome	Idiopathic ID
T-SAID	.87	.89	.95
hyperactivity			
T-SAID	.93	.93	.95
inattention			
T-SAID	.95	.91	.93
verbal comm			
T-SAID	.74	.74	.81
follow inst			
T-SAID	.97	.97	.98
total			

Table 4

Beta Coefficients of Regression Analyses for the T-SAID Hyperactivity/Impulsivity and Verbal Communication Subscale Scores

	MIS	PIC	II
Hyperactivity/impulsivity			
Age	-.07†	-.04**	-.03*
Female	-.15	-.11*	-.04
SES	-.01	-.01	.01
Diagnosis (ref: ID)			
Down Syndrome	-.03	.03	-.09
Autism	.16	.11*	.05
Level of ID (ref: mild)			
Moderate ID	.02	-.01	.05
Severe ID	.46†	.24**	.22**
Constant	1.37†	.93†	.45**
Verbal communication			
Age	-.08†	-.03**	-.06†
Female	-.09	-.04	-.05
SES	-.01	-.01	.01
Diagnosis (ref: ID)			
Down Syndrome	.09	.04	.12
Autism	.21*	.08	.14*
Level of ID (ref: mild)			
Moderate ID	.13	.04	.05
Severe ID	.72†	.27†	.36†

Constant	1.60†	.92†	.83†
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Note. MIS = Mean Item Score; PIC = Proportion of Items Checked; II = Intensity Index.

* $p < .05$. ** $p < .01$. † $p < .001$.

CHAPTER 11 GENERAL DISCUSSION

Although previous research exists to support the notion that attention difficulties exist in children with ID, progress in this area has been hampered by issues such as diagnostic overshadowing (Jopp & Keys, 2001; Mason & Scior, 2004); the belief that attention difficulties relate to cognitive deficits rather than being a comorbid diagnosis (Antshel, et al., 2006; Guerin, et al., 2009); and challenges associated with determining mental age thus making it difficult to know whether the child's behaviour is or is not developmentally appropriate (Barkley, 2006a). While neuropsychological research has demonstrated support for differing developmental trajectories across syndromes (Cornish, Scerif, et al., 2007; Cornish & Wilding, 2010; Karmiloff-Smith, 2009), research into the development of rating scales that can screen for and identify difficulties in attention, hyperactivity and impulsivity has been limited, and often studies have had to resort to use of scales designed for typically developing children.

With this background in mind, the present study had three aims: (1) to develop a reliable and valid rating scale that was more sensitive to exploring the range and severity of ADHD symptoms in school-aged children with intellectual disability; (2) that the new rating scale would have good convergent validity with existing measures of ADHD; and (3) to describe and compare the profiles of ADHD symptoms in children with known causes of ID.

11.1 Overview of findings

The findings of Chapter 8 suggested that the T-SAID is a reliable and valid measure of attention and hyperactivity/impulsivity in children with ID. It had excellent internal consistency and strong test-retest reliability. It had strong convergent validity with corresponding subscales on the Conners Third edition (Conners, 2008) and the Developmental Behaviour Checklist – Teacher version (Einfeld & Tonge, 1995, 2002) suggesting that these different scales measured the same construct. It also had moderate divergent validity with the total score on the Vineland Adaptive Behaviour Scales Second

edition - Teacher Rating Form (Sparrow, et al., 2005) suggesting a lack of association between these measures and that they measured different constructs. Good content validity was established via the method of item derivation and use of focus group discussions to develop and evaluate the scale (DeVellis, 2003). Although it was beyond the scope of this study to evaluate the properties of the T-SAID as a screening tool for ADHD, the T-SAID demonstrated discriminant validity across children with a diagnosis of ADHD and those who did not have this diagnosis. Regression analyses suggested that children with severe or profound ID had greater difficulties with attention, hyperactivity and impulsivity, with a broader range of behaviours and greater intensity being exhibited. The findings from this chapter supported the first aim stating that the T-SAID would be a reliable and valid measure of ADHD symptoms in school-aged children with ID. It supported the second aim stating that the scores on the T-SAID would have good convergent validity with existing measures of ADHD. It also supported the first hypothesis, stating that there would be a positive relationship between hyperactivity/impulsivity and degree of ID.

The findings of Chapter 9 suggested that T-SAID had a four factor solution. As expected, *Hyperactivity/Impulsivity* and *Inattention* were extracted, being the two core dimensions of ADHD symptomatology (American Psychiatric Association, 2013). A third subscale, labelled *Verbal Communication*, consisted of items relating to language such as volume and pace of speech, making requests and retaining information. The fourth subscale, labelled *Following Instructions*, contained items relating to instructions and compliance to rules. The internal consistency of these subscales was good to excellent. The extraction of four factors suggested that given children with ID may present with additional complexities, such as limited or no language or a physical disability, the nature of ADHD symptoms may present quite differently within this population as compared with typically developing

children. The findings from this chapter supported the first aim stating that the T-SAID would be a reliable and valid measure of ADHD symptoms in school-aged children with ID.

The findings of Chapter 10 suggested that children with autism spectrum disorder (ASD) displayed a significantly greater breadth of hyperactive/impulsive behaviours than children with idiopathic ID or Down Syndrome. Children with ASD also had significantly greater difficulties with behaviours that made up the *Verbal Communication* subscale than children with Down Syndrome or idiopathic ID, and that the intensity of these behaviours was also significantly greater. In the sample used in this study, the T-SAID was able to detect differences in hyperactivity/impulsivity across groups but the Conners Third edition (Conners, 2008) was unable to do so. These findings supported the third aim stating that the T-SAID would be able to describe and compare differences in ADHD symptomatology in children with ID. The findings from this chapter supported the third hypothesis. Higher levels of hyperactivity/impulsivity were reported in the ASD group. The findings from this chapter did not support the second hypothesis. While the Down Syndrome group had lower levels of hyperactivity/impulsivity, there were no differences between the Down Syndrome and idiopathic ID groups. Further, there were no group differences for inattention.

11.2 Points raised in Phase 1 of the study

The aim of the focus group discussions conducted in Phase 1 this study was twofold: a) to collect a list of behaviours from teachers and health professionals exhibited by children with attention difficulties and ID; and b) to obtain comments and feedback regarding the development of a new rating scale. The majority of themes generated from these discussions were consistent with those identified in previous observational studies, research and diagnostic manuals regarding attention difficulties within this population. However, some of the issues were specifically related to different professions which highlighted the value of exploring these issues with both teachers and health professionals.

Teachers identified and discussed more externalising behaviours i.e., hyperactivity and impulsivity, and fewer behaviours relating to inattention. This is consistent with research which suggests that ADHD – predominantly inattentive subtype is underdiagnosed, and that teachers are less likely than parents to report and/or identify inattentive behaviours consistent with ADHD (Murray, et al., 2007). This could be due to a number of reasons. In a busy classroom, it is likely that externalising behaviours will take up more of a classroom teacher's time and attention in trying to manage and/or minimise the impact these behaviours have on other students and their teaching. Children who are displaying inattentive behaviours such as staring off into space or taking a considerable amount of time to complete their work may be less likely to draw the attention of their teacher, or depending on the composition of students in the classroom may even escape their notice for long periods of time. Alternatively, teachers may observe these problem behaviours but perceive them as less severe as they are less disruptive to the learning of other students or the flow of the classroom in general. This highlights the importance of making teachers more aware of the problem of inattention in the classroom – both through improved identification and greater understanding of the impact it has on students. Even though these behaviours may not be as readily observable or disruptive to others compared with externalising behaviours, they can still have a significant impact on individual student outcomes and achievement.

Even experienced teachers within the focus groups sometimes had difficulty distinguishing behaviours that were specific to children with ID who had attention difficulties and those that were characteristic of children with ID generally. This raises the issue of the importance of educating teachers about children with ID who display ADHD symptoms so that they can become better at identifying them (irrespective of whether diagnosis is warranted) and tailoring their teaching to meet the needs of these students.

Issues of medication were also discussed briefly by both groups of teachers and one group of health professionals. These issues reflected the same challenges faced by families of typically developing children and adolescents with ADHD: parental concerns regarding giving their child medication; compliance issues with children; and the impact of side-effects (e.g., a child having to miss half of lunch time because the medication suppresses their appetite and therefore it takes them a long time to eat their lunch). The fact that medication was discussed illustrates that some children within their schools have received a diagnosis of ADHD and are being treated for it. This is encouraging to note, given comorbid psychopathology can be undiagnosed among individuals with ID due to diagnostic overshadowing (Jopp & Keys, 2001; Mason & Scior, 2004).

11.3 Strengths of the present study

11.3.1 Scale development

One of the main strengths of this study was the rigour with which the rating scale was developed, using the framework described by DeVellis (2003). Drawing upon behavioural data from past research, a review of existing rating scales, an examination of diagnostic manuals developed for individuals with ID and those who are typically developing, and consultation with teachers and health professionals ensured that the T-SAID contains items that are valid indicators of difficulties with attention, impulsivity and hyperactivity within this population.

At the individual item level, the T-SAID describes behaviours that provide richer information than vague, non-specific items such as *Restless* or *Overactive* which do little to describe specific difficulties to a health professional who may not have the opportunity to conduct observations of the child across settings. This information could then contribute to the formulation of behaviour management plans, strategies and interventions that address these specific difficulties.

11.3.2 Sample

Another strength of this study was in the breadth of the community sample. The socioeconomic status of families ranged from very low (e.g., single parent families with the parent being a full-time carer to one or more children with a disability) to high (e.g., dual income families with both parents in professional jobs). Families also came from a range of cultural backgrounds, with approximately one quarter identifying as being an ethnicity other than Australian. Recruitment would have been dependent, however, upon families being able to read the plain language statement sent home with their child. Families with English as a first language would therefore be more likely to respond to requests for research participation. Resources precluded the plain language statements being translated into other languages, but this may be one strategy that could be used in future research to ensure the sample is more representative of children in the community.

11.3.3 Teachers as informants

A third strength of the study is in the value of developing a teacher rating scale to measure attention difficulties. Teachers, unlike parents, have the opportunity to observe large groups of children working in the classroom. They can draw on behaviours they have observed both in the present cohort of students being taught and past students, and can use this information to make inferences about what behaviours deviate from the norm (Gadow, et al., 2006). Teachers are also exposed to the behaviour of their students for long periods of time (i.e., all day, 5 days a week) encompassing cognitively demanding tasks such as following instructions, maintaining attention, and engaging in prescribed activities where an outcome is expected, and activities encompassing creativity and play. This may contrast with the home environment of some children who engage in less goal-directed activities or free play where there may be fewer opportunities to observe such difficulties (Murray, et al., 2007).

11.4 Limitations of the present study

11.4.1 Focus group data

One of the limitations of the present study was in the use of focus groups to facilitate the identification of behaviours and to obtain their feedback on the new rating scale. Although it has been recognised that focus groups can encourage an exploration of issues that may not be presented in a one-on-one interview format (Vogt, King, & King, 2004), participation in the discussions was uneven at times. The facilitator monitored participation of the group members and elicited comments from those teachers and health professionals who had made a lesser contribution to the discussion, but it is possible that the issues presented and discussed were a product of the more articulate or dominant group members to the neglect of the viewpoints of more inhibited or reflective members.

The possibility of selection biases in the composition of the focus group participants is another potential limitation of this study. Teachers or health professionals who believed that attention difficulties are present in all children with ID may have been less likely to participate in a focus group discussion. Those who have had limited contact with such children may have felt that they had little to offer to a discussion about these issues. The transcript analysis revealed that the behaviours identified and opinions expressed regarding the rating scale items were quite heterogeneous, however, and thus the extent of selection bias or its impact on the findings is unclear.

While there are no straightforward tests for ensuring that qualitative research is reliable and valid, guidelines exist (Pyett, 2003) and every effort was made to adhere to these in conducting the focus groups and analysing the data. The focus group participants comprised teachers, psychologists and paediatricians. The diversity of the experience which these participants brought to the focus groups, and their knowledge of students with ID who experience attention difficulties, was important for a number of reasons. The diversity of

professions ensured that interviewer bias did not occur which may have precluded the consideration of important information or unique perspectives. The recruitment of teachers ensured that behaviours typically observed in the classroom were reported, enhancing the face validity of the T-SAID for the population for whom the scale was being designed. The recruitment of psychologists and paediatricians ensured that the items had diagnostic relevance and also enabled the collection of data on behaviours that may be highly relevant but observed and/or reported less frequently by teachers.

11.4.2 Respondents

Even though the present study has reported some preliminary findings suggesting differences in hyperactivity/impulsivity across neurodevelopmental disorders, it should be noted that a rating scale alone is insufficient to draw conclusions about these difficulties, and should be used in conjunction with developmental history, parent ratings, behavioural observations and results from neuropsychological tests (e.g., Wilding Monster Card Sorting task; Wilding, et al., 2001) in line with diagnostic guidelines (Barkley, 2006c). Future research using the T-SAID may benefit from collecting multiple sources of data to draw firmer conclusions about profiles and developmental trajectories of attention and activity.

While convergent validity of the T-SAID was measured by asking teachers to complete several rating scales that measured ADHD symptoms, it would have been useful to include one or more additional methods of assessing attention and hyperactivity/impulsivity such as a structured diagnostic interview or behavioural observations. Future research could compare additional methods of assessing attention profiles with the SAID to confirm whether it appears to be assessing the intended constructs.

Further consideration must also be given to the validity of the T-SAID for children with severe/profound ID who may have scored on some of the items due to their degree of disability rather than presence of ADHD symptoms. This was addressed somewhat in the

factor structure presented as the items which inferred a need for verbal ability clustered together onto the *Verbal Communication* factor. This recognised that verbal skills cannot be assumed among children with ID, as children with certain neurodevelopmental disorders (e.g., autism spectrum disorder) and/or severe/profound ID may be nonverbal. Another alternative could be to consider separate factor structures for children who are verbal or nonverbal, similar to the approach taken by Burbidge and colleagues (2010) for children with severe/profound ID who had communication and/or mobility issues.

11.4.3 Medication for ADHD

For those children with a diagnosis of ADHD who were taking medication, information on their dosage and compliance was not formally collected or monitored, and was dependent upon parent report. The study was also unable to control for medication type or length of time child had been on the medication. Medication may have modulated the frequency and intensity of behaviours observed and reported by teachers, but given the aim of this study was not to examine the effect of medication, this would not have impacted on the psychometric properties reported in Papers 1 and 2. It is worth noting, however, that only 20 children had a diagnosis of ADHD and two thirds of these were currently taking medication. Interactions between medication and observed behaviour may have potentially reduced the rates of symptomatology in the groups compared in Paper 3, but given these children represented such a small proportion of the groups or total sample they are likely to have had only a minimal impact on the findings.

11.4.4 Diagnoses of children

The present study was unable to verify the accuracy of diagnosis for some children at the time of recruitment to the study e.g., children recruited who were identified by their parents as having idiopathic ID but may have had ASD. Resources precluded the use of a gold standard screening instrument such as the Autism Diagnostic Observation Schedule

(ADOS; Lord, Rutter, DiLavore, & Risi, 1999) which may have identified some of these children as having ASD. Further, the screening instrument that was administered in the present study (i.e., the Social Communication Questionnaire; Rutter, Bailey, et al., 2003) was only administered to families of children with ASD, rather than being given to all families. However, given the high rate of awareness of autism and autism symptoms, it is likely that the rates of such undiagnosed cases of ASD were very low. Given that diagnostic accuracy was not one of the aims of this study, this limitation would not have impacted on the analyses of the psychometric properties of the T-SAID.

11.5 Directions for future research

11.5.1 Development of other versions

The most important direction for future research is the evaluation of the SAID using other informants, such as parents. While inter-rater reliability of parents and teachers when rating behaviour problems is noted across the literature as a significant challenge (Lavigne, Dulcan, LeBailly, & Binns, 2012; Wolraich, et al., 2004), the use of rating scale data from multiple informants is considered best practice when screening for ADHD symptoms (Barkley, 2006c), so this would be a necessary next step.

The development of a version of the SAID to identify difficulties with attention, hyperactivity and impulsivity in preschool-aged children is also needed. Research from the field of neuropsychology has described attention difficulties in toddlers and young children with neurodevelopmental disorders such as Williams Syndrome (Cornish, Scerif, et al., 2007; Scerif, et al., 2004) and Down Syndrome (J. H. Brown, et al., 2003). It is therefore clear that a reliable and valid, disability specific rating scale would be a useful and necessary tool for research into this population. Early identification and intervention may help minimise the impact these difficulties have on learning once children commence school.

11.5.2 Independent validation of the psychometric properties

Future research is needed to examine the psychometric properties of the T-SAID and to confirm or modify the factor structure identified in the present study, particularly given the modest sample size of this study. Independent studies are also needed to give further support to the reliability and validity of the scale. Given the clinical importance of obtaining information about attention and hyperactivity/impulsivity difficulties from multiple sources when making diagnostic decisions (Barkley, 2006c), further development and examination of the parent version of the scale (P-SAID) is also needed.

Preliminary results suggest that the T-SAID may have the ability to discriminate between children who have ADHD and those who do not, although its efficacy as a screening tool is yet to be evaluated. It should be noted, however, that in this study the ADHD diagnosis was determined via parent report only. An urgent area for future research is therefore to examine the validity of the T-SAID in a larger sample of children with a confirmed clinical diagnosis of ADHD. As the majority of clinicians use rating scales when considering this diagnosis (Chan, et al., 2005), further evidence supporting the efficacy of the T-SAID would make it a useful screening tool for clinicians when working with children who have ID.

11.5.3 Examining attention profiles in other neurodevelopmental disorders

Another direction for future research would be to examine the robustness of the T-SAID to identify attention and activity profiles across a wider range of neurodevelopmental disorders. Evidence suggests that different profiles and developmental trajectories may also exist across other syndromes including Klinefelter (Lo-Castro, D'Agati, & Curatolo, 2011) and DiGeorge Syndromes (Lo-Castro, et al., 2011). Understanding the differences (and commonalities) across syndromes would be beneficial to clinicians in their development of treatment, medication and intervention plans for these children. They could also be beneficial

to teachers of these children in their development of individual learning and behaviour management plans. Exploration of the T-SAID across a wide range of neurodevelopmental disorders would provide further evidence for the utility of this scale which has been developed specifically for children with ID.

11.6 Concluding remarks

The findings of our study suggest that the Scale of Attention in Intellectual Disability – Teacher version (T-SAID) is a reliable and valid measure for children aged 5 to 13 years with mild to profound ID. Further research is needed to ascertain its reliability and validity in older children/adolescents and its use among children who are nonverbal. Factor analysis extracted four subscales from the items developed: *Inattention*, *Hyperactivity/Impulsivity*, *Following Instructions* and *Verbal Communication*. Examination of the subscales across diagnoses suggests that the T-SAID may have the capacity to tease out differences across neurodevelopmental disorders. This would need to be verified, however, by further research combining this information with other sources such as behavioural observations, interviews and neuropsychological measures of attention.

Potential applications of the T-SAID in future research include use in clinical or neuropsychological studies examining ADHD symptomatology, and among clinicians to assist with screening for ADHD. The T-SAID could also be used in school settings by psychologists and teachers to inform the development of strategies and behaviour management plans that can target specific areas of difficulty in any of these areas. The intended outcome of its use in any of these settings is to improve the functioning and learning outcomes of children experiencing these difficulties, which will in turn enhance their long-term outcomes at home, in the classroom and in the general community.

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APPENDIX A: Focus group discussion outline

- Small group brainstorming exercise (4-5 students in each group)

Think about students you have worked with, both currently and in the past, who have had difficulties with hyperactivity, impulsivity, and paying attention in the classroom. What sort of behaviours come to mind? What behaviours stand out that make them different from other students with an intellectual disability?

Allow small groups to brainstorm their ideas and write them out on sheets of butcher's paper. Come back as a large group with a spokesperson from each group sharing their ideas. One of the moderators guides the discussion while the other one lists the behaviours named on the whiteboard. What are the similarities between groups? Differences?

- Focus group questions

We are developing the attached rating scale as part of our study. We have called it the Scale of Attention in Intellectual Disability, or SAID. We would like you to read the items that make up this scale and consider the following questions.

1. When reading each item:
 - a. Is it clearly written?
 - b. Do you understand the behaviour that you are being asked to rate?
 - c. Can you think of a way that this behaviour could be expressed better?
 - d. Do you think this item is needed on the rating scale?
 - e. Is the item redundant? Are there other items that appear to be asking the same thing?
2. Are there any behaviours that we have omitted that you think should be included as an item in this rating scale?
3. Given that this scale has been developed to be completed by teachers, do you think that they will be able to complete this rating scale?

Please feel free to write on the rating scale or make comments on a separate piece of paper. Any feedback you can give will be helpful.

APPENDIX B: The Scale of Attention in Intellectual Disability

Some students with developmental disabilities have problems with their attention, impulsivity, and hyperactivity. These issues can interfere with learning.

By completing this checklist, you will help us learn more about these problems. This will assist us to know how the student might respond to help.

Please rate each item based on your *general impression* of this student over the past month, and whether the student exhibits this behaviour *independently*, without assistance from a teacher or teacher's aide. Please circle the **2** if you have observed the behaviour **often** in this student. Circle **1** if you have **sometimes** observed the behaviour. If you have **never** or **rarely** observed the behaviour in this student circle the **0**.

0 = never or rarely 1 = sometimes 2 = often

If the student is unable to perform an item, circle the **0**. For example, if the student is unable to talk, then for the item "Speaks at a reasonable pace" circle the **0**.

Underline any behaviour you are particularly concerned about

Office Use Only	Please Circle			
1. ③	0	1	2	Asks before joining in a game (avoids butting in or trying to take over the game).
2. ③	0	1	2	Asks before taking or touching a pencil, toy or something belonging to another person (avoids grabbing things without asking).
3.	0	1	2	Avoids making the same mistake when corrected once.
4. ②	0	1	2	Can concentrate for 2 minutes when given an activity to do (does not become fatigued; avoids getting distracted or disengaged).
5. ②	0	1	2	Can easily give his/her attention to start a new task.
6. ②	0	1	2	Can finish work within a reasonable time limit.
7. ②	0	1	2	Can maintain attention without requiring rewards or praise.
8. ③	0	1	2	Can recall the main points in a short story that has been read aloud.
9. ④	0	1	2	Can understand and carry out a simple, two-part instruction (e.g., Take off your shoes and sit on the floor).
10. ③	0	1	2	Can verbally repeat back an instruction that has one step and does not require instruction repeated (e.g., Get your hat).
11. ③	0	1	2	Can verbally repeat back an instruction that has two steps and does not require instruction repeated (e.g., Get your bag and sit down).
12. ②	0	1	2	Completes one activity or task before moving on to another (avoids moving between tasks without completing any of them).
13. ②	0	1	2	Completes work with reasonable accuracy if work given is within his/her ability.
14.	0	1	2	Keeps hands still while participating in a short classroom task or listening to a story (does not excessively fidget, tap, fiddle or pick).

0 = never or rarely 1 = sometimes 2 = often
Underline any behaviour you are particularly concerned about

15. ①	0	1	2	Keeps hands to self when working in a group activity (does not poke or touch others).
16. ②	0	1	2	Keeps legs and feet still while participating in a short classroom task or listening to a story (does not excessively swing legs or rock on chair).
17. ①	0	1	2	Keeps legs and feet to self when working in a group activity (does not kick others).
18.	0	1	2	Keeps track of personal possessions (e.g., coat, lunch box, pencil case).
19. ②	0	1	2	Maintains attention when a topic is perceived as very interesting.
20.	0	1	2	Pays attention when spoken to directly (looking in teacher's direction, body turned towards teacher).
21. ②	0	1	2	Persists with a task for 2 minutes even if they find it difficult (avoids giving up).
22. ①	0	1	2	Plays quietly when they have free time inside (keeps noise down to a minimum).
23.	0	1	2	Remains calm (avoids getting agitated) when changing from one activity or place to another.
24. ②	0	1	2	Returns attention to task after being distracted by another student.
25.	0	1	2	Shows responsibility for own safety when indoors (e.g., avoids jumping off furniture).
26.	0	1	2	Shows responsibility for own safety when outdoors (e.g., avoids climbing trees or walls when they might not be able to get down again).
27.	0	1	2	Slows down to a walking pace if asked to do so.
28. ③	0	1	2	Speaks at a reasonable pace (can be understood, words do not run together).
29. ③	0	1	2	Speaks at a reasonable volume (not too loud or so soft that cannot be heard).
30. ①	0	1	2	Stays in own seat when expected to.
31. ③	0	1	2	Stays on topic when talking.
32.	0	1	2	Stays with group (e.g., avoids running or wandering off when on an excursion).
33. ④	0	1	2	Stays within school grounds during the day (avoids climbing the fence, running out the school gate, or attempting to leave the grounds).
34.	0	1	2	Takes his/her turn when doing group work in the classroom.
35. ①	0	1	2	Takes turns when playing with others.
36. ④	0	1	2	Understands instructions that have 10 words or less.
37. ①	0	1	2	Waits for his/her turn to talk during a conversation (avoids interrupting).
38. ①	0	1	2	Waits patiently in a line (e.g., when queuing for the toilet, when waiting to get on the bus).
39. ③	0	1	2	Waits until a question is finished before giving an answer.
40. ①	0	1	2	Waits until called on by the teacher before giving an answer (avoids calling out).
41. ①	0	1	2	Walks rather than runs from room to room when indoors.
42. ④	0	1	2	When given one simple instruction, can understand it and carry it out (e.g., Get your bag).
43. ②	0	1	2	When participating in a class activity, does not get easily distracted (e.g., outside noises, sudden noises).
44.	0	1	2	Works quietly during specific class activities (avoids humming, singing, talking to self or other throat noises).

APPENDIX C: Letter to principals explaining study

Dear Principal,

We are supervising a student research project on attention and activity profiles of children with different developmental disabilities. The student researcher is Nerelie Freeman who is currently undertaking a Doctor of Philosophy (Ph.D) degree. We are hoping to gain a better understanding of the attention strengths and weaknesses of children with an intellectual disability, autism, Down Syndrome, Fragile X Syndrome and Williams Syndrome. There are currently no measures to assist with assessing the attention difficulties of children with an intellectual disability. The development of parent and teacher questionnaires will assist in evaluating the attention difficulties that some children may experience.

We wish to involve children from your school. Participation in the study comprises first seeking permission from yourself. If you give permission, the student researcher will then send information in the mail advertising the study in the form of posters and a brief notice you might include in your school newsletter. Consent forms and explanatory statements will also be provided.

Children with parental consent will be administered a cognitive (IQ) assessment. If they have already had this assessment in the last two years, another one will not be conducted and the previous assessment scores will be used. If a child is given an assessment, the family will be provided with a report on the results. The results from this assessment could be used for the child's next Program for Students with Disabilities (PSD) review if it is coming up in the next two years. We hope that you will allow us to assess these children during school hours. We will provide all letters and materials needed for the study.

The assessment will take approximately 60-75 minutes. The student researcher or a research assistant will administer the assessment tasks. The student researcher is a registered psychologist and has had 5 years' experience working as a school psychologist, so she is experienced in administering and interpreting assessments.

If the assessment(s) indicate that the child is eligible to participate, their classroom teacher will be asked to fill out questionnaires which ask about the child's behaviour, attentional difficulties and their daily living skills. This will take approximately 75 minutes and will be completed individually in the teacher's own time, or they can be completed with the student researcher on request.

The *Vineland Adaptive Behaviour Skills – Second edition, Teacher Rating Form (VABS-II)* is a general assessment of adaptive behaviour examining the child's socialisation, communication and daily living skills. If the child has had a VABS completed in the last 2 years, the teacher will not be required to fill this out and the previous assessment scores will be used.

The *Scale of Attention in Intellectual Disability – Teacher Form* is a rating scale developed by the research team for this study. It comprises 46 items relating to inattention, hyperactivity, impulsivity and working memory.

The *Conners Rating Scales – Third edition* is a rating scale comprising 39 items which measures ADHD symptoms, conduct disorder and oppositional defiant disorder.

The *Developmental Behaviour Checklist – Teacher* is a questionnaire comprising 96 items which measures behavioural and emotional problems in children with a developmental delay.

A copy of the rating scales listed above can be sent to you on request.

All information provided by the student and teacher, and the scores obtained in the study, will be strictly confidential. Participating families may withdraw within 8 weeks of participating in the assessment phase of the study. We will not be analysing individual responses, rather the group as a whole. When the study is complete, a report will be made available to you. We wish to point out that this project has received ethics clearance from the Human Research Committee of Monash University and the Department of Education and Early Childhood Development (see attached approval letters).

If you have any queries whatsoever regarding this project, please feel free to contact Ms Nerelie Freeman or Dr Kylie Gray on 9594-1301 or by email at [REDACTED]. The student researcher will follow up this letter with a phone call in a couple of weeks, and would be happy to come to your school if you would like to discuss this project in more detail.

Yours sincerely,

Professor Kim Cornish
Head of School

Dr Kylie Gray
Senior lecturer

Ms Nerelie Freeman
Ph.D candidate

School of Psychology and Psychiatry
Monash University

APPENDIX D: Parent/Guardian Consent Form

Centre for Developmental Psychiatry & Psychology, Monash University

Title: Attention and activity profiles in children with different developmental disabilities
Conducted by: Dr Kylie Gray, Professor Kim Cornish, and Nerelie Freeman

PARENT / GUARDIAN CONSENT FORM

I	Print name
of	Address
	Contact number

has been asked to participate in the research project entitled 'Attention and activity profiles in children with different developmental disabilities' being conducted by Dr Kylie Gray, Professor Kim Cornish, and Nerelie Freeman and involving myself, my child's classroom teacher, and my child:

Name of child	Date of birth
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I give voluntary consent for my son/daughter for whom I am the guardian to participate in the above Monash University project. I have had the project explained to me, and I have read the Explanatory Statement, which I will keep for my records. I understand that the research study will be carried out in a manner conforming with the principles set out by the National Statement on Ethical Conduct in Research Involving Humans, and further that:

1. I understand the general purposes, methods, demands and benefits and possible risks, inconveniences and discomforts of the study as outlined in the 'Parent/Guardian Information Sheet' that has been given to me.
2. Although I understand that the purpose of this research project is to improve the quality of care, it has also been explained that my involvement may not be of any direct personal benefit to me or my son/daughter/person for whom I am the guardian.
3. My participation in the research study is voluntary, and I am free to withdraw at any time, and to continue receiving appropriate treatment for my son/daughter/person for whom I am the guardian, as will be the case if I do not volunteer to enter the study.
4. I have been given the opportunity to ask questions in relation to the research study, and I have received all the information and explanations I have requested.
5. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

Parent / guardian signature

Signature	<input type="text"/>	Date	<input type="text"/>
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APPENDIX E: Parent/Guardian Explanatory Statement

Title: Attention and activity profiles in children with different developmental disabilities

This information sheet is for you to keep.

My name is Nerelie Freeman and I am conducting a research project with Professor Kim Cornish, Head of Discipline, and Dr Kylie Gray, Senior Lecturer, in the Department of Psychology and Psychiatry towards a PhD at Monash University. This means that I will be writing a thesis which is the equivalent of a 300 page book.

I am looking for male and female students aged between 5 and 12 years who are attending school and have a diagnosis of: an intellectual disability, autism spectrum disorder (not Asperger Syndrome or high-functioning autism), Fragile X Syndrome, Down Syndrome or Williams Syndrome.

Aim/purpose of the research

The aim of this study is to develop a new rating scale that will examine the behaviours associated with attention-deficit hyperactivity disorder (ADHD) specific to students with an intellectual disability. It also aims to describe any differences in ADHD that may exist across children with different known causes of intellectual disability.

Possible benefits

There are currently no well-validated measures to assist with assessing the attention and activity profiles of children with an intellectual disability. The development of a teacher questionnaire will assist in evaluating the attention strengths and difficulties that some children may experience. The findings of this research will assist educators and health professionals in their understanding of the attention profiles of children with an intellectual disability, and this may enable them to tailor learning programs, treatments and interventions that are more specific to the needs of these children.

What does the research involve?

A cognitive (IQ) assessment will be completed if your child has not had one in the last two years. If it is not possible to conduct an assessment with your child, alternative results will be used such as those from an adaptive living skills assessment. The assessment will be done at school at a time negotiated with staff and will take approximately 60-75 minutes. If your child has had an assessment in the last two years, their previous assessment results will be used. If your child is given an assessment, you will be provided with a report on the results. These results may be of use to professionals involved in the care of your child. Copies of reports for other professionals will only be provided with your consent.

If your child has autism, you will be asked to fill out a questionnaire which asks about your child's communication and socialisation skills. This will take approximately 10 minutes. If your child has another diagnosis, you will not be required to fill out any questionnaires. Your child's classroom teacher will also be asked to fill out questionnaires which ask about your child's behaviour, attentional difficulties and their daily living skills. This will take approximately 45 minutes.

If any specific difficulties or problems are identified, a referral to appropriate services will be arranged. If you express any concerns or need any help, this will also be arranged.

If you agree to be a part of this project, please complete the attached consent form. A member of our research team will then contact you about the project. You can return the form to us in the reply paid envelope which is attached to the form. No stamp is necessary.

Inconvenience/discomfort

There is no risk of physical or psychological harm in the study. If any specific difficulties or problems are identified, a referral to appropriate services will be arranged. If you have any concerns, questions, or need any help please feel free to directly contact Ms Nerelie Freeman or Dr Kylie Gray (contact details below).

Voluntary participation

Being in this study is voluntary and you are under no obligation to consent to participation. However, if you do consent to participate, you may only withdraw within 8 weeks of participating in the assessment phase of the study. Whether you take part or not, it will not make any difference to the funding or services which your child or your family currently receives.

Confidentiality

Data on computers is securely stored and deidentified (names are not used). Only the research team will have access to the data. There will be nothing in any reports of the study that could identify individual children or families. Reports on the study will be submitted for publication, but individual participants will not be identifiable in such reports. Participation in this project is voluntary. You are free to withdraw from the project within 8 weeks of participating in the assessment phase of the study.

Storage of data

Storage of the data collected will adhere to the University regulations and kept on University premises in a locked cupboard/filing cabinet for 5 years. Only the research team will have access to the data. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Results

If you would like to be informed of the aggregate research finding, please contact Dr Kylie Gray (see details below). The findings will be available from December 2012.

If you would like to contact the researchers about any aspect of this study, please contact:	If you have a complaint concerning the manner in which this research is being conducted, please contact:
Ms Nerelie Freeman or Dr Kylie Gray Centre for Developmental Psychiatry & Psychology Monash Medical Centre 246 Clayton Rd Clayton VIC 3168 [REDACTED] [REDACTED] [REDACTED] [REDACTED]	Executive Officer, Human Research Ethics Monash University Human Research Ethics Committee (MUHREC) Building 3e Room 111 Research Office Monash University VIC 3800 [REDACTED] [REDACTED] [REDACTED]

Thank you for taking the time to assist us with our research project.

Dr Kylie Gray

Prof Kim Cornish

Nerelie Freeman

APPENDIX F: Item-Total Correlations Table for T-SAID Items

Item number	Item-Total correlation
1	.59
2	.63
3	.65
4	.65
5	.68
6	.72
7	.70
8	.68
9	.72
10	.62
11	.74
12	.70
13	.70
14	.63
15	.78
16	.76
17	.66
18	.72
19	.75
20	.71
21	.70
22	.69

23	.65
24	.61
25	.66
26	.74
27	.78
28	.75
29	.77
30	.77
31	.72
32	.69
33	.72
34	.73
35	.76
36	.68
37	.48
38	.45
39	.16
40	.51
41	.56
42	.67
43	.67
44	.71
45	.69
46	.65

APPENDIX G: Inter-Item Correlations Table for T-SAID Items

Item number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
1	–	.47	.32	.53	.47	.47	.41	.43	.51	.52	.50	.39	.49	.40	.46	.29	.30	.37	.41	.47	.44	.40	.36	.40	.52	.49	.47	.40
2	.47	–	.69	.41	.42	.46	.38	.38	.46	.35	.45	.42	.46	.37	.44	.59	.45	.43	.43	.47	.33	.37	.39	.34	.43	.53	.50	.48
3	.32	.69	–	.41	.44	.44	.44	.40	.40	.42	.41	.40	.41	.38	.50	.71	.42	.48	.41	.44	.35	.37	.37	.38	.39	.48	.51	.50
4	.53	.41	.41	–	.64	.54	.47	.50	.44	.54	.51	.38	.53	.40	.49	.42	.37	.44	.50	.39	.45	.45	.37	.39	.63	.53	.57	.50
5	.47	.42	.44	.64	–	.59	.47	.42	.41	.48	.49	.39	.55	.36	.49	.48	.46	.47	.49	.48	.38	.48	.41	.30	.52	.52	.57	.48
6	.47	.46	.44	.54	.59	–	.63	.66	.60	.44	.58	.46	.54	.49	.54	.49	.50	.58	.56	.45	.55	.45	.42	.43	.52	.56	.61	.43
7	.41	.38	.44	.47	.47	.63	–	.77	.63	.50	.61	.49	.55	.55	.56	.51	.42	.50	.64	.47	.59	.45	.39	.54	.48	.54	.60	.49
8	.43	.38	.40	.50	.42	.66	.77	–	.67	.50	.60	.55	.60	.56	.55	.46	.40	.50	.63	.48	.58	.48	.43	.43	.46	.56	.55	.47
9	.51	.46	.40	.44	.41	.60	.63	.67	–	.54	.59	.59	.66	.51	.59	.48	.48	.54	.66	.55	.59	.45	.43	.50	.45	.56	.57	.49
10	.52	.35	.42	.54	.48	.44	.50	.50	.54	–	.46	.40	.73	.39	.42	.45	.38	.38	.46	.40	.47	.39	.37	.38	.51	.47	.52	.47
11	.50	.45	.41	.51	.49	.58	.61	.60	.59	.46	–	.72	.53	.52	.67	.50	.52	.63	.70	.64	.66	.59	.58	.55	.53	.53	.56	.50
12	.39	.42	.40	.38	.39	.46	.49	.55	.59	.40	.72	–	.51	.46	.64	.49	.47	.58	.67	.53	.60	.62	.60	.54	.48	.54	.51	.55

13	.49	.46	.41	.53	.55	.54	.55	.60	.66	.73	.53	.51	–	.48	.51	.45	.48	.42	.55	.46	.52	.45	.45	.37	.53	.52	.62	.47
14	.40	.37	.38	.40	.36	.49	.55	.56	.51	.39	.52	.46	.48	–	.62	.51	.34	.43	.53	.43	.50	.32	.36	.42	.48	.49	.55	.42
15	.46	.44	.50	.49	.49	.54	.56	.55	.59	.42	.67	.64	.51	.62	–	.65	.51	.64	.67	.61	.64	.63	.62	.50	.49	.52	.60	.54
16	.29	.59	.71	.42	.48	.49	.51	.46	.48	.45	.50	.49	.45	.51	.65	–	.59	.57	.55	.55	.48	.53	.51	.43	.41	.60	.60	.63
17	.30	.45	.42	.37	.46	.50	.42	.40	.48	.38	.52	.47	.48	.34	.51	.59	–	.60	.52	.53	.49	.48	.46	.31	.33	.40	.43	.59
18	.37	.43	.48	.44	.47	.58	.50	.50	.54	.38	.63	.58	.42	.43	.64	.57	.60	–	.58	.61	.54	.56	.57	.46	.40	.50	.51	.54
19	.41	.43	.41	.50	.49	.56	.64	.63	.66	.46	.70	.67	.55	.53	.67	.55	.52	.58	–	.66	.75	.59	.57	.63	.51	.54	.58	.57
20	.47	.47	.44	.39	.48	.45	.47	.48	.55	.40	.64	.53	.46	.43	.61	.55	.53	.61	.66	–	.60	.56	.58	.46	.39	.45	.52	.54
21	.44	.33	.35	.45	.38	.55	.59	.58	.59	.47	.66	.60	.52	.50	.64	.48	.49	.54	.75	.60	–	.52	.58	.65	.47	.48	.55	.52
22	.40	.37	.37	.45	.48	.45	.45	.48	.45	.39	.59	.62	.45	.32	.63	.53	.48	.56	.59	.56	.52	–	.74	.51	.44	.50	.44	.50
23	.36	.39	.37	.37	.41	.42	.39	.43	.43	.37	.58	.60	.45	.36	.62	.51	.46	.57	.57	.58	.58	.74	–	.53	.43	.42	.40	.43
24	.40	.34	.38	.39	.30	.43	.54	.43	.50	.38	.55	.54	.37	.42	.50	.43	.31	.46	.63	.46	.65	.51	.53	–	.51	.48	.55	.44
25	.52	.43	.39	.63	.52	.52	.48	.46	.45	.51	.53	.48	.53	.48	.49	.41	.33	.40	.51	.39	.47	.44	.43	.51	–	.58	.58	.53
26	.49	.53	.48	.53	.52	.56	.54	.56	.56	.47	.53	.54	.52	.49	.52	.60	.40	.50	.54	.45	.48	.50	.42	.48	.58	–	.68	.61

27	.47	.50	.51	.57	.57	.61	.60	.55	.57	.52	.56	.51	.62	.55	.60	.60	.43	.51	.58	.52	.55	.44	.40	.55	.58	.68	–	.65
28	.40	.48	.50	.50	.48	.43	.49	.47	.49	.47	.50	.55	.47	.42	.54	.63	.59	.54	.57	.54	.52	.50	.43	.44	.53	.61	.65	–
29	.42	.55	.54	.51	.52	.53	.57	.48	.53	.57	.53	.51	.51	.44	.56	.61	.58	.58	.58	.56	.56	.49	.44	.50	.55	.63	.67	.80
30	.48	.43	.44	.41	.54	.63	.51	.55	.60	.47	.57	.54	.52	.58	.64	.58	.52	.57	.53	.57	.57	.48	.49	.36	.51	.60	.67	.61
31	.46	.41	.40	.37	.54	.57	.45	.52	.55	.40	.51	.48	.54	.52	.57	.53	.52	.57	.50	.56	.49	.45	.47	.33	.43	.53	.63	.55
32	.45	.45	.43	.42	.45	.53	.48	.51	.61	.46	.54	.54	.58	.53	.60	.49	.40	.49	.51	.50	.50	.43	.39	.42	.50	.52	.58	.48
33	.51	.63	.51	.49	.51	.57	.48	.48	.55	.49	.46	.47	.57	.43	.44	.60	.52	.50	.48	.43	.41	.46	.42	.43	.53	.76	.58	.55
34	.50	.58	.52	.49	.52	.48	.45	.43	.56	.46	.48	.48	.53	.40	.48	.61	.48	.51	.48	.51	.43	.48	.37	.43	.50	.72	.58	.61
35	.46	.56	.53	.51	.48	.58	.58	.53	.60	.43	.54	.51	.54	.56	.59	.60	.42	.51	.58	.59	.56	.47	.49	.49	.50	.66	.71	.58
36	.49	.46	.48	.52	.49	.59	.49	.47	.45	.35	.46	.36	.41	.48	.47	.49	.48	.49	.49	.52	.50	.43	.42	.44	.50	.48	.55	.53
37	.29	.20	.33	.25	.40	.40	.29	.28	.37	.28	.30	.27	.31	.33	.36	.32	.26	.39	.26	.37	.28	.35	.32	.32	.28	.31	.37	.29
38	.21	.19	.21	.25	.36	.29	.27	.25	.27	.27	.31	.35	.28	.35	.44	.38	.33	.31	.35	.31	.40	.44	.45	.33	.30	.29	.33	.31
39	.12	-.01	-.02	.18	.18	.10	.11	.14	.06	.14	.11	.18	.19	.06	.10	.07	.11	.07	.10	.11	.13	.25	.16	.17	.10	.08	.15	.10
40	.24	.27	.37	.35	.47	.27	.30	.19	.23	.29	.28	.30	.31	.25	.47	.49	.33	.35	.31	.40	.31	.46	.47	.28	.32	.28	.36	.37

41	.41	.34	.32	.33	.51	.49	.35	.38	.41	.31	.41	.41	.42	.36	.38	.39	.42	.42	.39	.44	.32	.46	.40	.29	.36	.33	.41	.31
42	.32	.41	.51	.44	.54	.49	.40	.41	.39	.38	.49	.44	.43	.42	.54	.62	.53	.52	.45	.47	.37	.51	.49	.30	.40	.42	.43	.47
43	.34	.35	.43	.41	.47	.44	.49	.46	.42	.37	.46	.47	.46	.42	.53	.58	.48	.53	.44	.44	.39	.53	.52	.39	.44	.55	.48	.48
44	.32	.59	.67	.45	.51	.43	.38	.34	.38	.40	.46	.40	.40	.37	.55	.67	.54	.53	.41	.47	.34	.46	.40	.34	.40	.53	.53	.63
45	.30	.53	.64	.44	.46	.39	.40	.37	.36	.40	.46	.37	.39	.42	.56	.66	.52	.51	.41	.46	.36	.49	.38	.34	.39	.47	.52	.62
46	.27	.50	.57	.35	.47	.37	.39	.30	.34	.39	.42	.39	.34	.31	.51	.62	.51	.47	.42	.46	.42	.46	.41	.33	.35	.42	.51	.62

Item number	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46
1	.42	.48	.46	.45	.51	.50	.46	.49	.29	.21	.12	.24	.41	.32	.34	.32	.30	.27
2	.55	.43	.41	.45	.63	.58	.56	.46	.20	.19	-.01	.27	.34	.41	.35	.59	.53	.50
3	.54	.44	.40	.43	.51	.52	.53	.48	.33	.21	-.02	.37	.32	.51	.43	.67	.64	.57
4	.51	.41	.37	.42	.49	.49	.51	.52	.25	.25	.18	.35	.33	.44	.41	.45	.44	.35
5	.52	.54	.54	.45	.51	.52	.48	.49	.40	.36	.18	.47	.51	.54	.47	.51	.46	.47
6	.53	.63	.57	.53	.57	.48	.58	.59	.40	.29	.10	.27	.49	.49	.44	.43	.39	.37
7	.57	.51	.45	.48	.48	.45	.58	.49	.29	.27	.11	.30	.35	.40	.49	.38	.40	.39
8	.48	.55	.52	.51	.48	.43	.53	.47	.28	.25	.14	.19	.38	.41	.46	.34	.37	.30
9	.53	.60	.55	.61	.55	.56	.60	.45	.37	.27	.06	.23	.41	.39	.42	.38	.36	.34
10	.57	.47	.40	.46	.49	.46	.43	.35	.28	.27	.14	.29	.31	.38	.37	.40	.40	.39
11	.53	.57	.51	.54	.46	.48	.54	.46	.30	.31	.12	.28	.41	.49	.46	.46	.46	.42
12	.51	.54	.48	.54	.47	.48	.51	.36	.27	.35	.18	.30	.41	.44	.47	.40	.37	.39
13	.51	.52	.54	.58	.57	.53	.54	.41	.31	.28	.19	.31	.42	.43	.46	.40	.39	.34

14	.44	.58	.52	.53	.43	.40	.56	.48	.33	.35	.06	.25	.36	.42	.42	.37	.42	.31
15	.56	.64	.57	.60	.44	.48	.59	.47	.36	.44	.10	.47	.38	.54	.53	.55	.56	.51
16	.61	.58	.53	.49	.60	.61	.60	.49	.32	.38	.07	.49	.39	.62	.58	.67	.66	.62
17	.58	.52	.52	.40	.52	.48	.42	.48	.26	.33	.11	.33	.42	.53	.48	.54	.52	.51
18	.58	.57	.57	.49	.50	.51	.51	.49	.39	.31	.07	.35	.42	.52	.53	.53	.51	.47
19	.58	.53	.50	.51	.48	.48	.58	.49	.26	.35	.10	.31	.39	.45	.44	.41	.41	.42
20	.56	.57	.56	.50	.43	.51	.59	.52	.37	.31	.11	.40	.44	.47	.44	.47	.46	.46
21	.56	.57	.49	.50	.41	.43	.56	.50	.28	.40	.13	.31	.32	.37	.39	.34	.36	.42
22	.49	.48	.45	.43	.46	.48	.47	.43	.35	.44	.25	.46	.46	.51	.53	.46	.49	.46
23	.44	.49	.47	.39	.42	.37	.49	.42	.32	.45	.16	.47	.40	.49	.52	.40	.38	.41
24	.50	.36	.33	.42	.43	.43	.49	.44	.32	.33	.12	.28	.29	.30	.39	.34	.34	.33
25	.55	.51	.43	.50	.53	.50	.50	.50	.28	.30	.10	.32	.36	.40	.44	.40	.39	.35
26	.63	.60	.53	.52	.76	.72	.66	.48	.31	.29	.08	.28	.33	.42	.55	.53	.47	.42
27	.67	.67	.63	.58	.58	.58	.71	.55	.37	.33	.15	.36	.41	.43	.48	.53	.52	.51

28	.80	.61	.55	.48	.55	.61	.58	.53	.29	.31	.10	.37	.31	.47	.48	.63	.62	.62
29	–	.64	.58	.53	.58	.61	.58	.56	.29	.28	.00	.33	.32	.48	.47	.64	.60	.62
30	.64	–	.86	.60	.50	.54	.59	.60	.44	.38	.09	.36	.46	.50	.52	.54	.53	.53
31	.58	.86	–	.58	.50	.53	.56	.58	.44	.34	.11	.35	.47	.46	.50	.48	.47	.47
32	.53	.60	.58	–	.58	.67	.59	.49	.39	.29	.10	.31	.38	.41	.37	.46	.43	.38
33	.58	.50	.50	.58	–	.85	.59	.48	.28	.23	.07	.30	.42	.46	.49	.56	.49	.43
34	.61	.54	.53	.67	.85	–	.63	.49	.31	.22	.08	.35	.40	.45	.50	.61	.53	.48
35	.58	.59	.56	.59	.59	.63	–	.57	.45	.33	.13	.40	.41	.45	.53	.48	.43	.46
36	.56	.60	.58	.49	.48	.49	.57	–	.49	.26	.05	.31	.43	.48	.47	.49	.50	.40
37	.29	.44	.44	.39	.28	.31	.45	.49	–	.27	.15	.43	.38	.35	.39	.37	.33	.36
38	.28	.38	.34	.29	.23	.22	.33	.26	.27	–	.47	.43	.30	.39	.43	.24	.30	.31
39	.00	.09	.11	.10	.07	.08	.13	.05	.15	.47	–	.24	.24	.15	.23	.03	.02	-.02
40	.33	.36	.35	.31	.30	.35	.40	.31	.43	.43	.24	–	.44	.58	.50	.43	.45	.51
41	.32	.46	.47	.38	.42	.40	.41	.43	.38	.30	.24	.44	–	.68	.43	.37	.37	.36

42	.48	.50	.46	.41	.46	.45	.45	.48	.35	.39	.15	.58	.68	–	.64	.64	.64	.53
43	.47	.52	.50	.37	.49	.50	.53	.47	.39	.43	.23	.50	.43	.64	–	.55	.56	.46
44	.64	.54	.48	.46	.56	.61	.48	.49	.37	.24	.03	.43	.37	.64	.55	–	.88	.74
45	.60	.53	.47	.43	.49	.53	.43	.50	.33	.30	.02	.45	.37	.64	.56	.88	–	.75
46	.62	.53	.47	.38	.43	.48	.46	.40	.36	.31	-.02	.51	.36	.53	.46	.74	.75	–
