

Monitoring progress in ASD

Overview

The consensus of most professionals is that autism is a lifelong condition but with abilities and difficulties, associated problems, function and participation, as well as management issues, changing over time. Thus, while identification and accurate diagnosis constitute a first step, ongoing monitoring is essential for helping the individual with ASD to reach their potential and manage developmental challenges that arise throughout the life course. This chapter will highlight the key issues in the process of monitoring and how this can be achieved along with current opportunities and pitfalls, where they exist.

Context

Heterogeneity and complexity

The landscape of autism spectrum disorder (ASD) is diverse and complex; each individual diagnosed with ASD varies in the severity of impairment across behavioural, social and cognitive dimensions, and each individual's behaviours or interests may be idiosyncratic. As ASD frequently co-occurs with other problems or difficulties such as epilepsy, intellectual disability, and other mental health diagnoses (Simonoff et al., 2008), ASD features may not be the focus of interventions or strategies to improve well-being, function and participation. For example anxiety, irritability, aggression, learning disability, and self-injurious behaviour (Maskey, Warnell, Parr, Le Couteur, & McConachie, 2013) often occur and require management. Individuals with multiple coexisting problems or difficulties will require closer monitoring over time compared to individuals who present with few or no comorbidities that impair occupational function. These factors result in a unique presentation in each individual, and unique challenges for intervention and other strategies and useful and relevant monitoring. Add to this the different values that each individual and their family bring and it becomes apparent that the goals of each individual, and hence the things that should be monitored will be as different as they are the same. Due to this intrinsic clinical variability, measuring changes in symptomatology and monitoring progress is necessarily complex, but also crucial to improving for the lives of each individual.

Validity, utility and appropriateness of tools

There are significant challenges in monitoring the impact of interventions in the context of ASD (Eldevik et al., 2009; Howlin, Magiati, & Charman, 2009) and one of the main difficulties involves the lack of reliable and valid tools that measure change and that can be repeated at different time points. As a result, evaluators have resorted to using measures that are primarily diagnostic instruments but typically these are not sensitive to change. Further, most longitudinal studies have focused on overall developmental trajectories using standardised developmental instruments. These measures have significant limitations as they are primarily developed for typically developing children and therefore delayed and different developmental patterns observed in ASD are difficult to track over time. Although there are some exceptions, most of these instruments do not allow measurements spanning the age range from preschool to adolescence and beyond.

Recent reviews of assessment tools have identified problems with validity and utility, including their appropriateness for measuring change over time and the need for measure of health related quality

of life to allow evaluation of economic impacts of interventions and management approaches (refs to be added) Also identified is that individuals with neurodisability, including autism, and their families value different outcomes to those commonly measured (refs to be added).

International classification of functioning, disability and health

The development of The International Classification of Impairments, Disabilities and Handicaps (World Health Organization, 1980), now The International Classification of Functioning, Disability, and Health (World Health Organization, 2001), provides a useful structure for assessing or monitoring individuals with autism and other disabilities, with a focus on impairment, function and participation within a framework of children's rights and the application of the biopsychosocial model. This approach has several advantages including that disability is understood as the consequences of underlying health conditions attributable to disease or injury and that the consequences are detailed as having a distinct impact on human experiences at the levels of body, person and society. In addition by differentiating these terms conceptually and semantically, it is emphasised that disability is not uni-dimensional but rather manifested at different levels of human functioning in the form of impairments, performance limitations and the experience of disadvantage. It also provides a taxonomy with numeric codes that can be used to document the elements unique to each of the three levels, with applicability for clinical and administrative purposes (Simeonsson et al., 2003).

The ICF allows the classification of functioning as universal human experiences involving 'body function and body structures' which can be conceptualized as well-being, 'personal activities and performance' such as mobility and self-care that can be conceptualized as function and 'participation in community' such as school, work and civic life. Since the barriers and facilitators within the environment at each of these three levels can also be recognized through the 'environmental factors qualifiers' option, this classification offers a distinct advantage in terms of assessing eligibility and prioritization of interventions as well as in monitoring progress. However one limitation is the application to and coverage of child characteristics and hence additional considerations are required during the early developmental years. For example, there are issues relating to assessing children with limited cognitive and language abilities resulting in a reliance on parental and care giver reports. It would be important to include wherever possible, reports of children through interview, play or other direct observations.

Individualised planning

Good practice dictates that intervention, management or care plans for ASD must be tailored to the individual's needs and goals, have research evidence supporting their effectiveness, and that goals must be measurable, continuously monitored and frequently revised (Prior, Roberts, Rodger, Williams, & Sutherland, 2011) suggest ref. Yet as young children with ASD mature into adolescents and young adults, delivery of best-practice becomes more challenging as the context and circumstances of individuals diverge. Even during the school years while some children with an ASD are schooled entirely in autism-specific or special education schools, the majority are included to some degree in general education programs. After school the diversity of possible environments increases further, ranging from university education, to the work place to supported employment options and accommodation arrangements. Individual plans should incorporate as much input from the individual with autism as possible and include all of those involved with their care such as the family, therapists and educators in a collaborative process. Although the specifics of an IP must

necessarily change as each individual progresses through their development, educational and other settings, the main guiding principles of an effective individual plan remain the same. These principles are seen as best-practice and they also govern recommendations from different developed nations such as the United States (Individuals with Disabilities Education Improvement Act 2004), the United Kingdom (Children and Families Act 2014), and Australia (The Australian Advisory Board on Autism Spectrum Disorders, 2014). Accordingly, the individual plan should be re-evaluated at least every six months and the emphasis of this approach should be on accurate and objective measurement of progress in accordance with the set goals that address individual strengths and needs as detailed in Table 1.

Table I *Key items needing attention in an Individualized Plan (IP) for children with ASD*

Overarching long term goal(s) for the person with ASD incorporating planning for transition
A thorough assessment of current performance in key developmental and academic/employment/adaptive skills areas
Measurable goals for each specified period (minimum six monthly interval);
A strategy for measuring progress and outline of when periodic progress reports will be provided;
Assessment of resources and consideration of which services and educational strategies are to be provided by whom in order to reach, monitor and assess the goals;
A process for the collaborative review and revision of the IP at least on a six-monthly basis

Goal setting as a core element of monitoring progress and transitions

Intervention and management vary over time, as do their goals and tools that would be used to measure whether goals have been achieved.

Key ages and stages

Four main stages in life can be identified that are likely to bring different goals, because of the changing environment, the change in ability and different priorities of individuals and families. The first is the preschool years, the second the primary years, the third the high school years and the fourth the adult years. Of course within these stages there are further important divisions, but for ease we will focus on these four in the hope that individual variation due to for example aging, can be catered for because of the flexibility of the approach that is being presented.

In the early years the focus will be on developmental impairments in the areas of receptive language, expressive language, social interaction, fine/gross motor skills, cognition, play skills, and adaptive behaviour/personal independence. However, over time, there will be a shift from assessing specific developmental domains and abilities to assessing participation in education, employment or civic life. Time points for assessments would also deserve special attention in the monitoring

process. For example there are well identified points of stress for the individual with autism and their families when goal specific assessment and planning would be critical and such time points may include immediately after diagnosis in terms of choice of early intervention, start of school or other educational programs, transition from one educational setting to another and in particular transition to high school, and then post high school as they move into vocational or career/employment related placements. Issues relating to life skills, personal, social and sexual relationships, driving and independent living as well as mental health would also deserve due consideration. Further, any other major life event in the life of individuals with autism will create additional needs for themselves and their families, over and above those experienced by the general population. Since it will be difficult to initiate contact with services and agencies for the first time during such times of crisis, specific attention to how families and individuals could easily connect with appropriate agencies at these times needs to be built in to the monitoring framework. Further, monitoring information should always cause professionals to pause and reflect on what could be creating the patterns that are being observed, and how that information would assist in decision making on any changes that needs to be made to the ongoing management plan. Things that might need modification could include the nature, frequency or setting of interventions, the way treatment plan is being coordinated and provided, or the environment, community supports, or other aspects of care. Ongoing monitoring and assessing progress is central to intervention, education and social programmes in ASD, and fundamental to all programs that include goals.

Fit-for-purpose monitoring

An approach that can add value to what we know about appropriate monitoring for different ages and stages of children with autism is consideration of the purpose of monitoring. In this approach, monitoring can be to identify autism, to assess autism interventions, to identify common problems early, or to ensure that ongoing management is maximising opportunities for an individual with autism and their family. Embedding the international classification of functioning, disability and health with this approach ensures monitoring that includes information about the impairment or wellbeing, function and participation as relevant.

Identifying autism

Monitoring for early signs and symptoms of ASD can assist timely identification and opportunities for early intervention. Although some of these symptoms may be evident from as early as the first year of life, ongoing surveillance is the key to monitoring these symptoms to determine their developmental course and accurate diagnosis. Studies based on the siblings of children with an affected older sibling have indicated delay or differences in early attentional control, emotion regulation, social orienting/approach, and communication development (Brian, Bryson, & Zwaigenbaum, 2015). These domains may also be appropriate targets for early intervention. Some of the main domains of ASD that are relevant to monitoring for symptoms suggestive of autism are described below.

Social communication: It has been suggested that early abnormalities in brain development in autism leads to early low-level deficits in recognition and orientation towards social stimuli which then cascades to lack of social engagement with primary caregivers during infancy and resulting in decreased exposure to the reciprocal social interactions critical for development of typical social behaviour. There is substantial evidence to support the presence of these types of deficits which in turn suggests a need for intervention to support the development of early social engagement and reciprocity designed to minimise divergence from a typical developmental trajectory (Webb, Jones, Kelly, & Dawson, 2014). Emerging evidence indicates that interventions that address early deficits in joint attention and social reciprocity using strategies that involve interpersonal exchange and positive affect, shared engagement with real-life materials and activities, sensitivity to child cues and adult responsivity etc. facilitate the development of age appropriate socio-communicative behaviours.

Restricted Repetitive Behaviours (RRB): As repetitive and restrictive behaviours are a core symptom of ASD, and can be a significant cause of impairment affecting multiple facets of life, these specific behaviours are frequently targeted by intervention programmes. However, while other core ASD symptoms are strongly related to general developmental level and correlate with cognition and IQ, insistence on sameness does not share this relationship with these variables (S. L. Bishop, Richler, & Lord, 2006; Richler, Huerta, Bishop, & Lord, 2010). Further, RRBs are not unique to ASD but can also occur in other psychiatric and neurological disorders such as Obsessive Compulsive Disorder and Tourette Syndrome. In OCD this is driven by a need to relieve anxiety and intrusive thoughts, while in Tourette Syndrome this follows a need to relieve a premonitory urge, and in ASD these behaviours are characterised largely by an insistence on sameness and unwavering rigidity in routine. Despite being a major target for therapy, repetitive behaviours and restrictive interests appear to persist in severity over time, even when children show progress in other areas of their symptomatology (Dawson et al., 2010; Vivanti et al., 2014).

Sensory sensitivities: Previous research has shown that there are distinct sensory profiles in autism relating to behaviours associated with sensory reactivity (the intensity of the response to a sensory stimulus) and multisensory integration (combining information from multiple sensory stimuli) which links with specific patterns of behaviours (Lane, Molloy, & Bishop, 2014). This would suggest that specific intervention strategies matching the sensory difficulties in those affected would be beneficial.

Evaluating interventions

Although it is outside the scope of this chapter to discuss the various behavioural and developmental interventions available, some background is necessary for an understanding of how the success of such interventions and management strategies may be measured.

Current clinical guidelines advise focussing on improvements in the core ASD characteristics, especially social interaction and reciprocal communication, by including techniques to expand the child or young person's communication, interactive play and social routines, and working with parents', carers', teachers' or peers' to facilitate greater understanding of, and responsiveness to, the child or young person's patterns of communication and interaction (National Institute for Health and Care Excellence, 2013). For the preschool age group some recommended techniques include the integration of play-based strategies with parents, carers and teachers with therapist modelling and video-interaction feedback to increase joint attention and engagement. Additionally, clinicians, educators and carers may employ techniques such as pivotal response training, prompting, reinforcement, and discrete trial teaching (Odom et al., 2003) over a short period of time to enact a change in a specific behaviour or to develop a targeted skill.

Typically, in efficacy studies each individual's developmental skills, cognitive ability, and behaviours that challenge or are unwanted will be assessed at the start and end of intervention. The monitoring tools, also called outcome measures in this context, selected will also reflect the form of intervention chosen. For example, if a child is undergoing a Comprehensive Treatment Model (CTM) which is designed to elicit a broad developmental response, progress may be monitored across autism severity and developmental milestones using treatment specific tools as well as other assessment tools for autism specific symptoms such as the Social and Communication Questionnaire (SCQ) and Autism Diagnostic Observation Schedule (ADOS), in addition to using additional measures such as the Mullen Scale of Early Learning (MSEL) and Vineland Adaptive Behaviour Scale (VABS) etc. to monitor overall development and adaptive functioning (Dawson et al., 2010; Eapen, Crnec, & Walter, 2013; Vivanti, Dissanayake, Zierhut, & Rogers, 2013). The measures commonly used in these instances to assess and monitor progress would change over time and some of the commonly used measures are detailed in Table 2. When establishing intervention goals in practice domains as described above it is important to include, along with overall development, other aspects of functioning, participation and quality of life, for the individual with autism and their family. In this section we will focus on autism characteristics, development and abilities, and will discuss other key elements of expected outcomes from intervention in later sections.

Autism features

Autism Diagnostic Observation Schedule (ADOS)

The *Autism Diagnostic Observation Schedule (ADOS)* (Lord et al. (2000)) is a standardized tool for the direct observation and measurement of autistic symptomatology. The ADOS consists of a series of investigator-led processes designed to elicit naturalistic social and communicative behaviours from the child. The investigator thus builds a profile of the child's social communication, social relatedness, play and imagination, and restricted and/or repetitive behaviours. Despite its reputation as the 'gold standard' measure of autistic severity, the ADOS was designed as a diagnostic tool to measure relatively stable traits in ASD which are not anticipated to vary greatly over a lifetime. Longitudinal studies have demonstrated the stability of these standardised scores throughout childhood (Chawarska, Klin, Paul, & Volkmar, 2007; Gotham, Pickles, & Lord, 2009; Hedvall et al., 2014). Indeed, even when children demonstrate vast gains in other domains such as expressive and receptive language and adaptive behaviours as a result of an autism-specific intervention, their ADOS scores did not significantly improve (Dawson et al., 2010; Vivanti et al., 2014). While improvements in such measures would undoubtedly indicate robust changes to behaviour, a lack of improvement may indicate insensitivity to subtle improvements and treatment effects, especially when the aim of an intervention does not broadly target ASD, but rather a specific behaviour or outcome. Hence, while the ADOS may help assess the progress of a CTM with limited sensitivity, it is unlikely to accurately reflect progress relating to specific tasks or behaviours. However it can be useful if such progress results in the child no longer reaching a diagnostic status on the repeat ADOS assessment.

Social Responsiveness Scale (SRS)

The Social Responsiveness Scale (Constantino & Gruber, 2005) is a brief quantitative measure of autism severity in children and teenagers. It focuses on the degree of impairment in the core ASD domains of social awareness, social information processing, reciprocal social communication, social anxiety/avoidance, and stereotypic behaviour/restricted interests. The SRS compares favourably with the ADI-R (Constantino et al., 2003), however is scored based on the observations of parents or teachers, and hence has the limitation of lacking clinician input.

Repetitive Behavior Scale- Revised (RBS-R)

The Repetitive Behavior Scale - Revised is a parent-completed questionnaire which characterizes the severity of repetitive behaviours across six subdomains: stereotyped behaviour, self-injurious behaviour, compulsive behaviour, ritualistic behaviour, sameness behaviour and restricted behaviour (Bodfish, Symons, Parker, & Lewis, 2000).

Early Social Communication Scales (ESCS)

The Early Social Communication Scales (Mundy et al., 2003) is used to measure social behaviour and joint attention skills in a structured setting. During the ESCS, the child is seated at a table while an experimenter presents a range of standardized probes assessing social responsiveness and communication skills, including initiation and response to joint attention, as reflected in frequencies of child alternating gaze, showing, and pointing to share. The ESCS has shown good reliability and validity and has been used in studies of children with ASD, including treatment studies (Kasari, Freeman, & Paparella, 2006; Remington et al., 2007; Salt et al., 2002).

Childhood Autism Rating Scale (CARS)

Childhood Autism Rating Scale (E. Schopler, Reichler, & Renner, 1986) and the revised version, CARS2 (E. Schopler, Bourgonien, Wellman, & Love, 2010) can be completed by a parent, teacher or a clinician, based on subjective observations of the child's behaviours. Based on the findings of a bimodal distribution among these scores, the scale includes criteria to differentiate between those with mild to moderate autism and those with severe autism (E. Schopler, Reichler, DeVellis, & Daly, 1980).

Social Communication Questionnaire (SCQ)

The Social Communication Questionnaire (SCQ) (Berument, Rutter, Lord, Pickles, & Bailey, 1999), formerly known as Autism Screening Questionnaire is based on a well-validated parent interview, the original Autism Diagnostic Interview (ADI; (Rutter, Le Couteur, & Lord, 2003)). The SCQ covers the areas of communication, reciprocal social interaction, and restricted and repetitive behaviours and interests, which are core diagnostic criteria for autism. There are two versions: a 'current' version designed for children under 5 yrs and a 'lifetime' version designed for children ≥ 5 yrs. The current version is helpful for treatment/planning in that it indicates the type and severity of the characteristics of autism in individual children. The items can be used for setting treatment goals for example, if the child has no ability to take turns in a conversation, conversational turn taking can be targeted in the intervention program. The SCQ can be used for monitoring purposes as it can measure change over time.

Autism Treatment Evaluation Checklist (ATEC)

The Autism Treatment Evaluation Checklist (ATEC) (Rimland & Edelson, 1999) is another tool that can be used by clinicians and parents to evaluate treatment outcomes and to monitor progress in ASD. The ATEC can be accessed and scored online by parents, teachers and/or other primary carers (http://legacy.autism.com/ari/atec/atec_report.htm). The scale covers 77 items in the areas of communication, sociability, sensory and cognitive awareness and health and physical behaviour, and also provides a total score.

Autism Impact Measure (AIM)

The Autism Impact Measure (AIM) (Kanne et al., 2014) is a 25-item questionnaire that has been specifically designed to **target sensitivity** to change of core ASD symptoms. It asks respondents to recall a 2-week period with items rated on two corresponding 5-point scales of frequency and impact of core ASD symptoms. Using exploratory factor analysis, four factors were found namely 1) repetitive behaviours, 2) odd/atypical behaviours, 3) communication/language, and 4) social/emotional reciprocity, and these were observed to concur with the reports of symptom severity/impact.

General Development and ability

In infants and toddlers, the symptoms of an ASD may only be starting to become apparent, and any differences between an affected child and their peers may not seem too extreme. However, over time the differences may become more pronounced and a child with ASD may lag further behind their peers. This is one of the greatest opportunities for an early intervention, as it provides intensive support for young children to make more early gains, potentially before their developmental trajectories uncouple from those of their peers. To focus on improving developmental outcomes in young children it is essential to accurately monitor and measure progress in the five developmental

domains of early childhood: physical, social, emotional, language and cognitive skills. A child with ASD may experience general or specific impairments in any or all of these domains and associated sub-domains, from a particular sensory processing abnormality to pervasive intellectual impairment.

In addition to monitoring core symptoms and psychopathology in children with ASD, it is also important to take into consideration a child's motor profile in their overall management plan. In a study by Papadopoulos et al (2011) of fifty-three 7-12 year old children with ASD, a significant positive correlation between impairments in motor proficiency (in particular ball skills and balance) and DBC measures of emotional/behavioural disturbance, autistic symptoms and communication disturbance was reported. These authors suggest that adjunct motor measures (in particular balance) may be a useful objective measure to help monitor the overall developmental profile of a child with ASD over time (Papadopoulos et al., 2011). For children with ASD who have significant motor impairment that might range from problems with clumsiness, difficulty with motor planning, hand writing difficulties and dystonia's, there is a need for clinical planning around whether motor symptoms should be directly addressed, for example, through intensive occupational therapy, or whether these difficulties should be 'monitored' over time. This is particularly relevant in the primary school years. Given that motor impairment is associated with reduced physical activity and participation, there are health as well as psychological benefits for ongoing monitoring of a child's motor development. By monitoring a child's functioning in relation to their individual motor profile and potential limitations, a holistic management approach can be put in place that includes the optimization of activity and participation (Emck, Bosscher, Beek, & Doreleijers, 2009).

The Mullen Scales of Early Learning

The Mullen Scales of Early Learning is (MSEL) (Mullen, 1995) is a standardized, normed developmental assessment for children aged birth through 68 months. It provides an overall index of ability, the Early Learning Composite, and subscale scores of Receptive Language, Expressive Language, Visual Reception, and Fine Motor skill.

Ages and Stages Questionnaire

The Ages and Stages Questionnaire (ASQ; Squires, Bricker, and Twombly (2009)): Parents or caregivers can use the ASQ questionnaires to check a child's general development and the ASQ:SE (socio-emotional) questionnaire to check a child's social emotional development.

Bayley Scales of Infant Development

The Bayley Scales of Infant Development

(Bayley, 1993): The Bayley Scales of Infant Development (BSID-III is the current version) is a standard series of measurements used to assess the motor (fine and gross), language (receptive and expressive), and cognitive development of children aged 0-3 years.

Griffiths Mental Developmental Scale

Griffiths Mental Developmental Scale (3rd edition; Griffiths (2006)) The six sub-scales include Locomotor (Gross motor skills including the ability to balance and to co-ordinate and control movements); Personal-Social (Proficiency in the activities of daily living, level of independence and interaction with other children); Language (Receptive and expressive language); Eye and Hand Co-ordination (Fine motor skills, manual dexterity and visual monitoring skills); Performance (Visuospatial skills including speed of working and precision) and Practical Reasoning

(ability to solve practical problems, understanding of basic mathematical concepts and understanding of moral issues).

Cognitive ability and intelligence

There is considerable variability in levels of cognition in individuals with ASD and therefore accurate intelligence assessment is important in treatment planning.

Stanford-Binet Intelligence Scales: Fifth Edition

The Stanford-Binet Intelligence Scales: Fifth Edition (SB5) (Roid, 2003) is a widely used standardized intelligence scale which assesses multiple components of intelligence. It includes ten subtests, five verbal and five nonverbal, which can be used to determine verbal intelligence (VIQ), nonverbal intelligence, and full-scale or abbreviated intelligence. Although it was originally thought that most people with ASD also suffered comorbid intellectual disability (ID; i.e., IQ < 70), more recent estimates have reduced this co-occurrence to approximately one third to one half of cases (Centers for Disease Control and Prevention, 2014). Additionally, epidemiological studies indicate that more than a quarter of participants with ASD have average or above average intelligence (i.e., IQ > 85) (Charman et al., 2011).

WISC/WPPSI and other tests of intelligence:

Wechsler Pre-school and Primary Scale of Intelligence (WPPSI; (Wechsler, 1989, 2002)) or the Wechsler Intelligence Scale for Children (WISC - IV; Wechsler (2003)) as appropriate; for those unable to be tested or those not reaching standardized T scores to derive an IQ score, an IQ estimate, a best estimate of the Developmental Quotient (DQ) can be calculated using any of the general developmental tests as above using the equation $\text{Mental Age (MA)} \div \text{chronological age} \times 100$.

Communication

Autism is unique in that essentially the development of communication may not be directly linked to the development of language. More than in any other condition, in autism, language development may occur separately from communication development (Jordan & Jones 2012). Very young children with autism usually show divergent communication development with differences in the development of joint attention and early engagement with others (Charman & Stone, 2008; Toth, Munson, Meltzoff, & Dawson, 2006). Also, young children with autism are less interested in people than in objects (Kasari et al., 2006) and primarily as a result of paying less attention to other people in their environment, have poor early social communication development. This extends to the development of language; for example at the most basic level the learning of the names for things is highly dependent on joint attention and interaction with primary caregivers. Assessment of communication in autism needs to be broad and address all aspects of communication including language development and the structure and function of language and communication. For preverbal, nonverbal and verbal individuals with autism, assessment of communication as well as of language development is essential. Accurate assessment of receptive and expressive communication also important because unlike other condition, in autism receptive language is often more impaired than expressive language (Hudry et al., 2010). This can be misleading when those around the child or adult with autism assume, not unreasonably, that they understand at the same level at which they speak. Children with autism appear to learn language primarily through a process of rote learning

chunks of language, which they associate with particular internal and external contexts. Speech often gives a stereotyped impression and echolalia is common. It is important to assess exactly what the child understands and what cues they are following. They may be expert at interpreting visual cues and contextual information while understanding very little of what is actually being said to them.

Children's Communication Checklist (CCC)

Children's Communication Checklist (CCC-2; D. Bishop (2003)) is a 70 item questionnaire completed by a caregiver and screens for communication problems in children aged 4 to 16 years. The test evaluates a broad range of language skills such as recalling and formulating sentences, word classes, word definition, understanding spoken paragraphs, semantic relationships. There is also a version for older adolescents and adults.

Clinical Evaluation of Language Fundamentals (CELF)

There are preschool and 5-22 years version of this assessment (CELF-P (Wigg, Secord & Semel, 2004), for pre-school to early school age children. Subtests include basic concepts, sentence and word structure, formulating labels, recalling meaning, and linguistic concepts.

CELF-5 (Wiig, Semel, Secord, 2013) is a quick and accurate assessment for ages 5 to 22 years to assess for a language disorder. The test evaluates a broad range of language skills such as recalling and formulating sentences, word classes, word definition, understanding spoken paragraphs, semantic relationships. The current battery of tests provides a comprehensive language assessment including a robust assessment of pragmatics using observations and interactive activities.

Communication and Symbolic Behaviour Scales Developmental Profile

Communication and Symbolic Behaviour Scales Developmental Profile (CSBS-DP) (Wetherby & Prizant, 2002). (6 months – 6 years). This assessment is a combination of parent report and face-to-face evaluation of the child. The assessment measures 7 language predictors: emotion and eye gaze, communication, gestures, sounds, words, understanding, and object use and is sensitive to early delays in social communication, expressive speech/language, and symbolic functioning.

MacArthur-Bates Communication Development Inventories

The MacArthur-Bates Communication Development Inventories (Fenson, Marchman, Thal, Dale, Reznick, Bates, 2007) (1-3), 3-37 months. The assessment consists of three inventories using parent report to probe use of gestures, words, and sentence.

Reynell Developmental Language Scales

The New Reynell Developmental Language Scales (NRDLS) (Edwards, Letts and Sinka, 2011). 2yrs-7yrs 5 months. This is a direct assessment of the child designed to identify speech and language delays and impairments in very young children

Peabody Picture Vocabulary

The Peabody Picture Vocabulary III (PPVTIII) (Dunn & Dunn, 1997) 2.5-90+ years. Measures listening comprehension of vocabulary in standard English.

Pragmatics Profile of Everyday Communication Skills in Children

The Pragmatics Profile of Everyday Communication Skills in Children (Dewart & Summers, 1996). Version for preschool aged children 0-4yrs, school aged children 5-10 yrs and adolescents/adults. The assessments are structured interviews with a primary carer designed to assess child

communicative functions, response to communication, interaction and conversation and contextual variation.

Preschool Language Scale

The Preschool Language Scale 5th ed (PLS5) (Zimmerman, Steiner & Pond, 2011). birth-7 years. This is a direct assessment of the child designed to evaluate maturational lags, strengths, and deficiencies by testing auditory comprehension and verbal ability.

Social Skills

Adaptive functioning

There is some evidence to suggest that there is a cognitive advantage over adaptive functioning in children with ASD and similar results have been found in a recent study in an older sample (Matthews et al., 2015). Compared to communication and socialization skills, adults with ASD showed relative strength in daily living skills although this was not true for adolescents. However, all standard scores were well below average, regardless of their level of cognitive functioning which suggests the need for interventions that target adaptive functioning across the lifespan.

Vineland Adaptive Behaviour Scale (VABS)

One critical indicator of an individual's functioning and progress is their ability to translate their theoretical intelligence to practical intelligence, or their cognitive potential into real-life skills, hereafter defined as adaptive behaviour. The Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) and (VABSII; Sparrow, Cicchetti, and Balla (2005)) assesses social, communication, motor and daily living skills reflective of an individual's ability to navigate life in the community. It is administered by parent interview and provides both age-equivalent and standardised scores.

Behaviour Assessment System for Children (BASC)

The Behavior Assessment System for Children (2nded.) (BASC-2; (2004)) can be used to measure adaptive functioning across core domains including adaptive/functional skill development and to monitor change. The assessment focuses on the measurement of adaptive and maladaptive behaviour, which are important outcomes for intervention programs. It is standardised (valid and reliable) for age range 2-21 years. For those in the 2-5 year age range, the 134 -160 items cover the key areas of activities of daily living, adaptability, aggression, anxiety, attention problems, depression, functional communication, hyperactivity, social skills, somatization, and withdrawal. There is a parent rating form and a teacher form (except activities of daily living scale) and the parent and teacher observation forms can be used to measure change following an intervention program or over time.

Child Behaviour Checklist (CBCL)

The Child Behavior Checklist (Achenbach & Rescorla, 2001) version 1.5 to 5 years (CBCL 1.5-5) or version 6-18 (CBCL 6-18) can be completed by parents and others who see the children in home-like settings. It obtains parents' reports of children's competencies & problems.

The Teachers Report Form 6-18 (TRF 6-18), is completed by teachers and other school staff who have known the child in school settings for at least 2 months. It obtains teachers' ratings of many of the problems rated on the CBCL 6-18, plus additional items appropriate for teachers.

The Youth Self-Report 11-18 (YSR 11-18), is completed by 11-18 year olds to describe their own functioning. It has most of the same competence & problem items as the CBCL 6-18, and open-ended responses to items covering physical problems, concerns, and strengths.

All forms have parallel Internalising, Externalising, and Total Problems scales. The TRF also includes Inattention and Hyperactivity-Impulsivity subscales. The following cross-informant syndromes can be derived from the forms: Anxious/Depressed; Withdrawn/Depressed; Somatic Complaints; Social Problem; Thought Problems; Attention Problems; Rule-Breaking Behaviour; Aggressive Behaviour.

Strengths and Difficulty Questionnaire (SDQ)

The Strengths and Difficulty Questionnaire (SDQ; (Goodman, 1997)) is a brief 25 item parent report measure to elicit emotional and behavioural attributes of children and adolescents ages 2 through 17 years old. The SDQ has 5 subscales namely emotional problems; conduct problems; hyperactivity/inattention; peer relationship problems; prosocial behaviours and there is also a total difficulties score based on 20 items.

Early identification of associated conditions

Maladaptive or disruptive behaviours

The presence of maladaptive behaviours in young people with ASD can significantly limit engagement in treatment programs, as well as compromise future educational and vocational opportunities (Fulton, Eapen, Črnčec, Walter, & Rogers, 2014). Therefore decreasing such behaviours or replacing these with alternative adaptive behaviours will be a critical focus for interventions and subsequent monitoring. Dominick et al. (2007) reported aggressive behaviors including hitting, kicking, and pinching and self-injurious behaviours (SIB) such as head banging, hitting oneself, and biting oneself, in around a third of children with ASD. More than three-quarters of children with these behaviours showed aggressive behaviours both at home and outside the home. Furthermore, around 70% had experienced a period of severe temper tantrums and for 60% of children with tantrums these occurred on a daily basis and were a constant, rather than episodic. Several authors have suggested that there is a relationship between inability to communicate and the prevalence of maladaptive behaviours (Dominick et al., 2007) and self-injurious behaviours (Vismara & Rogers, 2010). Both internalised behaviours (e.g. self injurious behaviour) and externalised behaviour (e.g. aggression to others) may also be a response to environmental stress (Bartak, Bottroff & Zeitz, 2006). Thus disruptive and challenging behaviours and their appropriate management and ongoing monitoring have significant implications for integration in educational settings and for the overall functioning of the person with ASD.

Developmental Behaviour Checklist (DBC)

The Developmental Behaviour Checklist (DBC)-Parent/ Caregiver or Teacher Version (DBC-P and DBC-T; Einfeld and Tonge (2002)) is a 96-item checklist of behavioural and emotional problems in children aged between 4-18 years old with developmental difficulties.

The DBC provides an excellent measure of emotional and behavioural problems in both children and adolescents with developmental conditions (Einfeld & Tonge, 1992, 1995, 2002). The DBC can be used for children with intellectual disabilities as well as for children who are cognitively able

(Brereton, Tonge, Mackinnon, & Einfeld, 2002; Einfeld & Tonge, 2002). The DBC has 96 items providing quantitative measures of behavioural and emotional disturbance. Each item is scored on a scale ranging from 0- “not true as far as you know” to 3- “often true or very true”. The total score of the DBC provides a measure of overall psychopathology. There are five subscales: Disruptive / Antisocial, Self-absorbed, Communication Disturbed, Anxiety and Social Relating (Dekker, Nunn, & Koot, 2002). In addition to measuring psychopathology, the DBC can be used as an Autism Screening tool (the DBC-ASA) in children as young as four years of age (Brereton et al., 2002).

The DBC also has screening measures that are able to identify and monitor individuals at risk of developing comorbidities. One example of use of the DBC is to monitor comorbid ADHD symptomology (see Gargaro et al. (2014)). Boys with ASD may be particularly at risk for ADHD comorbidity and require further monitoring, than age, IQ, cognitively and academically matched girls with ASD (May, Cornish, & Rinehart, 2014).

Aberrant Behaviour Checklist (ABC)

The Aberrant Behaviour checklist (ABC; Aman, Singh, Stewart, and Field (1985) This scale was primarily developed to assess drug and other treatment effects on severely mentally retarded individuals. Factor analysis of the 58 item has yielded a five-factors namely (I) Irritability, Agitation, Crying; (II) Lethargy, Social Withdrawal; (III) Stereotypic Behavior; (IV) Hyperactivity, Noncompliance; and (V) Inappropriate Speech.

Adult Behaviour Checklist (ABCL)

The Adult Self report (ASR/ 18-59) & Adult Behaviour Checklist (ABCL/18-59); (ASEBA, University of Vermont, Burlington, VT)

The ASR is used to obtain self-reports from adults on aspects of their adaptive functioning and problems. The ABCL on the other hand is used to obtain reports from people who know the adult person with problems well. There are normed scales for adaptive functioning, as well as empirically based syndromes such as Anxious/Depressed; Attention Problems; Withdrawn; Aggressive Behaviour; Somatic Complaints; Rule-Breaking Behaviour; Thought Problems; and Intrusive problems as well as Internalizing and externalizing problems. The profiles also include a Critical Items scale consisting of items of particular concern to clinicians and a total score.

Tics

Available evidence from the literature suggests that tics occur in around 20–40% of individuals with ASD, although there is significant variability in the extant research (Eapen, Črnčec, McPherson, & Snedden, 2013). Perhaps the largest and best controlled study to date has reported a rate of 6.5% for the occurrence of Tourette Syndrome in ASD (Baron-Cohen, Scahill, Izaguirre, Hornsey, & Robertson, 1999) with considerably higher rates of up to 50% for tics when individuals with intellectual disability and ASD are considered (Eapen, Robertson, Zeitlin, & Kurlan, 1997). Awareness of tic disorders will allow for tics to be sensitively managed and possible comorbidities anticipated and differentiated from tics, which in turn can lead to the minimum possible disruption to the young person. For example, tics may be mistaken for fidgetiness that can occur with ADHD, and coprolalia may attract negative consequences such as disciplinary action in children and stigma and social embarrassment in adults. Pharmacological treatment for tic disorders may include clonidine, especially when ADHD presents comorbidly, or antipsychotic agents such as risperidone when there are tics and comorbid behavioural problems such as irritability, aggression and insomnia (Eapen &

Gururaj, 2005). Presence of comorbid OCD would need attention and may necessitate treatment with specific serotonin reuptake inhibitors, while co-morbid ADHD would necessitate the use of stimulants (with caution, monitoring for tic exacerbation) or atomoxetine. The risk of drug interactions and side effects may be increased in those with brain damage or epilepsy, and gradual increase in dosage with close monitoring is recommended in these situations (Eapen & Črnčec, 2009). Psychotherapeutic techniques such as cognitive-behaviour therapy for OCD or comprehensive behavioural intervention for tics (CBIT) have established efficacy (Piacentini, Woods, Scahill, & et al., 2010; Watson & Rees, 2008); however, outcomes may be constrained in individuals where poor cognitive and learning abilities, and hyperactivity, are a factor. Yale Global Tic Severity Rating Scale (YGTSS; Leckman et al. (1989)) can be a useful tool in monitoring progress following intervention for tics.

Sleep problems

It is also important to monitor common comorbidities such as sleep disturbances which left untreated, can have significant impact on a child's cognition, academic functioning, behavior, and mental health. Although sleep problems in children with ASD are similar to those of the general population, they occur at markedly higher rates. Approximately 73-86% of children with ASD experience problems with sleep onset and maintenance (e.g., long sleep onset latency, short sleep duration, early morning waking (Liu, Hubbard, Fabes, & Adam, 2006; Polimeni, Richdale, & Francis, 2005). May et al. recently found that 78% of children with ASD had parent-reported sleep problems compared to 29% of typically developing controls, with 65% of children with ASD having persistent sleep problems one-year later (n=84; 5-12 years) (May, Cornish, Conduit, Rajaratnam, & Rinehart, 2013). This study also showed that children with ASD who were poor sleepers were more aggressive, hyperactive and experienced greater social problems. Papadopoulos et al. (2015) recently showed that a brief, behaviourally focussed intervention delivered to parents resulted in significantly improved sleep problems and behavioural problems for children with ASD. In addition, parents reported improvements in their own mental health after participating in this program. This is an important finding given sleep problems in children with ASD have a pervasive impact on the family, including elevated risk for parental stress and poor mental health (Doo & Wing, 2006).

Children's Sleep Habits Questionnaire (CSHQ)

A useful tool for monitoring sleep in children with ASD is the Children's Sleep Habits Questionnaire (CSHQ; Owens, Spirito, and McGuinn (2000)). The CSHQ is 33-item, behaviour parent-reported validated measure of disorders of initiating and maintaining sleep that can distinguish clinical from community samples. Eight subscale scores reflect major behavioural sleep disorders (bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, sleep disordered breathing, daytime sleepiness).

Sleep Diary

Sleep diaries are also commonly used to monitor sleep disturbances in children with ASD. Sleep diaries typically involve parents recording the time their child gets into bed at night, falls asleep, any awakenings, and morning wake time, permitting the calculation of sleep duration, sleep onset latency, and number and duration of night wakings.

Eating Problems

Children with ASD have been described to have atypical eating behaviors and food selectivity is the most frequent of these problems. The everyday management of mealtime behaviors among children with ASD can have a negative impact on family routines and become a significant stressor for families. In a recent study Postorino et al. (2015) investigated the clinical and behavioral features in individuals with ASD with the aim of identifying distinctive clinical profiles in children with and without food selectivity. These authors observed that, while there was no statistically significant difference on gastrointestinal symptoms and growth adequacy between those with and without food sensitivity, parents of those with food sensitivity reported significantly higher levels of parental stress and attributed a larger degree of their children's behavioural problems to this. These findings suggest that early identification and appropriate intervention coupled with ongoing monitoring of distinctive clinical and behavioural patterns linked to food sensitivity should be an important consideration in children with ASD.

Anxiety and Obsessive Compulsive Behaviours

High levels of anxiety are observed in around 40% of children with ASD with a recent meta-analysis revealing that the most common type of anxiety is specific phobia (30%), followed by Obsessive Compulsive Disorder (OCD; 17%), social anxiety disorder and agoraphobia (17%), generalized anxiety disorder (15%), separation anxiety disorder (9%), and panic disorder (2%) (van Steensel, Bögels, & Perrin, 2011). Early identification and appropriate management of anxiety symptoms should form a critical component in the comprehensive management of ASD.

Depression, self-harm and suicidality

Low mood, self-harm and suicidal behaviours are higher in individuals with ASD as compared to the general population with one recent study reporting that over 35% of individuals with Asperger Syndrome diagnosis had attempted suicide in the past, making it much higher than the 4.6% lifetime prevalence seen in the general population (Paquette-Smith, Weiss, & Lunsky, 2014). However, identifying those at risk may be difficult due to the challenges in obtaining accurate history from individuals with ASD and careful informal and formal enquiries with the young person as well as corroborative evidence from parental or care giver reports would be crucial in assessing for depression and suicidal behaviours.

Bullying and victimization

Bullying and victimization are more prevalent among youth with ASD than in the general population. The role of anxiety in these situations is complex with a recent study observing that parenting stress moderates the association between bullying victimization and anxiety (Weiss, Cappadocia, Tint, & Pepler, 2015). This study also found that when mothers reported high levels of stress, the severity of anxiety was most strongly associated with bullying victimization which has implications for the management of both child anxiety and parental stress in addressing bullying and victimization.

Psychosis and catatonia

Co-occurrence of psychotic symptoms in patients with ASD can be challenging as some of the core features of ASD such as deficits in social reciprocity and communication, as well as restricted behaviours and interests, can be mistaken for psychosis. There are also instances of mis-diagnosis or missed diagnosis of psychosis in ASD as there is a subset of patients who present with a complex neurodevelopmental disorder with impairments that cross diagnostic categories (Cochran, Dvir, &

Frazier, 2013). Further, symptoms of catatonia are being increasingly recognized at a rate of 4–17% in adolescents and adults with ASD (Dhossche, 2014). However it is to be noted that behaviours such as repetitive movements, mutism, posturing, and frantic agitation can occur in autism and hence caution should be exercised and a diagnosis of catatonia should not be made unless there is a sharp and sustained increase of these symptoms persisting for several days or weeks. DeJong, Bunton, and Hare (2014) in a recent review reported 22 papers that described the treatment of catatonic symptoms in a total of 28 children and adults with ASD using Electroconvulsive therapy (ECT), high-dose lorazepam, and behavioural therapy.

Pharmacotherapy and monitoring to evaluate the outcome of medication use

No drug is currently known to improve autism characteristics. A key principle is to identify target symptoms and medication choice is matched to those goals. For example risperidone has been found to reduce disruptive behaviour disorder symptoms including aggression and conduct problems in children aged 5 to 18 in the short term and on follow up over 6 months (Loy, Merry, Hetrick, & Stasiak, 2012), measuring outcomes with the irritability subscale of the Aberrant Behaviour Checklist (ABC; Aman et al. (1985)) and Conduct Problem subscale of the Nisonger Child Behaviour Rating Form (NCBRF-CP; Aman, Tassé, Rojahn, and Hammer (1996)). Thus whether using second generation antipsychotics including risperidone and aripiprazole for severe behavioural disturbance such as tantrums, aggression, self-injury, etc. (Stigler, 2014), stimulants for ADHD, melatonin for sleep problems, or Selective Serotonin Reuptake Inhibitor (SSRI) for anxiety, OCD, or depression, both careful assessment of baseline symptoms as well as any change in symptoms following treatment will need to be carefully monitored using relevant scales that are specific to each of these conditions and symptom profiles as well as measures of overall improvement such as the Clinical Global Impression Severity Scale (Busner & Targum, 2007). CGI-S is a widely used clinical rating scale of the severity of symptoms, and it is treatment sensitive. Similarly there is a need to include monitoring for adverse events of medication use. It is essential to monitor the side effects of individual medication using specific questionnaires to elicit the relevant side effects as applicable to each drug. There are also some general principles of monitoring that would be in order in certain situations. One such example is the need for monitoring weight gain and metabolic abnormalities when using second generation antipsychotics (SGAs) such as risperidone as these drugs are commonly used in ASD. Given that the current evidence points to the occurrence of the key antecedents of metabolic syndrome soon after initiation of the medication, suggested practice guideline for cardiometabolic monitoring in young people on antipsychotic medication include 3-monthly in the first year and biannually thereafter (Eapen, Shiers, & Curtis, 2013).

Maximising opportunities: wellbeing, function and participation

Individual with autism

Learning and adjustment in school

Programming and progress monitoring is particularly complex in this context as many core aspects of an individualised plan may not align to a prescribed curriculum and may focus instead on non-academic skills. For example, skills such as communication, socialization and independence which underpin success in all areas of learning and are associated with positive outcomes, are intrinsically difficult to measure and incorporate into a curriculum. Individualised plans must include measurable

academic and functional goals that are not merely restatements of curriculum, standards or expectations, but are observable, relevant and assessable objectives intended to facilitate specific gains in academic standards and life skills.

The usual approach to measuring achievement in school is standardised testing. Administering a standardised test to a child with ASD can be difficult, and the results somewhat misleading. Students with ASD may demonstrate challenging behaviour during the assessment, and research shows that test scores may improve significantly if specialised procedures are implemented to increase the student's engagement in the assessment task (Koegel, Koegel, & Smith, 1997). Further, although criterion-based or observation-based assessments often provide valuable complementary information, numerous studies have shown that contextual variables such as the amount of attention given to the student prior to the assessment (McComas, Thompson, & Johnson, 2003; Roantree & Kennedy, 2006), the environment (Lang et al., 2009), the person implementing the assessment (Ringdahl & Sellers, 2000) and the motivation of the person with autism and interest in the test materials can all affect the outcome.

It is important to consider what data will need to be collected to document student progress towards IP goals, which tools will be used to generate the data, and how frequently and who will collect data and report progress. Popular methods employed by educators include: direct methods, indirect methods and authentic methods. As has been discussed, each of these approaches in isolation may not be effective in assessing the child with ASD. Direct methods include behaviour observation, such as frequency, duration and interval recording, and curriculum-based assessment. Indirect methods are often auxiliary and include rubrics, which describe performance in qualitative or quantitative terms, attainment scaling, in which the educator rates the student responses on a best-to-worst scale, and student self-monitoring. Authentic methods such as anecdotal notes of informal interviews with students and portfolios of student work involving relevant skills as appropriate for the age.

PEP3:

The Psycho Educational Profile 3 (PEP3; Eric Schopler, Lansing, Reichler, and Marcus (2005)) is designed to provide information to inform educational programming (IEP) by evaluating uneven learning strengths and weaknesses that characterise ASD, and provide information on developmental skill levels. The test also provides a measure of severity, establishes developmental/adaptive levels and serves as a research tool in outcome research and learning. This is particularly useful for program development and targets social communication and adaptive behaviour. It can be administered by competent and experienced staff and is norm referenced, and provides a measure across core domains of communication, motor and adaptive/maladaptive behaviour, and collects information from a variety of sources; parents, teachers and direct observation (enabling triangulation of data).

Teacher Rating Scale of School Adjustment

(TRSSA; Betts and Rotenberg (2007)) has been demonstrated to have acceptable internal consistency and stability and can be used to evaluate school adjustment and participation across different time points. An exploratory factor analysis of the TRSSA has yielded three associated factors namely On-Task Classroom Involvement, Positive Orientation, and Maturity.

Function

One of the important considerations in monitoring progress following intervention in ASD involves reduction of characteristics that have a functional impact. While reduction in ASD characteristics has been extensively studied, the improvement in functioning has not been sufficiently addressed in ASD. While some characteristics may be persistent, pervasive or occur frequently but have limited impact on day-to-day functioning, others although infrequent may have a more profound functional impact. Also, it has been suggested that functional impairment may be independent of the presence and frequency of the characteristics as is the case with psychiatric disorders, where the course and outcomes are different based on the presence or not of functional impairment (Bird et al., 1996). Evidence that indicates the relationship between autism characteristics and function is not straightforward is now emerging (ref). Further there are issues pertaining to inconsistencies with the operational definition as well as the measurement of functional impairment (Canino, Costello, & Angold, 1999). While assessment of overall improvement is the focus with measures such as the Children's Global Assessment of Functioning (Shaffer et al., 1983), others such as the Vineland -II (Sparrow et al., 2005), have a focus on specific aspects of adaptive functioning and activities of daily living. Both these methods have distinct advantages and disadvantages and further, these measures do not link the functioning with specific characteristics in that they do not consider the impact of individual problems on functioning. Measures such as the AIM hold promise in this regard by linking the frequency, impact and interference of each symptom with overall functioning that would have significant advantage in assisting with treatment planning and outcome assessment (Kanne et al., 2014).

Participation

School

For all children the crudest measure of participation in school is attendance. Attendance includes participation in the academic curriculum, that can be achieved at a school campus or in the home environment. Unfortunately today many children with autism do not participate in the school curriculum either because they have been excluded from it or because they refuse to go to school. The former indicates problems with ability to manage the types of problems that can occur in children and young people with autism and the latter a failure in addressing issues or concerns to minimise the risk of refusal.

Participation in the social curriculum (sometimes called the "hidden curriculum") is also important. It is not as immediately available to children and young people in home schooling. Attendance at a school campus is not sufficient to ensure participation in the social curriculum. As such monitoring is needed to ensure it is occurring. For children who are attending school monitoring of participation should include information from the classroom and outside the classroom. Monitoring should be linked to specific program goals designed to enable the student to participate in non-academic aspects of school life. Assessments such as the Participation and Environment Measure for Children and Youth (PEMICY) (Coster, Law, Bedell, Khetani, Anaby, Teplicky, Lin, 2013) may also be useful.

After school

Post-school participation is typically conceptualised along three dimensions: employment, independent living, and participation in post-secondary education. For a student with ASD, the high school years and IP should be catered to maximising these outcomes and their educational focus

shift from aiming to fill in missing gaps in the student’s developmental profile to optimise their post-school lifestyle and opportunities preparation for independence. In the United States, for example, students with disabilities are generally required to develop a transition plan as the driving force of their IP at age 14. Hence, while progress in ASD may still be measured broadly in regards to cognition and adaptive functioning at this stage in life, there will also be a greater emphasis on the attainment of specific practical skills. Overall, in terms of assessment and monitoring of progress, instead of continuing to assess what the student cannot do and working towards improvements in those areas, the IP must be based on student interests, preferences, strengths, work habits and describe the supports and modifications necessary for their future success.

At this stage, evaluation of ability should comprise both formal assessment tools as well as more of the auxiliary methods previously described, such as structured observations and grading and feedback of work samples. It should include assessment of: student interests and preferences, career awareness, cognitive development, academic achievement, adaptive behaviour, self-determination, interpersonal relationship and social skills, communication skills, emotional development and mental health, employment and community skills and community participation and independent living skills. In this regard, age appropriate, specific and measurable goals as detailed in Table 3 must be set relevant to school and post-school participation in education, employment and independent living skills..

Table 3: Examples of target goals, measurement of such goals and relevant interventions in ASD

Skill area	Targeted behaviour	Measurement	Intervention	Reference
Academics	Essay writing - total words written and function essay elements included	Number of words and elements	Video modeling and self-monitoring	(Delano, 2007a)
	Essay writing - total words written, number of unique verbs, adverbs and adjectives	Number of target elements	Instruction, modeling, practice and feedback	(Delano, 2007b)
Adaptive skills	Setting the table and putting away groceries	Percentage of tasks performed correctly	Task analysis and video prompting	(Cannella-Malone et al., 2006)
	Packing and unpacking bag, brushing teeth	Percentage of tasks performed correctly	Task analysis and video prompting	(Rayner, 2010)
	Washing dishes	Percentage of tasks performed correctly	Task analysis and video prompting	(Sigafos et al., 2007)
Problem behaviour	Disruptions, physical and verbal aggression, and straightening (obsessive) behaviour	Problem behaviour per minute and percentage of items straightened	Functional communication training with extinction	(Kuhn, Hardesty, & Sweeney, 2009)
	Physical aggression and destructive behaviour	Frequency of aggressive behaviour	Mindfulness exercise	(Singh et al., 2011)
Social skills	Conversational basics; providing positive feedback to a speaker and answering open-ended questions	Percentage of steps performed correctly	Group instruction, modeling, roleplay and feedback	(Dotson, Leaf, Sheldon, & Sherman, 2010)
	Initiation to peers and responses to peers	Frequency of behaviour	Script and prompting	(Krantz & McClannahan, 1993)
Vocational skills	Prepare folders with advertising material,	Percentage of tasks completed successfully	Simulation training: most-to-	(Lattimore, Parsons, &

	prepare folders and information notebooks	and independently	least prompting and task instruction	Reid, 2008)
	Cleaning of sinks and mirrors in a company bathroom, and washing up in the break room	Percentage of tasks completed successfully and independently	Simulation training: most-to-least prompting and task instruction	(Lattimore et al., 2008)

Community

With regards to participation in community activities, available evidence from the literature suggests that children with ASD participate in activities less frequently and with less variety compared to children with other developmental disabilities as well as those who are developing normally (LaVesser & Berg, 2011). Measures that have been used in this context include assessments based on self-reports such as the Child Assessment of Participation and Enjoyment (CAPE; King et al. (2006)) although children with ASD would find this difficult to undertake and assessors would find it difficult to interpret the responses due to the child's limited social-communication abilities. Measures that use interview with a caregiver such as the Preschool Activity Card Sort (Berg & LaVesser, 2006) are difficult to administer as they are resource intensive and require considerable amount of interviewer time. While there are some measures that focus on specific activities as is the case with Participation in Childhood Occupations Questionnaire (PICO-Q; Bar-Shalita, Yochman, Shapiro-Rihtman, Vatine, and Parush (2009)) or in specific contexts such as the Child Routines Inventory (Sytsma, Kelley, & Wymer, 2001); Children Helping Out: Responsibilities, Expectations, and Supports, (CHORES; Dunn (2004)) etc., valid general measures of activity participation for use in ASD population are lacking. In a recent study, Little et al. (2014), investigated the use of Home and Community Activities Scale (HCAS; adapted fromDunst, Hamby, Trivette, Raab, and Bruder (2000)) in a large cohort of 713 children with ASD and found that activity participation of school-age children fell into six dimensions namely Parent-Child Household Activities, Community Activities, Routine Errands, Neighborhood-Social Activities, Outdoor Activities, and Faith-Based Activities(Little, Sideris, Ausderau, & Baranek, 2014).

Families: parents, carers and siblings

Families of children with ASD face unique challenges, and as a result ASD families experience higher levels of stress (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009) which can have a significant impact on their quality of life. Siblings can also experience significant challenges and a number of factors may affect the dynamic of the relationship, continually evolving and changing across the course of life (Orsmond & Seltzer, 2007). Monitoring progress in ASD would therefore need to include family adjustment and quality of life, stress and coping as well as parental satisfaction, competence and confidence to manage their child as well as parental perception of their capacity to participate in their community.

The interactions between brothers and sisters provide them with opportunity to experience sharing, companionship, rivalry, and other outcomes. Researchers who study ASD do not have a clear understanding of why some sibling pairs experience warm, supportive relationships, whereas others experience conflict and isolation (Rivers & Stoneman, 2003). Many individuals with ASD have

behaviour repertoires that might be expected to affect sibling relationships and the social, behavioural, and psychological adjustment of their typically developing siblings. Findings regarding the effects of having a sibling with ASD have been mixed and inconsistent (Macks & Reeve, 2007; Mascha & Boucher, 2006; Verté, Roeyers, & Buysse, 2003). Some researchers (e.g., (Hastings, 2003b; Ross & Cuskelly, 2006)) (e.g., Hastings, 2003b; Ross & Cuskelly, 2006) have reported negative outcomes (e.g., loneliness, behavioural difficulties, depression) for the typically developing siblings, whereas other researchers (e.g., Kaminsky & Dewey, 2001; Mascha & Boucher, 2006) have found positive outcomes (e.g., less conflict within the relationship, high self-esteem and self-concept) or no evidence of negative effects (Hastings, 2003a; Orsmond & Seltzer, 2007). Orsmond and Seltzer investigated adult siblings of individuals with ASD and DS and found that typically developing adult siblings of individuals with ASD reported significantly less contact and less positive effect in the relationship with their sibling with ASD than did the DS group. Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev (2004) reported that most siblings of individuals with ASD were well adjusted, but emphasized that the stress of having a sibling with ASD cannot be overlooked.

Comprehensive monitoring of outcomes should include the well being of parents, siblings and carers involved in the life of a young person with ASD. Thus for the overall improvement, independent living outcomes, maladaptive behaviours as well as general well being, family stress, coping and quality of life, other relevant measures are indicated. Examples include Autism Treatment Evaluation Checklist (ATEC: Rimland and Edelson (1999)), Parent Stress Index (PSI: (Abidin, 1990a)) and Quality of Life in Autism (QoLA: Eapen et al. (2014)).

The Depression Anxiety Stress Scales

The Depression Anxiety Stress Scales (DASS; Lovibond & Lovibond, 1995) is a 21-item self-report measure that assesses negative affect, generating separate scores for the subscales of Depression, Anxiety and Stress. The Anxiety scale assesses what causes arousal, what situations cause anxiety and what experiences have led to this effect. The Stress scale assesses whether the person has difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatient. Higher scores indicate greater symptomatology. The DASS-21 has been shown to have excellent psychometric properties (Antony, Bieling, Cox, Enns, & Swinson, 1998; Henry & Crawford, 2005; Lovibond & Lovibond, 1995).

The Parenting Sense of Competence Scale

The Parenting Sense of Competence Scale (PSOC; Johnston & Mash, 1989) includes 17 items designed to measure parental self-efficacy. Based on the factor structure found in Australian populations (Rogers & Matthews, 2004), the scale generates scores on three subscales: Satisfaction, Efficacy, and Interest, with higher scores indicative of higher levels of parental satisfaction and self-efficacy. The PSOC has been found to have strong psychometric properties (Rogers & Matthews, 2004).

Parenting Stress Index

Parenting Stress Index Short Form (PSI-SF) (Abidin, 1990b): The PSI Short Form (PSI/SF) has 36 items written at a 5th-grade reading level, for parents of children 12 years and younger. The PSI/SF yields a Total Stress score from three scales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child.

Pediatric Quality of Life Inventory (PedsQL)

The Pediatric Quality of Life Inventory (PedsQL) (Varni and Seid 1999) follows a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL Measurement Model integrates seamlessly both generic core scales and disease-specific modules into one measurement system and different developmentally appropriate (Ages 2-18; Child Self-Report Ages 5-7, 8-12, 13-18; Parent Proxy-Report Ages 2-4, 5-7, 8-12, 13-18) forms are available. While disease specific modules are available for some of the chronic health conditions, there is no specific module for autism.

The Quality of Life in Autism

The Quality of Life in Autism (QoLA) contains two subscales: Part A, with questions pertaining to overall quality of life, and Part B, with questions asking parents to rate the impact of autism-specific symptoms of their child on parental daily activities. A preliminary study showed good psychometric properties with strong internal consistency and convergent validity (Eapen et al., 2014)

Conclusions and directions for future research

Fit-for-purpose monitoring of individuals with ASD and their families offers the opportunity to individually tailor interventions, with timely adaptations based on emerging skills and difficulties, identify commonly occurring problems early, with the hope of preventing or minimising any negative impact, and to ensure that every individual with autism and their family are reaching their potential for function and community participation. Along the way we are likely to also discover new information about how to build on the strengths of individuals with autism and how the environment and community can accommodate difference to minimise avoidable disability.

We are not yet equipped with tools that are ideal for these tasks, and so tools development is needed. In particular, appropriate measures to evaluate participation and functional impact are needed. Although Home and Community Activities Scale (HCAS) has been recently adapted for use in ASD, further research is needed to validate the HCAS factor structure and to expand the responses to be more sensitive to a range of frequency options as well as ratings of enjoyment. In addition, studies are needed to better address questions such as with whom participation occurs and level of functioning and activity participation as individuals with ASD transitions from preschool to school and to post school options and adult life. Nor do we have services that value monitoring or that make it easy for this to be integrated across different types of services that are accessed by individuals with autism and their families. Seamless monitoring across the lifespan of developmental progress, scholastic achievement and also functional impact and participation in activities and civic life is the exception rather than the rule. A greater understanding of the link between and relative importance of the characteristics of autism and function and participation is also needed, from the perspective of individuals with autism and their families. Only this will ensure that monitoring is fit-for-purpose and relevant.

References

- Abidin, R. R. (1990a). *Parenting Stress Index (PSI)*: Pediatric Psychology Press.
- Abidin, R. R. (1990b). *Parenting Stress Index:(Short Form)*: Pediatric Psychology Press.
- Achenbach, T. M., & Rescorla, L. A. (2001). *Manual for the ASEBA School-Age Forms & Profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.
- Aman, M. G., Singh, N. N., Stewart, A. W., & Field, C. J. (1985). The aberrant behavior checklist: a behavior rating scale for the assessment of treatment effects. *American journal of mental deficiency*(89), 485-491.
- Aman, M. G., Tassé, M. J., Rojahn, J., & Hammer, D. (1996). The Nisonger CBRF: A child behavior rating form for children with developmental disabilities. *Res Dev Disabil*, 17(1), 41-57. doi: [http://dx.doi.org/10.1016/0891-4222\(95\)00039-9](http://dx.doi.org/10.1016/0891-4222(95)00039-9)
- Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment*, 10(2), 176.
- Bar-Shalita, T., Yochman, A., Shapiro-Rihtman, T., Vatine, J.-J., & Parush, S. (2009). The participation in childhood occupations questionnaire (PICO-Q): A pilot study. *Physical & occupational therapy in pediatrics*, 29(3), 295-310.
- Baron-Cohen, S., Scahill, V. L., Izaguirre, J., Hornsey, H., & Robertson, M. (1999). The prevalence of Gilles de la Tourette syndrome in children and adolescents with autism: a large scale study. *Psychological Medicine*, 29(05), 1151-1159.
- Bartak, L., Bottroff, V., & Zeitz, J. (2006). Therapist Insights in Working with Stress in People with Autism Spectrum Disorder. In M. G. Baron, J. Groden, G. Groden, & L. Lipsitt (Eds.), *Stress and Coping in Autism* (pp. 246- 273). New York: Oxford University Press.
- Bayley, N. (1993). *Bayley scales of infant development: Manual*: Psychological Corporation.
- Berg, C., & LaVesser, P. (2006). The Preschool Activity Card Sort. *OTJR: Occupation, Participation and Health*, 26(4), 143-151. doi: 10.1177/153944920602600404
- Berument, S. K., Rutter, M., Lord, C., Pickles, A., & Bailey, A. (1999). Autism screening questionnaire: diagnostic validity. *The British Journal of Psychiatry*, 175(5), 444-451.
- Betts, L. R., & Rotenberg, K. J. (2007). A Short Form of the Teacher Rating Scale of School Adjustment. *Journal of Psychoeducational Assessment*, 25(2), 150-164. doi: 10.1177/0734282906296406
- Bird, H. R., Andrews, H., Schwab-Stone, M., Goodman, S., Dulcan, M., Richters, J., . . . Hoven, C. (1996). Global measures of impairment for epidemiologic and clinical use with children and adolescents. *International Journal of Methods in Psychiatric Research*.
- Bishop, D. (2003). *Children's Communication Checklist - Second Edition (CCC-2)*. London, UK: The Psychological Corporation.
- Bishop, S. L., Richler, J., & Lord, C. (2006). Association Between Restricted and Repetitive Behaviors and Nonverbal IQ in Children with Autism Spectrum Disorders. *Child Neuropsychology*, 12(4-5), 247-267. doi: 10.1080/09297040600630288
- Bodfish, J., Symons, F., Parker, D., & Lewis, M. (2000). Varieties of Repetitive Behavior in Autism: Comparisons to Mental Retardation. *J Autism Dev Disord*, 30(3), 237-243. doi: 10.1023/a:1005596502855
- Brereton, A. V., Tonge, B. J., Mackinnon, A. J., & Einfeld, S. L. (2002). Screening Young People for Autism With the Developmental Behavior Checklist. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41(11), 1369-1375. doi: 10.1097/00004583-200211000-00019

- Brian, J. A., Bryson, S. E., & Zwaigenbaum, L. (2015). Autism spectrum disorder in infancy: developmental considerations in treatment targets. *Current opinion in neurology*, 28(2), 117-123.
- Busner, J., & Targum, S. D. (2007). The Clinical Global Impressions Scale: Applying a Research Tool in Clinical Practice. *Psychiatry (Edgmont)*, 4(7), 28-37.
- Canino, G., Costello, E. J., & Angold, A. (1999). Assessing Functional Impairment and Social Adaptation for Child Mental Health Services Research: A Review of Measures. *Mental Health Services Research*, 1(2), 93-108. doi: 10.1023/A:1022334303731
- Cannella-Malone, H., Sigafoos, J., O'Reilly, M., Cruz, B. d. I., Edrisinha, C., & Lancioni, G. E. (2006). Comparing Video Prompting to Video Modeling for Teaching Daily Living Skills to Six Adults with Developmental Disabilities. *Education and Training in Developmental Disabilities*, 41(4), 344-356. doi: 10.2307/23879661
- Centers for Disease Control and Prevention. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *Surveillance Summaries*, 63(02), 1-21.
- Charman, T., Pickles, A., Simonoff, E., Chandler, S., Loucas, T., & Baird, G. (2011). IQ in children with autism spectrum disorders: data from the Special Needs and Autism Project (SNAP). *Psychological Medicine*, 41(03), 619-627. doi: doi:10.1017/S0033291710000991
- Charman, T., & Stone, W. (2008). *Social and communication development in autism spectrum disorders: Early identification, diagnosis, and intervention*: Guilford Press.
- Chawarska, K., Klin, A., Paul, R., & Volkmar, F. (2007). Autism spectrum disorder in the second year: stability and change in syndrome expression. *Journal of Child Psychology and Psychiatry*, 48(2), 128-138. doi: 10.1111/j.1469-7610.2006.01685.x
- Cochran, D. M., Dvir, Y., & Frazier, J. A. (2013). "Autism-plus" Spectrum Disorders: Intersection with Psychosis and the Schizophrenia Spectrum. *Child and Adolescent Psychiatric Clinics of North America*, 22(4), 609-627. doi: <http://dx.doi.org/10.1016/j.chc.2013.04.005>
- Constantino, J. N., Davis, S. A., Todd, R. D., Schindler, M. K., Gross, M. M., Brophy, S. L., . . . Reich, W. (2003). Validation of a Brief Quantitative Measure of Autistic Traits: Comparison of the Social Responsiveness Scale with the Autism Diagnostic Interview-Revised. *J Autism Dev Disord*, 33(4), 427-433. doi: 10.1023/a:1025014929212
- Constantino, J. N., & Gruber, C. P. (2005). *The Social Responsiveness Scale*. Los Angeles: Western Psychological Services.
- Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., . . . Varley, J. (2010). Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model. *Pediatrics*, 125(1), e17-e23. doi: 10.1542/peds.2009-0958
- DeJong, H., Bunton, P., & Hare, D. (2014). A Systematic Review of Interventions Used to Treat Catatonic Symptoms in People with Autistic Spectrum Disorders. *J Autism Dev Disord*, 44(9), 2127-2136. doi: 10.1007/s10803-014-2085-y
- Dekker, M., Nunn, R., & Koot, H. (2002). Psychometric properties of the revised Developmental Behaviour Checklist scales in Dutch children with intellectual disability. *Journal of Intellectual Disability Research*, 46(1), 61-75.
- Delano, M. E. (2007a). Improving Written Language Performance of Adolescents with Asperger Syndrome. *Journal of Applied Behavior Analysis*, 40(2), 345-351. doi: 10.1901/jaba.2007.50-06
- Delano, M. E. (2007b). Use of Strategy Instruction to Improve the Story Writing Skills of a Student With Asperger Syndrome. *Focus on Autism and Other Developmental Disabilities*, 22(4), 252-258. doi: 10.1177/10883576070220040701
- Dhossche, D. M. (2014). Decalogue of Catatonia in Autism Spectrum Disorders. *Frontiers in Psychiatry*, 5, 157. doi: 10.3389/fpsy.2014.00157

- Dominick, K. C., Davis, N. O., Lainhart, J., Tager-Flusberg, H., & Folstein, S. (2007). Atypical behaviors in children with autism and children with a history of language impairment. *Res Dev Disabil*, *28*(2), 145-162. doi: 10.1016/j.ridd.2006.02.003
- Doo, S., & Wing, Y. K. (2006). Sleep problems of children with pervasive developmental disorders: correlation with parental stress. *Developmental Medicine & Child Neurology*, *48*(8), 650-655. doi: 10.1111/j.1469-8749.2006.tb01334.x
- Dotson, W. H., Leaf, J. B., Sheldon, J. B., & Sherman, J. A. (2010). Group teaching of conversational skills to adolescents on the autism spectrum. *Research in Autism Spectrum Disorders*, *4*(2), 199-209.
- Dunn, L. (2004). Validation of the CHORES: a measure of school-aged children's participation in household tasks. *Scandinavian Journal of Occupational Therapy*, *11*(4), 179-190.
- Dunst, C. J., Hamby, D., Trivette, C. M., Raab, M., & Bruder, M. B. (2000). Everyday family and community life and children's naturally occurring learning opportunities. *Journal of Early Intervention*, *23*(3), 151-164.
- Eapen, V., #x10C, rn, #x10D, ec, R., Walter, A., & Tay, K. P. (2014). Conceptualisation and Development of a Quality of Life Measure for Parents of Children with Autism Spectrum Disorder. *Autism Research and Treatment*, *2014*, 11. doi: 10.1155/2014/160783
- Eapen, V., & Črnčec, R. (2009). Tourette syndrome in children and adolescents: Special considerations. *Journal of Psychosomatic Research*, *67*(6), 525-532. doi: 10.1016/j.jpsychores.2009.08.003
- Eapen, V., Črnčec, R., McPherson, S., & Snedden, C. (2013). Tic Disorders and Learning Disability: Clinical Characteristics, Cognitive Performance and Comorbidity. *Australasian Journal of Special Education*, *37*(02), 162-172.
- Eapen, V., Crncec, R., & Walter, A. (2013). Clinical outcomes of an early intervention program for preschool children with Autism Spectrum Disorder in a community group setting. *BMC Pediatr*, *13*(1), 3. doi: 10.1186/1471-2431-13-3
- Eapen, V., & Gururaj, A. K. (2005). Risperidone Treatment in 12 Children With Developmental Disorders and Attention-Deficit/Hyperactivity Disorder. *Primary Care Companion to The Journal of Clinical Psychiatry*, *7*(5), 221-224.
- Eapen, V., Robertson, M. M., Zeitlin, H., & Kurlan, R. (1997). Gilles de la Tourette's syndrome in special education schools: a United Kingdom study. *Journal of Neurology*, *244*(6), 378-382.
- Eapen, V., Shiers, D., & Curtis, J. (2013). Bridging the gap from evidence to policy and practice: Reducing the progression to metabolic syndrome for children and adolescents on antipsychotic medication. *Australian and New Zealand Journal of Psychiatry*, *47*(5), 435-442. doi: 10.1177/0004867412463169
- Einfeld, S. L., & Tonge, B. J. (1992). *Manual for the Developmental Behaviour Checklist Primary Carer Version (DBC-P)* (Vol. 40): School of Psychiatry, University of NSW and Center for Developmental Psychiatry, Monash University.
- Einfeld, S. L., & Tonge, B. J. (1995). The Developmental Behavior Checklist: The development and validation of an instrument to assess behavioral and emotional disturbance in children and adolescents with mental retardation. *J Autism Dev Disord*, *25*(2), 81-104. doi: 10.1007/bf02178498
- Einfeld, S. L., & Tonge, B. J. (2002). *Manual for the Developmental Behaviour Checklist: Primary Carer Version and Teacher Version* (2 ed.): School of Psychiatry, University of NSW and Center for Developmental Psychiatry, Monash University.
- Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Meta-Analysis of Early Intensive Behavioral Intervention for Children With Autism. *Journal of Clinical Child & Adolescent Psychology*, *38*(3), 439-450. doi: 10.1080/15374410902851739
- Emck, C., Bosscher, R., Beek, P., & Doreleijers, T. (2009). Gross motor performance and self-perceived motor competence in children with emotional, behavioural, and pervasive

- developmental disorders: a review. *Developmental Medicine & Child Neurology*, 51(7), 501-517. doi: 10.1111/j.1469-8749.2009.03337.x
- Forlin, C., Chambers, D., Loreman, T., Deppeler, J., & Sharma, U. (2013). *Inclusive Education for Students with Disability: A review of the best evidence in relation to theory and practice*.
- Fulton, E., Eapen, V., Črnčec, R., Walter, A., & Rogers, S. (2014). Reducing Maladaptive Behaviors in Preschool-Aged Children with Autism Spectrum Disorder Using the Early Start Denver Model. *Frontiers in Pediatrics*, 2, 40. doi: 10.3389/fped.2014.00040
- Gargaro, B. A., May, T., Tonge, B. J., Sheppard, D. M., Bradshaw, J. L., & Rinehart, N. J. (2014). Using the DBC-P Hyperactivity Index to screen for ADHD in young people with autism and ADHD: A pilot study. *Research in Autism Spectrum Disorders*, 8(9), 1008-1015. doi: <http://dx.doi.org/10.1016/j.rasd.2014.05.004>
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A Research Note. *Journal of Child Psychology and Psychiatry*, 38(5), 581-586. doi: 10.1111/j.1469-7610.1997.tb01545.x
- Gotham, K., Pickles, A., & Lord, C. (2009). Standardizing ADOS Scores for a Measure of Severity in Autism Spectrum Disorders. *J Autism Dev Disord*, 39(5), 693-705. doi: 10.1007/s10803-008-0674-3
- Griffiths, R. (2006). *Griffiths Mental Development Scales*. Oxford, UK: Hogrefe Ltd.
- Hastings, R. P. (2003a). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *J Autism Dev Disord*, 33(2), 141-150.
- Hastings, R. P. (2003b). Brief report: Behavioral adjustment of siblings of children with autism. *J Autism Dev Disord*, 33(1), 99-104.
- Hedvall, A., Westerlund, J., Fernell, E., Holm, A., Gillberg, C., & Billstedt, E. (2014). Autism and developmental profiles in preschoolers: stability and change over time. *Acta Paediatr*, 103(2), 174-181. doi: 10.1111/apa.12455
- Henry, J. D., & Crawford, J. R. (2005). The short - form version of the Depression Anxiety Stress Scales (DASS - 21): Construct validity and normative data in a large non - clinical sample. *British Journal of Clinical Psychology*, 44(2), 227-239.
- Hoffman, C. D., Sweeney, D. P., Hodge, D., Lopez-Wagner, M. C., & Looney, L. (2009). Parenting stress and closeness mothers of typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 24(3), 178-187.
- Howlin, P., Magiati, I., & Charman, T. (2009). Systematic review of early intensive behavioral interventions for children with autism. *Journal Information*, 114(1).
- Hudry, K., Leadbitter, K., Temple, K., Slonims, V., McConachie, H., Aldred, C., . . . Charman, T. (2010). Preschoolers with autism show greater impairment in receptive compared with expressive language abilities. *International journal of language & communication disorders*, 45(6), 681-690.
- Individuals with Disabilities Education Improvement Act of 2004, Pub. L. No. 108-446, §611-619 (2004).
- Johnston, C., & Mash, E. J. (1989). A Measure of Parenting Satisfaction and Efficacy. *Journal of Clinical Child Psychology*, 18(2), 167-175. doi: 10.1207/s15374424jccp1802_8
- Jordan, R., & Jones, G. (2012). *Meeting the needs of children with autistic spectrum disorders*. Routledge.
- Kaminsky, L., & Dewey, D. (2001). Siblings relationships of children with autism. *J Autism Dev Disord*, 31(4), 399-410.
- Kanne, S. M., Mazurek, M. O., Sikora, D., Bellando, J., Branum-Martin, L., Handen, B., . . . Warren, Z. (2014). The Autism Impact Measure (AIM): initial development of a new tool for treatment outcome measurement. *J Autism Dev Disord*, 44(1), 168-179. doi: 10.1007/s10803-013-1862-3

- Kasari, C., Freeman, S., & Paparella, T. (2006). Joint attention and symbolic play in young children with autism: a randomized controlled intervention study. *Journal of Child Psychology and Psychiatry*, *47*(6), 611-620. doi: 10.1111/j.1469-7610.2005.01567.x
- King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., . . . Petrenchik, T. (2006). Predictors of the Leisure and Recreation Participation of Children With Physical Disabilities: A Structural Equation Modeling Analysis. *Children's Health Care*, *35*(3), 209-234. doi: 10.1207/s15326888chc3503_2
- Koegel, L. K., Koegel, R. L., & Smith, A. (1997). Variables Related to Differences in Standardized Test Outcomes for Children with Autism. *J Autism Dev Disord*, *27*(3), 233-243. doi: 10.1023/a:1025894213424
- Krantz, P. J., & McClannahan, L. E. (1993). Teaching Children With Autism To Initiate To Peers: Effects Of A Script-Fading Procedure. *Journal of Applied Behavior Analysis*, *26*(1), 121-132. doi: 10.1901/jaba.1993.26-121
- Kuhn, D. E., Hardesty, S. L., & Sweeney, N. M. (2009). Assessment and treatment of excessive straightening and destructive behavior in an adolescent diagnosed with autism. *Journal of Applied Behavior Analysis*, *42*(2), 355-360.
- Lane, A. E., Molloy, C. A., & Bishop, S. L. (2014). Classification of Children With Autism Spectrum Disorder by Sensory Subtype: A Case for Sensory - Based Phenotypes. *Autism Research*, *7*(3), 322-333.
- Lang, R., O'Reilly, M., Lancioni, G., Rispoli, M., Machalicek, W., Chan, J. M., . . . Franco, J. (2009). Discrepancy in functional analysis results across two settings: implications for intervention design. *Journal of Applied Behavior Analysis*, *42*(2), 393-397. doi: 10.1901/jaba.2009.42-393
- Lattimore, L. P., Parsons, M. B., & Reid, D. H. (2008). Simulation Training of Community Job Skills for Adults with Autism: A Further Analysis. *Behavior Analysis in Practice*, *1*(1), 24-29.
- LaVesser, P., & Berg, C. (2011). Participation Patterns in Preschool Children with an Autism Spectrum Disorder. *OTJR: Occupation, Participation and Health*, *31*(1), 33-39. doi: 10.3928/15394492-20100823-01
- Leckman, J. F., Riddle, M. A., Hardin, M. T., Ort, S. I., Swartz, K. L., Stevenson, J., & Cohen, D. J. (1989). The Yale Global Tic Severity Scale: initial testing of a clinician-rated scale of tic severity. *Journal of the American Academy of Child & Adolescent Psychiatry*, *28*(4), 566-573.
- Little, L. M., Sideris, J., Ausderau, K., & Baranek, G. T. (2014). Activity participation among children with autism spectrum disorder. *The American Journal of Occupational Therapy*, *68*(2), 177.
- Liu, X., Hubbard, J., Fabes, R., & Adam, J. (2006). Sleep Disturbances and Correlates of Children with Autism Spectrum Disorders. *Child Psychiatry and Human Development*, *37*(2), 179-191. doi: 10.1007/s10578-006-0028-3
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Jr., Leventhal, B. L., DiLavore, P. C., . . . Rutter, M. (2000). The autism diagnostic observation schedule-generic: a standard measure of social and communication deficits associated with the spectrum of autism. *J Autism Dev Disord*, *30*(3), 205-223.
- Lovibond, S., & Lovibond, P. F. (1995). *Manual for the depression anxiety stress scales*: Psychology Foundation of Australia.
- Loy, J. H., Merry, S. N., Hetrick, S. E., & Stasiak, K. (2012). Atypical antipsychotics for disruptive behaviour disorders in children and youths. *The Cochrane Library*.
- Macks, R., & Reeve, R. (2007). The Adjustment of Non-Disabled Siblings of Children with Autism. *J Autism Dev Disord*, *37*(6), 1060-1067. doi: 10.1007/s10803-006-0249-0
- Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *The British Journal of Developmental Disabilities*, *52*(102), 19-28.
- Maskey, M., Warnell, F., Parr, J., Le Couteur, A., & McConachie, H. (2013). Emotional and Behavioural Problems in Children with Autism Spectrum Disorder. *J Autism Dev Disord*, *43*(4), 851-859. doi: 10.1007/s10803-012-1622-9

- Matthews, N., Smith, C., Pollard, E., Ober-Reynolds, S., Kirwan, J., & Malligo, A. (2015). Adaptive Functioning in Autism Spectrum Disorder During the Transition to Adulthood. *J Autism Dev Disord*, 1-12. doi: 10.1007/s10803-015-2400-2
- May, T., Cornish, K., Conduit, R., Rajaratnam, S. M. W., & Rinehart, N. J. (2013). Sleep in High-Functioning Children With Autism: Longitudinal Developmental Change and Associations With Behavior Problems. *Behavioral Sleep Medicine*, 13(1), 2-18. doi: 10.1080/15402002.2013.829064
- May, T., Cornish, K., & Rinehart, N. (2014). Does Gender Matter? A One Year Follow-up of Autistic, Attention and Anxiety Symptoms in High-Functioning Children with Autism Spectrum Disorder. *J Autism Dev Disord*, 44(5), 1077-1086. doi: 10.1007/s10803-013-1964-y
- McComas, J. J., Thompson, A., & Johnson, L. (2003). The effects of pre-session attention on problem behavior maintained by different reinforcers. *Journal of Applied Behavior Analysis*, 36(3), 297-307. doi: 10.1901/jaba.2003.36-297
- Mullen, E. (1995). *Mullen Scales of Early Learning (AGS ed.)*. Circle Pines, MN: American Guidance Service Inc.
- Mundy, P., Delgado, C., Block, J., Venezia, M., Hogan, A., & Seibert, J. (2003). Early social communication scales (ESCS). *Coral Gables, FL: University of Miami*.
- National Institute for Health and Care Excellence. (2013). Autism: the management and support of children and young people on the autism spectrum *NICE clinical guidelines*. London: NICE.
- Odom, S. L., Brown, W. H., Frey, T., Karasu, N., Lee Smith-Canter, L., & Strain, P. S. (2003). Evidence-Based Practices for Young Children With Autism: Contributions for Single-Subject Design Research. *Focus on Autism and Other Developmental Disabilities*, 18(3), 166-175. doi: 10.1177/10883576030180030401
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(4), 313-320.
- Owens, J. A., Spirito, A., & McGuinn, M. (2000). The Children's Sleep Habits Questionnaire (CSHQ): psychometric properties of a survey instrument for school-aged children. *SLEEP-NEW YORK*, 23(8), 1043-1052.
- Papadopoulos, N., McGinley, J., Tonge, B., Bradshaw, J., Saunders, K., Murphy, A., & Rinehart, N. (2011). Motor Proficiency and Emotional/Behavioural Disturbance in Autism and Asperger's Disorder: Another Piece of the Neurological Puzzle? *Autism*. doi: 10.1177/1362361311418692
- Papadopoulos, N., Sciberras, E., Hiscock, H., Mulraney, M., McGillivray, J., & Rinehart, N. (2015). The Efficacy of a Brief Behavioral Sleep Intervention in School-Aged Children With ADHD and Comorbid Autism Spectrum Disorder. *Journal of Attention Disorders*. doi: 10.1177/1087054714568565
- Paquette-Smith, M., Weiss, J., & Lunsky, Y. (2014). History of suicide attempts in adults with asperger syndrome. *Crisis: The Journal of Crisis Intervention and Suicide Prevention*, 35(4), 273.
- Piacentini, J., Woods, D. W., Scahill, L., & et al. (2010). Behavior therapy for children with tourette disorder: A randomized controlled trial. *JAMA*, 303(19), 1929-1937. doi: 10.1001/jama.2010.607
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 45(4), 855-865.
- Polimeni, M. A., Richdale, A. L., & Francis, A. J. P. (2005). A survey of sleep problems in autism, Asperger's disorder and typically developing children. *Journal of Intellectual Disability Research*, 49(4), 260-268. doi: 10.1111/j.1365-2788.2005.00642.x
- Postorino, V., Sanges, V., Giovagnoli, G., Fatta, L. M., De Peppo, L., Armando, M., . . . Mazzone, L. (2015). Clinical differences in children with autism spectrum disorder with and without food selectivity. *Appetite*(0). doi: <http://dx.doi.org/10.1016/j.appet.2015.05.016>

- Prior, M., Roberts, J., Rodger, S., Williams, K., & Sutherland, R. (2011). A review of the research to identify the most effective models of practice in early intervention for children with autism spectrum disorders. *Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia*. Retrieved May, 11, 2012.
- Rayner, C. S. (2010). Video-modelling to improve task completion in a child with autism. *Developmental Neurorehabilitation, 13*(3), 225-230. doi: 10.3109/17518421003801489
- Remington, B., Hastings, R. P., Kovshoff, H., Espinosa, F. d., Jahr, E., Brown, T., . . . Ward, N. (2007). Early Intensive Behavioral Intervention: Outcomes for Children With Autism and Their Parents After Two Years. *American Journal on Mental Retardation, 112*(6), 418-438. doi: doi:10.1352/0895-8017(2007)112[418:EIBIOF]2.0.CO;2
- Reynolds, C. R., & Kamphaus, R. W. (2004). *Behavioral Assessment System for Children, Second Edition (BASC-2)*. Bloomington, MN: Pearson.
- Richler, J., Huerta, M., Bishop, S. L., & Lord, C. (2010). Developmental Trajectories of Restricted and Repetitive Behaviors and Interests in Children with Autism Spectrum Disorders. *Dev Psychopathol, 22*(1), 55-69. doi: 10.1017/s0954579409990265
- Rimland, B., & Edelson, M. (1999). *Autism Treatment Evaluation Checklist*. San Diego, CA: Autism Research Institute.
- Ringdahl, J. E., & Sellers, J. A. (2000). The effects of different adults as therapists during functional analyses. *Journal of Applied Behavior Analysis, 33*(2), 247-250. doi: 10.1901/jaba.2000.33-247
- Rivers, J., & Stoneman, Z. (2003). Sibling Relationships When a Child Has Autism: Marital Stress and Support Coping. *J Autism Dev Disord, 33*(4), 383-394. doi: 10.1023/A:1025006727395
- Roantree, C. F., & Kennedy, C. H. (2006). A paradoxical effect of pre-session attention on stereotypy: antecedent attention as an establishing, not an abolishing, operation. *Journal of Applied Behavior Analysis, 39*(3), 381-384.
- Rogers, H., & Matthews, J. (2004). The parenting sense of competence scale: Investigation of the factor structure, reliability, and validity for an Australian sample. *Australian Psychologist, 39*(1), 88-96. doi: 10.1080/00050060410001660380
- Roid, G. (2003). Stanford-Binet Intelligence Scales (SB5). *Rolling Meadows, IL: Riverside*.
- Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability, 31*(2), 77-86.
- Rutter, M., Le Couteur, A., & Lord, C. (2003). *Autism diagnostic interview - revised*. Los Angeles: Western Psychological Services.
- Salt, J., Shemilt, J., Sellars, V., Boyd, S., Coulson, T., & Mc Cool, S. (2002). The Scottish Centre for Autism Preschool Treatment Programme: II: The Results of a Controlled Treatment Outcome Study. *Autism, 6*(1), 33-46. doi: 10.1177/1362361302006001004
- Schopler, E., Bourgonien, M. E., Wellman, G. J., & Love, S. R. (2010). *Childhood autism rating scale, second edition (CARS2)*. Los Angeles: Western Psychological Services.
- Schopler, E., Lansing, M. D., Reichler, R. J., & Marcus, L. M. (2005). *Psychoeducational Profile, Third Edition (PEP-3)*. Austin, TX: Pro-ed Incorporation.
- Schopler, E., Reichler, R. J., DeVellis, R. F., & Daly, K. (1980). Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *J Autism Dev Disord, 10*(1), 91-103. doi: 10.1007/bf02408436
- Schopler, E., Reichler, R. J., & Renner, B. R. (1986). *The childhood autism rating scale (CARS)*. Irvington, New York.
- Semel, E., Wiig, E. H., & Secord, W. A. (2003). *Clinical evaluation of language fundamentals, fourth edition (CELF-4)*. Toronto, Canada: The Psychological Corporation/A Harcourt Assessment Company.
- Shaffer, D., Gould, M. S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H., & Aluwahlia, S. (1983). A children's global assessment scale (CGAS). *Archives of General psychiatry, 40*(11), 1228-1231.

- Sigafoos, J., O'Reilly, M., Cannella, H., Edrisinha, C., de la Cruz, B., Upadhyaya, M., . . . Young, D. (2007). Evaluation of a Video Prompting and Fading Procedure for Teaching Dish Washing Skills to Adults with Developmental Disabilities. *Journal of Behavioral Education, 16*(2), 93-109. doi: 10.1007/s10864-006-9004-z
- Simeonsson, R. J., Leonardi, M., Lollar, D., Bjorck-Akesson, E., Hollenweger, J., & Martinuzzi, A. (2003). Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability. *Disability and Rehabilitation, 25*(11-12), 602-610. doi: 10.1080/0963828031000137117
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*(8), 921-929. doi: <http://dx.doi.org/10.1097/CHI.0b013e318179964f>
- Singh, N. N., Lancioni, G. E., Manikam, R., Winton, A. S., Singh, A. N., Singh, J., & Singh, A. D. (2011). A mindfulness-based strategy for self-management of aggressive behavior in adolescents with autism. *Research in Autism Spectrum Disorders, 5*(3), 1153-1158.
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland Adaptive Behavior Scales*. Circle Pines, MN: American Guidance Service.
- Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland adaptive behavior scales: Second Edition (Vineland™ II)*. Livonia, MN: Pearson Assessments.
- Squires, J., Bricker, D., & Twombly, E. (2009). *Ages & Stages Questionnaires*. Baltimore, Maryland, 257-182.
- Stigler, K. A. (2014). Psychopharmacologic Management of Serious Behavioral Disturbance in ASD. *Child and Adolescent Psychiatric Clinics of North America, 23*(1), 73-82. doi: <http://dx.doi.org/10.1016/j.chc.2013.07.005>
- Sytsma, S. E., Kelley, M. L., & Wymer, J. H. (2001). Development and initial validation of the Child Routines Inventory. *Journal of Psychopathology and Behavioral Assessment, 23*(4), 241-251.
- The Australian Advisory Board on Autism Spectrum Disorders. (2014). Supporting Individuals with Autism Spectrum Disorder. A guide for families and professionals. *Australian Government Department of Families, Housing, Community Services, and Indigenous Affairs*.
- Toth, K., Munson, J., Meltzoff, A. N., & Dawson, G. (2006). Early predictors of communication development in young children with autism spectrum disorder: Joint attention, imitation, and toy play. *J Autism Dev Disord, 36*(8), 993-1005.
- van Steensel, F. J., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical child and family psychology review, 14*(3), 302-317.
- Verté, S., Roeyers, H., & Buysse, A. (2003). Behavioural problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health and Development, 29*(3), 193-205. doi: 10.1046/j.1365-2214.2003.00331.x
- Vismara, L. A., & Rogers, S. J. (2010). Behavioral Treatments in Autism Spectrum Disorder: What Do We Know? *Annual Review of Clinical Psychology, 6*(1), 447-468. doi: 10.1146/annurev.clinpsy.121208.131151
- Vivanti, G., Dissanayake, C., Zierhut, C., & Rogers, S. (2013). Brief report: Predictors of outcomes in the Early Start Denver Model delivered in a group setting. *J Autism Dev Disord, 43*(7), 1717-1724. doi: 10.1007/s10803-012-1705-7
- Vivanti, G., Paynter, J., Duncan, E., Fothergill, H., Dissanayake, C., & Rogers, S. (2014). Effectiveness and Feasibility of the Early Start Denver Model Implemented in a Group-Based Community Childcare Setting. *J Autism Dev Disord, 44*(12), 3140-3153. doi: 10.1007/s10803-014-2168-9
- Watson, H. J., & Rees, C. S. (2008). Meta-analysis of randomized, controlled treatment trials for pediatric obsessive-compulsive disorder. *Journal of Child Psychology and Psychiatry, 49*(5), 489-498. doi: 10.1111/j.1469-7610.2007.01875.x

- Webb, S. J., Jones, E. J. H., Kelly, J., & Dawson, G. (2014). The motivation for very early intervention for infants at high risk for autism spectrum disorders. *International journal of speech-language pathology, 16*(1), 36-42. doi: 10.3109/17549507.2013.861018
- Wechsler, D. (1989). Wechsler Preschool and Primary Intelligence Scale-Revised. San Antonio, TX: Psychological Corporation.
- Wechsler, D. (2002). *The Wechsler Primary and Preschool Scale of Intelligence - Third Edition*. San Antonio, TX: The Psychological Corporation.
- Wechsler, D. (2003). *Wechsler Intelligence Scale for Children - WISC-IV*. San Antonio, TX: Psychological Corporation.
- Weiss, J. A., Cappadocia, M. C., Tint, A., & Pepler, D. (2015). Bullying Victimization, Parenting Stress, and Anxiety among Adolescents and Young Adults with Autism Spectrum Disorder. *Autism Research*, n/a-n/a. doi: 10.1002/aur.1488
- Wiig, E. H., Secord, W., & Semel, E. M. (2004). *CELF preschool 2: clinical evaluation of language fundamentals preschool*. Pearson/PsychCorp.
- World Health Organization. (1980). *International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease, published in accordance with resolution WHA29. 35 of the Twenty-ninth World Health Assembly, May 1976*: World Health Organization.
- World Health Organization. (2001). *International Classification of Functioning, Disability, and Health*: World Health Organization.

Table 2: Commonly used assessment tools for monitoring progress throughout life.

	<u>Type of change</u>	<u>Toddlers</u>	<u>Preschool age group</u>	<u>Primary school age</u>	<u>Secondary school age</u>	<u>Adults</u>
<u>Evaluating interventions</u>	<u>Autism characteristics</u>	<u>ADOS – toddler version</u>	<u>ADOS -1 to 4 depending on level of language</u>	<u>ADOS -1 to 4 depending on level of language</u>	<u>ADOS -1 to 4 depending on level of language</u>	<u>ADOS -1 to 4 depending on level of language</u>
			<u>SRS</u>	<u>SRS</u>	<u>SRS</u>	<u>Social Responsiveness Scale-Adult version (SRS-A)</u>
			<u>RBS-R</u>	<u>RBS-R</u>	<u>RBS-R</u>	<u>RBS-R</u>
			<u>CARS-2</u>	<u>CARS-2</u>	<u>CARS-2</u>	<u>CARS-2</u>
			<u>SCQ</u>	<u>SCQ</u>	<u>SCQ</u>	<u>SCQ</u>
			<u>AIM</u>	<u>AIM</u>	<u>AIM</u>	
	<u>Joint attention</u>	<u>ADOS – toddler version</u>	<u>ADOS -1 to 4 depending on level of language</u>	<u>ADOS -1 to 4 depending on level of language</u>	<u>ADOS -1 to 4 depending on level of language</u>	<u>ADOS -1 to 4 depending on level of language</u>
		<u>Early Social Communication Scales (ESCS)</u>				

			<u>ATEC</u>		<u>ATEC</u>		<u>ATEC</u>
<u>Sensory sensitivity</u>			<u>ABC</u>		<u>ABC</u>		<u>ABC</u>
<u>Development and abilities</u>		<u>ASQ & ASQ:SE</u>					
		<u>BASC-2</u>	<u>BASC-2</u>		<u>BASC-2</u>		<u>BASC-2</u>
		<u>BSID-III</u>					
		<u>CBCL 1.5-5</u>	<u>CBCL 1.5-5</u>	<u>CBCL 6-18, TRF 6-18, & YSR 11-18</u>	<u>CBCL 6-18, TRF 6-18 & YSR 11-18</u>		
			<u>DBC</u>	<u>DBC</u>	<u>DBC</u>		
		<u>GMDS</u>	<u>GMDS</u>	<u>GMDS</u>	<u>GMDS</u>		
		<u>MSEL</u>	<u>MSEL</u>				
		<u>SB5</u>	<u>SB5</u>	<u>SB5</u>	<u>SB5</u>	<u>SB5</u>	<u>SB5</u>
		<u>SDQ</u>	<u>SDQ</u>	<u>SDQ</u>	<u>SDQ</u>	<u>SDQ</u>	
		<u>VABS II</u>	<u>VABS II</u>	<u>VABS II</u>	<u>VABS II</u>	<u>VABS II</u>	<u>VABS II</u>
		<u>WPPSI</u>	<u>WPPSI</u>	<u>WPPSI or WISC - IV</u>	<u>WISC - IV</u>		
<u>Communication</u>			<u>CCC-2</u>	<u>CCC-2</u>	<u>CCC-2</u>		
			<u>CELF-4</u>	<u>CELF-4</u>	<u>CELF-4</u>		<u>CELF-4</u>

	<u>Adaptive ability</u>		<u>AIM</u>		<u>AIM</u>	
<u>Early identification of associated conditions</u>	<u>Maladaptive behaviours</u>					
	<u>Sleep problems</u>		<u>CSHQ</u>		<u>CSHQ</u>	
			<u>PEP3</u>		<u>PEP3</u>	
			<u>TRSSA</u>		<u>TRSSA</u>	
		<u>VABS II</u>	<u>VABS II</u>		<u>VABS II</u>	<u>VABS II</u>
<u>Maximising potential: individual</u>	<u>Function</u>					
	<u>Participation</u>				<u>CAPE</u>	
					<u>CHORES</u>	
					<u>PICO-Q</u>	
	<u>Quality of life</u>					
<u>Maximising potential:</u>	<u>Stress</u>					

