

Evidence-Based Practices for Children and Adolescents with Autism Spectrum Disorders:

*Review of the Literature
and Practice Guide*

Evidence-Based Practices
for Children and Adolescents with
Autism Spectrum
Disorders:

*Review of the
Literature and
Practice Guide*

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Section 1

Evidence-Based Practices for Children and Adolescents with Autism Spectrum Disorders:

Executive Summary of Review of the Literature and Practice Guide

INTRODUCTION

This document reflects the work to date of Children’s Mental Health Ontario in identifying evidence-based practices for children and adolescents with Autism Spectrum Disorders. This project is a first step in identifying and promoting up-to-date evidence-based practices to assist children’s mental health practitioners in their work with this special group of young people and their families.

A knowledgeable and dedicated Advisory Committee provided critical guidance for this project. As well, the wisdom and experience of the Expert Panel was extremely valuable both in raising appropriate questions and in providing essential input for this document. Discussion groups that included clinical managers and supervisors in the field provided reality-based information and suggestions to help ensure that the project’s research and training activities begin to effectively meet the needs of the field. Members of the Project Advisory Committee, Expert Panel, and Discussion Groups are listed in Appendix II.

The Review of the Literature and Practice Guide was researched and written by Dr. Adrienne Perry and Dr. Rosemary Condillac. Their extensive research and clinical skills, as well as their knowledge of the field, contributed tremendously to the development of this document and to the project as a whole. They worked closely with other members of the Project Team, as listed in Appendix II.

Debbie Garbe
Project Co-ordinator

1. EXECUTIVE SUMMARY

Background

The purpose of this Evidence-Based Practice Guide is to provide a summary of empirically-based assessment and intervention approaches for children and adolescents with Autism Spectrum Disorders (ASDs) and best practices for supporting families. It is primarily intended for mental health professionals in the children's mental health sector, but it is hoped that it will also be useful to parents and professionals in other sectors who provide services to children with ASDs and their families. This executive summary provides an overview of the findings of this report, but is intended for use in conjunction with the report and not as an independent entity.

Evidence-based treatment guidelines are especially important in the field of ASDs as this field has been plagued by significant differences of opinion and controversies over treatment methods. Many widely promoted new approaches have no empirical support. It is extremely difficult for parents and practitioners to critically evaluate the volumes of information regarding a myriad of potential new treatments, and not all sources of information are equally credible. New treatments, though they may be promising and worthy of investigation, may also be unhelpful or even harmful. It is crucial that staff and families be supported to learn to ask pertinent questions and think critically regarding Autism treatments.

Although parents and professionals sometimes feel there is no harm in trying a new approach, this is not necessarily true. The risks involved in trying new treatment approaches need to be carefully weighed against the potential benefits. Risks include potential harmful side effects, as well as the waste of time, money, and emotional energy for individuals with ASDs, families, and service providers. Professionals working in this area need to be aware of these dynamics, and assist parents in the cost/benefit analysis required each time a new treatment option arises. It is essential that professionals consult the current research and assist parents to understand the nature and strength of the scientific evidence surrounding treatments.

The empirical evidence gathered in this report has been gleaned from primary research articles, book chapters, and literature reviews, including reports from consensus panels (e.g., groups of knowledgeable researchers and clinicians). This practice guide describes and evaluates interventions based on available data as to whether they are evidence-based (i.e., convincing evidence they are effective) or empirically disconfirmed (i.e., convincing evidence they are not effective or harmful). In the latter case, it is important to consider whether the treatment approach has negative side effects which may cause harm or may interfere with interventions known to be effective. However, in many cases, the interventions covered fall into a third category: they cannot be actively recommended because there is insufficient evidence either way. In this case, the research available is described, even if it is not very conclusive.

In terms of the interventions in this third category, consumers need to critically evaluate the theoretical premises upon which the approach is based, evaluate whatever evidence does exist,

and then make an informed judgment. It is important to consider whether the unproven treatment is consistent with theories and principles associated with effective treatments. Certain approaches may be helpful in specific situations or with a certain child, even when group design studies have not demonstrated this. Further, some approaches or activities are enjoyable for the child or adolescent and may be appropriate activities that enhance the individual's quality of life, even though they do not ameliorate the symptoms of the disorder.

Overview of ASDs

Description

Autism Spectrum Disorder (ASD) is a term that was coined by both Wing and Allen to describe a subset of the Pervasive Developmental Disorders (PDDs) currently outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). These disorders share three common areas of concern:

- qualitative impairments in social skills;
- qualitative impairments in verbal and nonverbal communication; and
- restricted and repetitive interests or behaviours.

When using the term ASDs, most professionals are referring to the subset of PDDs that includes Autistic Disorder (usually referred to as Autism), PDD-NOS (not otherwise specified), and Asperger's Disorder.

The term "spectrum" is also used to refer to a continuum of developmental severity. Autistic Disorder, considered to be at the more severe end of the spectrum, is accompanied by significant cognitive impairments in about 75%-80% of cases. On the other hand, most individuals with Asperger's Disorder tend to have average to above average intellectual functioning. Research shows an inverse relationship between the severity of autistic symptoms and the level of intellectual functioning across a large number of young children with and without ASDs. About 50% of individuals with Autistic Disorder never develop functional language, while individuals with Asperger's Disorder, by definition, do not have clinically significant delays in language development.

The prevalence of ASDs for the broader spectrum is reported to be approximately 3 in every 1000. There is a higher ratio of boys to girls (4:1) overall, but this decreases to an almost 1:1 ratio when profound cognitive impairments are present. Though research is demonstrating an increase in overall incidence of ASDs, it appears that a broader definition of Autism, increased awareness, and more systematic assessment practices may be responsible for this apparent increase. Hypotheses linking the increased rates to the measles, mumps, and rubella (MMR) vaccination have been disproven.

The etiology of ASDs remains elusive, though research continues in the areas of genetics, neurology, and metabolic disorders. Family heritability appears to be a reasonable avenue of investigation, as siblings of children with Autism are more likely than the general population to develop Autism or a related disorder. In the area of neurological research, several studies have investigated anatomical differences in the brains of individuals with ASDs. Studies using neural-imaging techniques and post-mortem studies have not yielded consistent results. This suggests that there may be multiple neurological and developmental pathways to ASDs.

Early Identification, Assessment, and Diagnosis

The literature quite clearly supports early screening and referral programs to promote early diagnosis and early intervention. Parents who report concerns about their child's development should be taken seriously; they are usually right, and it does them and the child a disservice to delay a full assessment. Early "red flags" which suggest a child should be referred for a full assessment include:

- lack of babbling and/or gestures at 12 months;
- lack of single words by age 16 months;
- lack of two-word combinations at 24 months; and
- any regression or loss of words or loss of skills.

Other early developmental indicators include lack of joint attention (e.g., lack of pointing to show), lack of response to name, and unusual or absent eye contact and use of facial expressions.

Skilled, comprehensive assessment is a crucial first step to understand and assist children and adolescents with ASDs, as well as to help their families. Assessments of people with ASDs may be done for a variety of reasons at various times in their lives, including:

- to obtain or clarify an initial diagnosis;
- to document diagnostic status necessary for access to services or funding; and/or
- to help understand the person.

A "best practice" approach to assessment means that the specific measures used and the whole assessment process should be carefully tied to the most recent professional literature. The process should also be based on evidence-based evaluation of the measures and procedures, which are constantly changing. This paper describes two recent consensus documents which set the standard for "best practices" in screening and assessment. Clinical practice should also be consistent with relevant legislation, professional college regulations, standards, ethics, agency policies, and other relevant guidelines. In Ontario, the Regulated Health Professions Act (RHPA) defines diagnosis as a "controlled act" which may only be performed by professionals registered with either the College of Psychologists or the Royal College of Physicians and Surgeons.

Autistic Disorder

The DSM-IV sets out the standard diagnostic criteria for the diagnosis of Autistic Disorder. Clinical evaluation should be based on a combination of parent report and observation for each criterion, preferably over more than one occasion, and in more than one setting (i.e., with parents, with other adult, alone, during free toy play, during structured demands). In very young and/or very low functioning individuals, several criteria cannot be rated because they are beyond the child's developmental level (e.g., pretend play). Difficult diagnoses or ambiguous distinctions require more observation (preferably in settings with peers), additional testing in some cases, and often collegial consultation.

Assessment and diagnosis of children with Autism should include the following components:

- a standardized Autism observation measure such as the Autism Diagnostic Observation Schedule (ADOS-G) or the Childhood Autism Rating Scale (CARS);
- a standardized measure of cognitive ability (including verbal and non-verbal domains), as well as a measure of adaptive behaviour, which together form the basis for the diagnosis of the degree of concomitant developmental disability which may be present;
- a curriculum-referenced developmental measure that can assist in intervention planning and monitoring change;
- when necessary, a comprehensive assessment of problematic behaviours (e.g., aggression, self-injury), as discussed later in this paper;
- when appropriate, accompanying medical investigations (e.g., lead screen if child engages in pica, or sleep EEG if the child exhibits developmental regression or seizures).

Asperger's Disorder

Unlike Autistic Disorder which can be reliably diagnosed by age 2, Asperger's Disorder is most often diagnosed when children reach school age. This is likely due to the fact that children with Asperger's Disorder typically present with average or above average verbal skills, adequate early social development, and lack the developmental delays and behaviour problems associated with early referral for assessment services.

There is considerable discussion in the literature about the clinical differences, if any, between Asperger's Disorder and Autistic Disorder in individuals with higher cognitive achievement. The overlap in diagnostic criteria in the social and behavioural areas reflects the major similarities between these disorders. The major differences appear to be in the areas of cognitive, motor, and language development. The current research supports the notion that Asperger's Disorder and Autistic Disorder are distinct (can be differentiated) but clearly related disorders.

The assessment of Asperger's Disorder has received considerably less attention in clinical

research than that of Autistic Disorder, and there is far less consensus on assessment procedures. Most would agree that differential diagnosis between Autistic Disorder and Asperger's Disorder requires the assessment of cognitive, communication, and motor skills, as well as careful inquiry related to early history, current functioning, and observational measures of symptomatology. For some individuals, neuropsychological testing might be beneficial to investigate underlying neuro-motor deficits and concerns regarding impaired executive functioning. Whenever possible, a multidisciplinary assessment including participation as necessary from a psychologist, a developmental pediatrician, a psychiatrist, a speech and language pathologist, and an occupational therapist is recommended.

During the diagnostic assessment, it is also essential to be vigilant for possible comorbid disorders, including Tourette's Disorder, Obsessive Compulsive Disorder, Depression (in older children and adolescents), and Attention Deficit Hyperactivity Disorder (in younger children). Children and adolescents with Asperger's Disorder (and those with high functioning Autism) show a higher rate of problems related to anxiety and depression than a large community sample.

Differential diagnosis between Asperger's Disorder and other psychiatric or developmental disorders must also be considered. Clinicians should give careful consideration to conditions that share some symptomatology with Asperger's Disorder, including Obsessive Compulsive Disorder, Schizoid Personality Disorder, Semantic-Pragmatic Language Disorder, and Non-verbal Learning Disability.

PDD-NOS

There is very little specific information regarding the appropriate way to assess and diagnose PDD-NOS, so most clinicians follow the assessment protocols for Autistic Disorder or Asperger's Disorder. According to DSM-IV protocols, however, the diagnosis of PDD-NOS should be used when a child does not strictly meet criteria for either Autistic Disorder or Asperger's Disorder, but has difficulties in the areas of social, communication, and repetitive behaviour. The data from the DSM-IV field trials revealed 7 of the 12 DSM-IV Autism criteria were related to a clinical diagnosis of PDD-NOS (the 4 social criteria, impaired conversation, stereotypical language, and repetitive mannerisms). The suggested scoring rule for PDD-NOS is a minimum of 3 criteria met, including at least 1 social item.

Interventions

Pro-Social and Play Related Interventions

The goal of social interventions is to promote children's development of meaningful interpersonal relationships. This goal is achieved by teaching skills that support the development of social interest, social initiation, social responsiveness, and empathy and understanding of other's perspective. It is critical that intervention plans include strategies to enhance social understanding, social relating, and play skills, and that these strategies take into account the individual's cognitive and learning abilities. Though the majority of research has focused on children with Autistic Disorder, many of the strategies outlined show great promise for children with Asperger's Disorder.

The research on the following social interventions indicates they are somewhat effective, although, without exception, there are problems with generalizing skills from training to natural conditions:

- Social Stories
- Peer-Mediated Instruction
- Social Script Training
- Theory of Mind Training

As yet, there is no published research demonstrating the effectiveness of the following social intervention:

- Relationship Development Intervention (RDI)

Therefore, if using RDI, carefully evaluate its effectiveness for the individual child, and use it only as an adjunct to other interventions proven to be effective.

Language and Communication-Based Interventions

Individuals with ASDs can have a wide range of language and/or communication impairments, especially in the social and pragmatic areas of language development. Language problems associated with ASDs include delays in language development, significant language impairment, idiosyncratic language difficulties including problems with prosody (tone, cadence, and quality of speech production), and inability to sustain a conversation despite proficient language development. Base individualized intervention choices on a Speech and Language assessment.

The following interventions have been demonstrated as effective for individuals with an ASD:

- Augmentative Communication

- Picture Exchange Communication System (PECS)
- Verbal Behaviour Approach

As yet, there is no published research demonstrating the direct effectiveness of the following communication intervention:

- Developmental Social-Pragmatic Model (DSP)

Therefore, when using the DSP model, carefully evaluate its effectiveness for the individual child, and use it only as an adjunct to other interventions proven to be effective.

Research has repeatedly demonstrated the ineffectiveness and potentially harmful effects of the following intervention:

- Facilitated Communication (FC)

As such, FC is not recommended for use with individuals with ASDs.

Sensory and Motor Interventions

It is often reported clinically that individuals with Autism and other ASDs have unusual responses to sensory stimuli or "sensory issues" and/or motor apraxias. These are often among the earliest symptoms parents report (e.g., unresponsive to loud sounds, loves rubbing a certain texture, etc.). Although these sensitivities may be quite salient in some individuals, it should be noted that these sensory differences are not unique to ASDs, are not universally present in clients with ASDs (though they are common), and are highly idiosyncratic when they do occur.

The following interventions have inadequate scientific evidence, and should only be used (a) in conjunction with proven therapies, (b) with careful evaluation, and (c) if they do not interfere with proven therapies:

- Sensory Integration Therapy
- Sensory Diet (sensory summation approach)
- Alert Program
- Deep Pressure
- "Squeeze machine" or "hug machine"
- Touch Therapy/Massage
- Patterning
- Neurodevelopmental Therapy
- Cranio-sacral Therapy
- Physical exercise
- Auditory Integration Training (AIT)
- Irlen Lenses
- Oculomotor exercises

Intervention for Challenging Behaviour

Individuals with ASDs are clearly at increased risk for developing problematic behaviour. Some of these behaviours fall under the category of restricted and repetitive behaviours and interests. These behaviours are considered problematic because they interfere with opportunities for learning and social interaction. Others are prone to increased risk of developing aberrant behaviours including aggression, self-injurious behaviour, and many different forms of disruptive behaviours. These behavioural issues can increase the risk of social isolation and decrease the quality of life experienced by individuals with developmental disabilities, are very stressful for families, and add an additional layer of difficulty in providing supports to those with ASDs.

The following summarizes the recommended practice for individuals with ASDs:

- A large body of evidence provides empirical support for the use of positive behavioural supports as the first course of treatment for problem behaviour.
- If necessary, medication should be used as an adjunct to behavioural treatment or to treat specific behavioural/psychiatric disorders (e.g., OCD, ADHD).
- Direct-care staff should be trained in crisis intervention procedures approved by their settings and consistent with Ministry guidelines.
- Intrusive behaviour reduction procedures should be considered only as a last resort, and should be used under careful supervision, with proper documentation.

Biomedical Interventions

There is no specific or universal medical treatment or cure for the core symptoms of ASDs. However, a number of biomedical approaches have been tried in an effort to treat particular symptoms or comorbid disorders, and/or to increase the likelihood that the individual will benefit from concurrent educational or behavioural interventions.

The following medications have been demonstrated to be somewhat effective for individuals with ASDs, though careful monitoring should be implemented to measure effects and side effects:

- Neuroleptics/Antipsychotics
- Risperidone
- Clomipramine
- Selective Serotonin Reuptake Inhibitors (SSRIs)
- Antidepressants
- Stimulants
- Anticonvulsants

The following medications have been demonstrated to be ineffective and/or harmful for children and adolescents with ASDs:

- Fenfluramine
- Naltexone
- Secretin
- Adrenocorticotrophin Hormone (ACTH)

Other biomedical treatments not recommended due to minimal evidence and potential risk include:

- Corticosteroids
- Intravenous Immune Globulin (IVIG)
- Vitamin and dietary supplements
- Exclusion diets (casein and gluten-free diet)
- Anti-yeast therapies
- The DAN! (Defeat Autism Now!) Protocol

General Skill Building

Service providers must frequently adapt existing approaches or technologies to support individuals with ASDs. When participating in traditional group intervention, for example, these individuals often require constant reminders about the social rules in group situations. In other circumstances, individuals with ASDs require additional skills to be able to participate in traditional programs. For example, individuals with serious cognitive deficits might require instruction in basic life-skills, while those with well-developed cognitive skills might require assistance to stay on topic or learn an unfamiliar routine. The following interventions can be used to enhance learning of communication and social skills, and assist with redirecting, replacing, or otherwise decreasing problematic behaviour. These interventions have been demonstrated effective in supporting individuals with ASDs:

- Behavioural Teaching
- Environmental supports/structure
- Picture Activity Schedules
- Visually Cued Instruction

Expressive Psychotherapies

Many mental health services offer a variety of expressive therapies to treat children and adolescents with a wide range of mental health needs. There is inadequate scientific evidence

to support the extension of these services to the majority of individuals with Autistic Disorder, likely due to the large proportion of individuals with significant cognitive impairments. For individuals with Asperger's Disorder and those with better developed cognitive skills, there is some evidence to support using problem-solving based (e.g., cognitive) therapies and counseling techniques as adjuncts to more direct skill development strategies. Only Cognitive Behaviour Therapy (CBT) has demonstrated efficacy with individuals with ASDs.

The following insight-oriented and creative therapies have not been found to be effective, though some are enjoyable recreational activities:

- Music Therapy
- Holding Therapy
- Sand Tray Therapy
- Art Therapy

Professionals and families need to be aware that:

- there has been no demonstrated therapeutic benefit to these therapies;
- these therapies should be considered experimental; and
- these therapies should not be allowed to interfere with treatments that are proven effective.

Comprehensive Programs

The term "comprehensive programs" refers to ASD-specialized, intensive intervention programs (usually for many hours per week), involving a combination of the approaches and strategies described in other sections of this paper. They typically include an educational or skill development orientation, together with some therapeutic intervention(s) for problem behaviour, often using a multidisciplinary team (including the parents). Multiple systems are usually involved, and intervention likely takes place in various settings (home, school, agency).

The following comprehensive program has strong evidence of effectiveness, though individualized evaluation is a necessary component to ensure the best match of the curriculum to the child's needs:

- Intensive Behavioural Intervention (IBI)

While the following comprehensive programs share many features of good comprehensive programs, they do not have strong research evidence at this time, and should be evaluated on an individual basis with each child:

- TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children)
- The Denver Model
- The Developmental, Individual Difference, Relationship (DIR) Model

Families of Children and Adolescents with ASDs

Having a child with an ASD is one of the most difficult things that can happen to a family. Although most families cope remarkably well most of the time, they have some tough challenges along the way. The needs of families are quite variable, and depend on:

- the particular characteristics of their child (age, level of functioning, particular symptom severity, response to intervention, and so on);
- the parents' own intrapsychic and interpersonal resources; and
- the availability and effectiveness of supports and services.

Having a child with Autism can have a devastating impact on parents' mental health (most of this research is based on Autism; little has been done on other ASDs). In fact, family stress research has repeatedly demonstrated that parents (especially mothers) of children with Autism experience greater stress, depression, and mental health difficulties than parents of children with other types of disabilities or no disability. Different aspects of life with a child with ASD may affect mothers as opposed to fathers, and evidence indicates that mothers bear the greater burden (although fathers' experiences have been much less studied). Also, the family's culture is an important factor in the meaning they attribute to having a child with ASD and their tendency to seek help outside the family. Other significant stressors include:

- the poor understanding of Autism in the community;
- inferences or outright accusations of improper parenting when the child "looks normal" but acts "strangely" in public;
- difficulty experienced in the process of obtaining a diagnosis;
- the exhausting process of advocating for scarce intervention and educational programs; and
- the financial strain of certain therapies.

There are certain issues or needs that parents and siblings (and sometimes extended family members) may have at various times throughout their life with a child with Autism. These needs have important implications for family support services and case management. Table 6 in the full text of this document highlights child and parent issues and clinical responses appropriate at each developmental stage. It is important for mental health professionals to help families work actively on transition-planning at two main junctures: from preschool to school (about age 5 or 6), and from high school to early adulthood (about age 18–21). Intensive case management and concurrent emotional support may be needed at these times.

Siblings

Early clinical literature on siblings of children with Autism (again, most studies deal with Autism and not other ASDs) suggested high rates of psychopathology and emotional distress, especially in oldest girls. This distress was ostensibly because of parental neglect, additional household responsibilities, and social embarrassment. However, systematic studies of siblings of children with Autism, compared to siblings of children with other disabilities or no disabilities, have provided mixed results. A minority of siblings experience clinically significant internalizing and/or externalizing disorders, and may benefit from the social support of sibling groups, accurate information about ASDs, and/or individual therapeutic intervention. However, many do not display such disorders and do not necessarily require formal supports. It is also important to realize that, because of the genetic factors involved in the etiology of ASDs, a sizable number of siblings might be expected to show some signs of learning or language disorders and concomitant school achievement difficulties. These disorders and difficulties may require support and remediation.

Family-Based Interventions

There is a great deal of variability in the experiences of families who have a child with ASD, depending upon family factors as well as characteristics of the child. These factors and characteristics can and do vary considerably over time, even in the same family. Many of the issues faced are not dissimilar to those faced by other kinds of families, and the intervention approaches are also similar. Other needs are unique to their experience of having a child with ASD.

Services and supports that families may need include:

- early, accurate diagnosis with clear explanations of assessment;
- intensive early intervention (strongly evidence-based);
- case management, future planning;
- professional therapeutic supports (e.g., supportive counseling, family therapy);
- information and education about Autism for parents and siblings, including assistance evaluating new treatment approaches;
- parent training regarding social and communication skill development and/or behaviour management (evidence-based; should be specialized for ASDs);
- respite care to decrease or prevent family stress (evidence-based);
- parent support groups and sibling support groups (somewhat evidence-based);
- appropriate and effective special education interventions and supports for child during school years;
- appropriate programs and supports for adolescents and adults; and
- appropriate residential placements when needed (children and adults).

Summary and Conclusions

Individuals with ASDs are a heterogeneous group, and as such they have diverse needs. It is essential that intervention plans be based on individual patterns of strengths and limitations. A comprehensive developmental and diagnostic assessment that considers symptom severity, cognitive ability, communication, and academic skills/developmental curriculum is an integral part of intervention planning. Medical investigations should also be completed by an experienced physician. Further, the families of individuals with ASDs may require additional services including assistance with case management, counseling and/or mental health services, and parent and/or sibling support groups.

There are many interventions currently being used to treat individuals with ASDs, however all interventions are not equal. It is incumbent upon professionals supporting these individuals and their families to be discerning in their recommendations for treatment options. Some interventions have adequate scientific evidence and are effective in well-designed empirical studies (e.g., Intensive Behavioural Intervention, Positive Behavioural Supports), while other interventions are ineffective and potentially harmful (e.g., Secretin, Facilitated Communication). A third category of interventions have inadequate scientific evidence at this time, and require careful scrutiny. This third broad category includes some promising interventions with empirical support (e.g., Social Stories, Picture Activity Schedules), interventions with little to no research (e.g., Sensory Integration, Relationship Development Intervention), as well as interventions with limited research that are not recommended until carefully controlled studies demonstrate their effects and side effects (e.g., Elimination Diets, Chelation).

When recommending, designing, and/or implementing intervention plans, carefully consider the level of scientific evidence, and put evaluation procedures into place to monitor the effectiveness of the intervention and any potential side effects. Inform parents and individuals with ASDs of the degree to which procedures are proven or experimental, and ensure they understand the importance of objective evaluation of the intervention as it is implemented for the particular individual. Though there is much needed large-scale research, individual therapists can make a great contribution by systematically evaluating their own work with clients.

Section 2

Evidence-Based Practices for Children and Adolescents with Autism Spectrum Disorders:

Review of the Literature and Practice Guide

2. BACKGROUND

2.1. Introduction

The purpose of this document is to provide a summary of empirically-based assessment and intervention approaches for children and adolescents with Autism and related disorders. It is primarily intended for mental health professionals in the children's mental health sector, but it is hoped that it will also be useful to parents and professionals in other sectors who provide services to children with Autism and their families.

This document came about as part of a larger project on Autism Spectrum Disorders (ASDs) commissioned by the Ministry of Community, Family, and Children's Services. A Project Advisory Committee from Children's Mental Health Ontario (CMHO) oversaw the overall project. The project was comprised of two parts: the development of this practice guide, and the development and implementation of a training plan for the delivery of education and training in the field regarding empirically-based practices for children and adolescents with ASDs and their families. As part of this process, a survey was conducted to determine which children's mental health agencies are providing services to children with ASDs and their families, the kinds of services being provided, and the training needs of children's mental health agencies with respect to this population.

This literature review is based on known literature up to and including the consensus panels discussed below, and supplemented by current research articles. The articles were selected after a thorough review of approximately 1200 recent abstracts (since 1998) derived from a computerized literature search on ASDs and various related topics (e.g., intervention, assessment, diagnosis, etiology). When appropriate, research conducted in Ontario is highlighted.

2.2. Evidence-Based Treatment Guidelines

There has been a recent proliferation of evidence-based practice guidelines in various fields of medical and psychosocial treatment, including the field of children's mental health (Children's Mental Health Ontario [CMHO], 2001a, 2001b). The American Psychological Association (APA) recently revised and expanded its policy and guidelines for those seeking to develop and/or evaluate treatment guidelines, also known as clinical practice guidelines (usually disorder-specific), as well as professional practice guidelines (more general and practitioner-focused; Reed, McLaughlin, & Newman, 2002).

According to the American Psychological Association (APA, 2002), treatment guidelines should address both treatment efficacy and clinical utility. The determination of treatment efficacy is based on empirical research literature regarding what has been demonstrated to be effective (i.e., is the treatment more effective than another treatment or no treatment, are there positive or negative side effects, for whom does it work or not work, are effects

sustained over time, and so on). This determination also takes into account the methodological strengths and limitations of the studies, and includes consideration of clinical consensus where empirical data are lacking. Clinical utility refers to the generalizability and practicality of treatments in real-world settings (in other words, the effectiveness of the approach under real-world conditions). The present document takes into account both treatment efficacy and effectiveness or clinical utility (where possible), and is also informed by the survey information regarding present practices in Ontario agencies.

It is acknowledged that treatment guidelines are aspirational in nature. They are "...not intended to be mandatory, exhaustive, or definitive; may not apply to every clinical situation; and are not intended to take precedence over [clinical] judgement" (Reed et al., 2002, p. 1042). Further, treatment guidelines are based on a body of knowledge at a point in time, and need to be re-examined and revised periodically (probably every 5 years in a rapidly changing field such as ASD).

It is important to clarify that the term "treatment," as used in the empirically-supported treatment literature, is a very broad term. It encompasses treatments intended to cure the disease or disorder, interventions intended to eliminate or reduce the intensity of specific symptoms associated with the disorder, or supportive strategies and accommodations designed to improve the quality of life of the person and/or those around them. There is no "treatment" in the Autism field resembling a "cure" for a "disease." Rather, the approaches reviewed in this paper consist of interventions intended to "treat" specific symptoms (e.g., medication for activity level), specific adaptations of general instructional strategies which could be used in any population (e.g., behavioural teaching), supports to the child or adolescent with ASD (e.g., Picture Activity Schedules), or supports to the family (e.g., respite care).

The Autism field has been plagued by differences of opinion (and strong opinions at that) and controversies over treatment methods. Though not unique to ASDs, the field is well-known for the "cure of the month" phenomenon. Potential new approaches are promoted through traditional mass media and the Internet, or by those providing the approach, often without any scientific evidence. Many parents are very well-informed (and frequently bring new approaches to the attention of professionals); others are less sophisticated. However, it is extremely difficult for parents and practitioners to critically evaluate the volumes of information regarding a myriad of treatments. Not all sources of information are equally credible. New treatments, though they may be promising and worthy of investigation, may also be unhelpful or even harmful.

It is irresponsible for service providers to simply make information on different options available to families without helping them sort through the pros and cons of each. It is crucial that staff and families be supported to learn to ask pertinent questions and think critically regarding Autism treatments (American Academy of Child and Adolescent

Psychiatry [AACAP], 1999; Freeman, 1997; Green, 1996; New York State Department of Health [NYSDH], 1999). These questions include:

- Does the theory behind the proposed treatment make sense, given what is known about Autism?
- Is the treatment individualized, based on assessment?
- Is it monitored for effectiveness (based on data) and changes in dosage or intensity?
- What training and supervision are needed to administer the treatment?
- How much does it cost?
- What are the potential side effects or risks?
- What research has been done to demonstrate the effectiveness of the approach?
- Was appropriate methodology used?

Although parents sometimes feel there is no harm in trying a new approach, this is not necessarily true. Risks need to be considered, including potential harmful side effects, as well as the waste of time, money, and emotional energy for individuals with Autism, families, and service providers. It is incumbent upon professionals working in Autism to be aware of these dynamics and assist parents in the cost/benefit analysis required each time a new treatment option presents itself.

As noted above, one of the crucial questions people need to ask is, "What kind of evidence is there?" While a detailed explanation of research methodology is beyond the scope of this report, a few points regarding research may be helpful.

Research methods are not all of equal value. There is a continuum of types of evidence, beginning with anecdotal or testimonial evidence (the weakest kind of evidence, but often emotionally persuasive). While anecdotal evidence may provide possible hypotheses to be tested by research, it really has no value by itself.

Then there are pre-post studies, which measure some important variables prior to and then again following treatment. Evidence from this sort of study (e.g., developmental scores increasing from pre- to post-) is consistent with the possibility of effectiveness, but this design can never allow us to tell for sure, because other factors may come into play that could have caused the change in scores (e.g., maturation, school, attention, interventions other than the one of interest).

Group design studies really need to have comparison or control groups to help determine whether the intervention actually caused the observed change and to rule out other possible explanations. For example, if a group receiving intervention X improves, it implies that the intervention is effective. However, if the control group (who did not receive intervention X) also improves to the same extent, something other than intervention X was responsible for

the change. When people participate in research, their beliefs and expectations that the intervention will work (or in this case, parents' and teachers' expectations) may influence the outcome quite significantly. This is called the "placebo effect," and it is another reason why control or comparison groups are important.

There are different types of comparison and control groups, depending on the circumstances. From a research design point of view, the strongest design methodology involves random assignment to either intervention X or no intervention (or to intervention Y), but this is very difficult to accomplish for ethical and technical reasons. Another option often used is matching of groups (two groups, equivalent on important features such as age, cognitive level, etc., one of which receives intervention X, the other receives no intervention or intervention Y). Another is a wait-list comparison group, which would include children or adolescents similar to those in the intervention group, but for whom resources do not permit intervention X at the time of the study. In any case, however it is accomplished, the important thing is that the two groups are not systematically different in ways that could influence the results of the study. For example, if the children or adolescents in intervention X group were lower functioning than those in the comparison group, and intervention X actually is effective but only with higher functioning children, the study results might show that the comparison group improved just as much as the intervention group. As a result, we might wrongly conclude that intervention X is not helpful. Or, if a certain intervention is most effective with very young children, a study with children and adolescents of various ages might conclude that the intervention is only moderately effective.

In drug studies, a frequently used methodology is called double-blind, placebo-controlled crossover design. Placebo-controlled means there is an active drug condition and a placebo condition. The double-blind means that the family does not know and the doctor does not know whether the pill or injection is the placebo or the "real thing," so no one's expectations can influence the outcome. The crossover means that half the group gets placebo first, then the real drug; the other half gets the reverse order (but no one finds out until after the study is over).

Another issue affecting the validity of research designs is the representativeness of the research participants. Studies in Autism tend to use rather small samples from clinical settings, and these groups may not be like other children and adolescents seen in another setting. It is therefore important to describe the sample carefully, including age, diagnostic procedures used, and cognitive, adaptive, and/or language level. In this way, the reader can determine whether the people in the study are similar to the people in mind for the particular intervention.

Not all good research needs to involve large numbers and control groups. There are a whole variety of experimental designs known as "single subject designs" which can demonstrate a

functional (i.e., causal) relationship between the treatment and the change in behaviour (usually demonstrated visually on a graph). Although they are called "single subject" designs, they may include several participants in one study, or one person with data on several behaviours or in several settings (called multiple baseline designs). The beauty of these designs is that they can be individually tailored to the particular behaviours targeted for that individual (which can be different for each person). The drawback is that they are highly specific and results may not necessarily be generalizable to other individuals.

Even a study with a strong research design is only one study, and results need to be "replicated." That is, different research groups with different groups of children and adolescents must demonstrate the results and be published in reputable peer-reviewed journals before an approach can be considered as strongly evidence-based. The amount and type of research needed depends on the nature of the intervention and the potential risks involved.

In the following section, interventions will be described and evaluated based on whether there is convincing evidence they are either effective or not effective or harmful. However, in many cases, the interventions fall into a third category: they cannot be actively recommended because there is insufficient evidence either way. In this case, the research available will be mentioned, even if it is not conclusive.

For those interventions where the evidence is inconclusive, consumers need to critically evaluate the theoretical premises upon which the approach is based, evaluate the existing evidence, and then make an informed judgement. Certain approaches may be helpful in specific situations or with a certain child, even when group design studies have not demonstrated this. Further, some approaches are enjoyable for the child or adolescents and may be appropriate from a quality of life point of view, without necessarily being effective in a technical sense.

2.3. Professional Consensus Panel Reports Regarding Autism

In a field which has experienced considerable controversy and in which knowledge is increasing rapidly, the "consensus panel" is becoming a well-accepted process of articulating a current, accurate, non-partisan summary of knowledge on a particular topic at a particular point in time. Literature reviews and Practice Parameters have been developed from the point of view of one discipline (e.g., AACAP, 1999), but typically consensus panels consist of a group of eminent experts, usually representing different disciplines (medicine, psychology, psychiatry, neurology, pediatrics, genetics, speech and language, education, etc.) and a range of theoretical orientations (medical, behavioural, developmental, etc.). They usually develop a process for evaluating the quality of existing research evidence given the methodological limitations of the studies, review the literature, and then summarize what is known and

what remains unclear. In situations in which empirical evidence is substantially lacking or methodological issues preclude firm conclusions, they may provide opinions based on clinical practice. They may also be charged with addressing particular questions and providing recommendations for future research.

Several sets of literature reviews and consensus panel reports have been issued in the past five years or so on various aspects of assessment and intervention regarding ASDs. These reports will be relied upon in the present document. They include:

(a) National Institutes of Health State of the Science in Autism (Bristol, 1996)

A consensus panel process was undertaken by the National Institutes of Health (NIH) in the U.S. in 1995, and the results were published as a special issue of the Journal of Autism and Developmental Disorders (JADD) the next year. It included papers summarizing the state of the science in Autism by task forces working in eight areas: diagnosis, epidemiology, etiology, brain mechanisms, communication/social/emotional development, medical intervention, social and behavioural intervention, and biostatistical and general. They addressed specific questions posed to them, and made recommendations to the NIH regarding funding priorities for future research in each area. Although these papers had clinical implications, they were not intended as treatment guidelines.

(b) National Institutes of Health (1999 and 2000)

More recently, a similar process was initiated by the NIH to summarize the state of knowledge, but also to make recommendations for clinical practice in two major areas:

- Screening, assessment, and diagnosis (published in JADD, by Filipek et al., 1999)
- Treatments (published as a series of papers in a special issue of JADD in 2000 [5] and summarized online at www.nimh.gov/research)

The "treatments" reviewed in this process included intensive behavioural intervention for young children, communication interventions, interventions to enhance socialization, auditory, visual, and sensory approaches, pharmacological treatments, and emerging biomedical approaches for people with Autism (of any age).

(c) The New York State Department of Health Clinical Practice Guidelines (NYSDH, 1999)

The NYSDH has commissioned expert panels to develop Clinical Practice Guidelines in a number of areas, including one for young children (0 to 3 years) with Autism. The Guidelines address both assessment and intervention.

The panels engaged in a rigorous process of evaluating the strength of evidence from the 224 assessment articles and 520 intervention articles they reviewed. The intervention section dealt with intensive behavioural approaches, as well as other experiential approaches, medication, diet, and other therapies.

(d) The National Research Council (NRC, 2001)

Most recently, the U.S. federal Department of Education Office of Special Education requested that the National Research Council assemble an esteemed body of experts to integrate the scientific, theoretical, and policy literature regarding effective interventions for young children with Autism (age 0–8). This panel emphasized school settings, however the applications are broader. They conducted a critical review of the literature (with explicit evaluation criteria for validity of studies), commissioned papers and presentations, and conducted stakeholder consultations. The report was published in book form by the National Academy Press (NRC, 2001) and is also available online (at www.nap.edu). Supplementary material was published in JADD in 2002, issue 5.

3. DESCRIPTION AND ASSESSMENT

3.1. Introduction to Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) is a term coined by Wing (1988) and Allen (1988) to describe a subset of the pervasive developmental disorders (PDDs) currently outlined in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* (American Psychiatric Association, 1994). These disorders share three common areas of concern: qualitative impairments in social skills, qualitative impairments in communication skills, and restricted and repetitive interests or behaviours. The five PDDs in DSM-IV are:

- Autistic Disorder
- Asperger's Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS).

When using the term Autism Spectrum Disorder, most professionals are referring to the subset of PDDs that includes Autistic Disorder (usually just referred to as Autism), PDD-NOS, and Asperger's Disorder (see Figure 1).

Figure 1. The Autism Spectrum



The term "spectrum" is also used to refer to a continuum of developmental severity. Autistic Disorder, considered to be at the more severe end of the spectrum, is accompanied by significant cognitive impairments in about 75%-80% of cases. In contrast, most individuals with Asperger's Disorder tend to have average to above average intellectual functioning (American Psychiatric Association, 1994; NRC, 2001). About 50% of individuals with Autistic Disorder never develop functional language, while individuals with Asperger's Disorder, by definition, do not have clinically significant delays in language development. Research has shown an inverse relationship between the severity of autistic symptoms and the level of intellectual functioning across a large number of young children with and without ASDs (Perry, Condillac, Freeman, Dunn-Geier, & Belair, 2003).

In this document, the term "individuals with ASDs" will be used to describe inclusive groups of individuals with Autistic Disorder and/or PDD-NOS and/or Asperger's Disorder. When information pertains to one diagnostic group only, or research was done with one subgroup specifically, then that name will be used (e.g., Asperger's Disorder). The terms "high functioning" (i.e., no cognitive impairment, could include Autism or Asperger's) and "low functioning" (i.e., Autism with cognitive impairment) are also used when referencing interventions, because their appropriateness often depends on the child/adolescent's overall developmental level.

3.2. DSM-IV Criteria for Pervasive Developmental Disorders

3.2.1. DSM-IV Criteria for Autism Spectrum Disorders (American Psychiatric Association, 1994)

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
 - (2) qualitative impairments in communication, as manifested by at least one of the following:
 - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 - (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
 - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)
 - (d) persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:
- (1) social interaction
 - (2) language as used in social communication, or
 - (3) symbolic or imaginative play

- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

3.2.2. Case Examples of Autistic Disorder

The following case examples (Perry & Black, 2003) illustrate the manifestations of Autistic Disorder in children and adolescents. Both are reprinted with permission from Brown and Percy (2003).

Ben Loves Trains:

Ben is 2 1/2 and he loves trains. He is content to play with them alone for hours. Yet he doesn't seem to really understand that they are trains. He doesn't pretend to make them go on the track or have crashes or imagine what the cars are carrying or talk, as he plays alone. He just lines them up in the same way every time. He gets very upset if anyone rearranges his trains. Sometimes he carries a train around with him and rubs it against his chin or waves it in front of his eyes. He never brings a train to show his father, never points to the trains to show his sister. In fact, he completely ignores his sister. He doesn't talk to her, doesn't look at her no matter how hard she tries to be a good big sister. Ben doesn't talk at all, rarely looks at other people and rarely smiles. His mother suspects something is wrong, but her doctor told her Ben is probably just slow talking and will outgrow the other odd behaviour. He will be starting nursery school soon and his mother hopes that will turn him around.

Carolyn Just Wants To Be Friends:

Carolyn is 12 and is great at puzzles. She can do them just as fast whether they are picture side up or upside down! She struggles with her school work, especially language arts and social studies, but is pretty good at spelling and math and has an excellent memory. She was in special education classes when she was younger but is now in a regular class. She seems very friendly and talkative, though a bit immature. She goes up and asks questions of anyone she comes in contact with, even if they're not interested in talking to her. She doesn't know how to relate to other kids very well but really wants to be friends. She is enrolled in a social skills group at a local treatment agency. Her mother worries about what is in store for Carolyn as a teenager and adult. Though she has come so far, from the 3-year-old who used to repeat back nursery rhymes and TV commercials, she still has some very pervasive difficulties.

3.2.3. DSM-IV Criteria for Pervasive Developmental Disorder - Not Otherwise Specified (American Psychiatric Association, 1994)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical Autism" — presentations that do not meet the criteria for Autistic Disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

3.2.4. DSM-IV Criteria for Asperger's Disorder (American Psychiatric Association, 1994)

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (1) marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (2) failure to develop peer relationships appropriate to developmental level
 - (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - (4) lack of social or emotional reciprocity
- B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (4) persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

3.2.5. Case Examples of Asperger's Disorder

The following case examples illustrate the manifestations of Asperger's Disorder in children and adolescents.

Dennis wants to play:

Dennis is a bright boy, with a rather vast vocabulary for a 7-year-old. He prefers to spend time with the adults in his life, rather than playing with his three cousins who live next door. Dennis has a real passion for airplanes, and can tell you the names, engine configurations, flight numbers, schedules and runways for all planes that takeoff and land from his local airport. He is a bit slow to warm up, and is awkward in social situations. He becomes very anxious when there are sudden changes in his schedule, power-failures, and other unpredictable events in his life. At school, Dennis loves to read, but hates to do puzzles or activities that require him to draw or copy from the board. He is rather clumsy, so he has a difficult time in gym class, and is often the last one to be picked for team sports. At recess, he talks with his teaching assistant, as he is rarely invited to play with the other children.

Justin feels awkward:

Justin is a very intelligent 16 year old who is excelling at school, especially in computer science and physics where he takes top honours in his class. He is very interested in playing the piano, and is able to play very complicated classical pieces that he has heard on the radio. Justin spends most of his time studying, using his computer, or playing piano rather than hanging out with other teens. Justin complains to his mother that he has no friends. He has never attended a high school dance or been on a date. At school he eats lunch with a younger boy from a special education class, but they don't hang around together after school. Whenever his mother arranges for him to spend time with other teens who are friends of the family, things go poorly and Justin never quite knows why. Lately, he has become even more withdrawn than normal, and his grades are slipping. He is having trouble getting out of bed in the morning, and often falls asleep before he has finished his homework. He is not eating well, and seems to be losing weight.

3.3. Prevalence and Etiology

The prevalence of ASDs is reported to be approximately 3 in every 1000 for the broader spectrum (Yeargin-Allsopp et al., 2003). There remains a higher ratio of boys to girls (4:1) overall, but this decreases to an almost 1:1 ratio when profound cognitive impairments are present. Though research is demonstrating an increase in overall incidence of ASDs (Croen, Grether, Hoogstrate & Selvin, 2002; Wing & Potter, 2002), it appears that a broader definition of Autism, increased awareness, and more systematic assessment practices may be responsible for the apparent increase (NRC, 2001; Wing & Potter, 2002). Hypotheses linking the increased rates to the measles, mumps, and rubella (MMR) vaccination have been disproven (Roberts & Harford, 2002).

The etiology of ASDs remains elusive, though research continues in the areas of genetics, neurology, and metabolic disorders (Gillberg & Coleman, 2000; Kabot, Masi, & Segal, 2003). Many are hopeful that genetic research will determine a specific genetic marker for these disorders. Family heritability appears to be a reasonable avenue of investigation, as siblings of children with Autism are more likely than the general population to develop Autism or a related disorder. In a study of 48 twin pairs, Bailey, Le Couteur, Gottesman, and Bolton (1995) found that 60% of identical twins and no fraternal twins had an ASD. When they re-examined the pairs for broader cognitive and social abnormalities, they found concordance in 92% of identical twins and 10% of fraternal twins. They conclude there is a great degree of genetic influence in ASDs, however what is inherited may be a broader range of cognitive and social difficulties. This is also evident in the increased rate of anxiety disorders and affective disorders in family members of individuals with ASDs. Another genetic issue relates to Fragile X and Tuberous Sclerosis. There is a higher incidence of Autism among individuals with Fragile X and individuals with Tuberous Sclerosis, however individuals with ASDs are not more likely than the general population to have Fragile X or Tuberous Sclerosis.

In the area of neurological research, several studies have investigated anatomical differences in the brains of individuals with ASDs (Tanguay, 2000). This has been accomplished through various neural-imaging techniques (e.g., Magnetic Resonance Imaging) and through post-mortem studies. Neural imaging has not yielded consistent findings across studies searching for anatomical differences, but individuals with Autism have been found to have larger brain volume (macrocephaly) that is not apparent at birth but appears to develop in early and middle childhood. Post-mortem studies have also yielded inconclusive results, in that there are inconsistent anatomical differences within the brains of individuals with Autism (e.g., increased neuronal density and decreased Purkinje cells in the cerebellum). This suggests there may be multiple neurological and developmental pathways to the Autism Spectrum Disorders.

3.4. Early Identification

The current literature quite clearly supports early screening and referral programs to promote early diagnosis and early intervention. Parents who report concerns about their child's development should be taken seriously — they are usually right, and it does them (and the child) a disservice to delay a full assessment (Filipek et al., 1999).

Filipek et al. (1999) distinguish between developmental surveillance, which involves routine screening for all children, more specific screening for ASDs, and full assessment/diagnosis. Several tools have been developed, some locally in Ontario (the Rourke Baby Record and the Nipissing Developmental Screen), to assist in the early identification of children who may need to be assessed for possible Autism. (Asperger's is not usually considered as a diagnosis this early, neither is it readily apparent at this age — see below.)

Red flags for possible Autism are lack of babbling and/or gestures by 12 months, lack of single words by 16 months, lack of two-word (non-echoed) combinations by 24 months, and any regression or loss of skills (at any age). Other early indicators from research on the earliest signs of Autism include lack of joint attention (e.g., lack of pointing to show), lack of response to name, unusual or absent eye contact, unusual or absent facial expression, and possibly subtle attentional and motor abnormalities. Ongoing research is attempting to find even earlier behavioural or physiological signs of Autism.

It is not unusual for parents to report a pattern of regression or loss of skills between 18–24 months, however the majority of children do not follow this pattern. It should be noted that very young children with ASDs do not necessarily show unusual behaviours such as stereotypies (flapping, rocking); it is the absence of typical developmental behaviours (e.g., pointing, gaze monitoring), which is more predictive. Also, they often enjoy physical contact (tickling, rough and tumble play) on their own terms, and this does not preclude a possible Autism diagnosis.

If the child is identified by this developmental surveillance process, a specific Autism screen should be conducted, such as the Checklist for Autism in Toddlers (CHAT), or Pervasive Developmental Disorders Screening Test (PDDST), or the series of questions provided in Filipek et al. (1999). If warranted, the child should be referred for a full diagnostic assessment and for early intervention of whatever kind may be accessible, even before a formal diagnosis (Filipek et al., 1999; NRC, 2001).

3.5. Assessment and Diagnosis of Autistic Disorder

Good assessment is crucial to understanding and assisting children and adolescents with ASDs, as well as helping their families. Assessments of people with ASDs may be done for a variety of reasons at various times in their lives (Perry, Condillac, & Freeman, in press), including:

To obtain or clarify an initial diagnosis. For parents of young children with Autism, the initial diagnosis is inevitably a very difficult process (see Practices for Families Section). However, it is frequently more time consuming, frustrating, and confusing than necessary because of a lack of community expertise regarding Autism, and some practitioners' assumptions that the child is too young to make a diagnosis. Research has demonstrated the validity of the early diagnosis of Autism by age 2 (e.g., Lord, 1995; Stone et al., 1999), and thus families should be referred as soon as concerns emerge.

To document diagnostic status necessary for access to services or funding. At various stages later in the child or adult's life, a diagnostic reassessment may be required to document a particular diagnosis, such as Autism, or a certain classification, such as developmental disability. The purpose of this diagnosis or classification may be to determine school placement, or access funding supports or services in any of the social services, health care, and education systems. Further, a reassessment conducted ostensibly for this purpose frequently has the beneficial collateral effect of providing to caregivers a greater understanding of the person's abilities, resulting in better-tailored interventions and environments.

To help understand the person. The primary clinical reason for any kind of assessment is to provide useful information about the person to help professionals and parents understand the individual better and guide the design of appropriate educational and therapeutic intervention (Sattler, 2001). It is important to incorporate the principle of individualization into program planning by taking into account each person's developmental level, strengths and needs, degree of scatter among skills, likes and dislikes, behavioural difficulties, effective teaching strategies, and motivational systems.

A "best practice" approach to assessment means that the specific measures used and the whole assessment process should be carefully tied to the most recent professional literature. They should also be grounded in evidence-based evaluation of the measures and procedures, which are constantly changing. Two recent consensus documents set the standard for "best practices": Filipek et al. (1999) and NYSDH (1999). Clinical practice should also be consistent with relevant legislation, professional college regulations, standards, ethics, agency policies, and other relevant guidelines. In Ontario, the *Regulated Health Professions Act (RHPA)* defines diagnosis as a "controlled act" which may only be performed by professionals registered with either the College of Psychologists or the College of Physicians and Surgeons. In some centres, multidisciplinary team members contribute to a comprehensive assessment, but the practice of

communicating the diagnosis to the family should only be done by one of these licensed professionals. Other staff are cautioned against inadvertently giving the impression to a family of delivering a diagnosis. In addition to possible negative clinical consequences for the family (see Family section), there could be personal consequences, as the RHPA makes provision for heavy fines for violation of this legislation.

The DSM-IV sets out the standard diagnostic criteria (listed earlier) for the diagnosis of Autistic Disorder. Clinical evaluation should be based on a combination of parent report and observation for each criterion, preferably over more than one occasion and in more than one setting (i.e., with parents, with other adult, alone, during free toy play, during structured demands). Several criteria cannot be rated in very young and/or very low functioning individuals because they are beyond the child's developmental level (e.g., pretend play). Difficult diagnoses or ambiguous distinctions require more observation (preferably in settings with peers), additional testing in some cases, and often collegial consultation.

Best practice requires the use of a standardized Autism observation measure, with the Autism Diagnostic Observation Schedule (ADOS-G; Lord et al., 2000) and the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988) being the two most prominent measures. In addition, there are a number of parent interview measures and questionnaires designed for different purposes (reviewed by Lord, 1997; NYSDH, 1999; NRC, 2001; Parks, 1988).

The vast majority of people with Autistic Disorder (approximately 75–80%) also meet the criteria for a diagnosis of mental retardation or MR (American Psychiatric Association, 1994; NRC, 2001; Sattler, 2002). Many of the learning problems and behavioural difficulties experienced by people with Autism are also seen in developmental disabilities (DD) and may be more related to the person's "level of functioning" than their Autism. Thus, it is crucial that this area be thoroughly assessed according to professional guidelines in the MR/DD field (American Association on Mental Retardation, 1992; American Psychiatric Association, 1994; Jacobson & Mulick, 1996), which involves measures of both cognitive and adaptive behaviour. There is a characteristic pattern in cognitive profiles often seen in Autism which is different from DD, however, involving significantly higher Performance than Verbal skills, with strengths often in visual-motor and rote memory tasks. Extreme "savant" skills are occasionally seen (e.g., amazing mental arithmetic calculations) and it is important to realize these are usually very isolated skills in a person who is otherwise quite "low functioning".

For intervention planning, it is wise to include a curriculum-referenced developmental measure. In addition, in some cases comprehensive assessment of problematic behaviours (e.g., aggression, self-injury) will be needed, as discussed elsewhere in this paper.

A summary of recommended multidisciplinary assessments and specific assessment measures are summarized in Table 1.

Table 1. Summary of Best Practices Assessment for Autistic Disorder¹

Assessment Area	Routinely Used Measures	Optional Measures	Comments
Diagnosis	DSM-IV, and CARS or ADOS-G	ADI-R, ABC, other questionnaires, interviews, observations	diagnosis derived from clinical judgement of experienced clinician (physician or psychologist) based on observation (including social interactions and communication), history, and standardized measures
Cognitive Level	One of: WISC, WPPSI, Bayley, Stanford-Binet, Mullen	other specific cognitive, memory, attention, neuropsychological tests as warranted	use test most suitable for age and developmental level, including verbal, nonverbal, and global score, with adequate floor and recent norms; high degree of skill in administration needed
Adaptive Level	VABS or SIB-R		information based on parent interview
Language/Communication	One of: Rosetti, CSBS, MacArthur, SICD	informal preverbal, phonological/speech assessment if warranted	based on combination of standardized testing (high degree of skill in administration needed), observation, and parent interview
Functional/ Curriculum/ Behavioural	One of: ABLLS, Brigance, Portage	functional assessment of problem behaviours if warranted	include social and play, not just academic/language, etc.
Medical Investigations & Other Assessments	obtain medical history and previous reports	assess for sensory-motor dysfunctions if warranted, lead screen if pica or environmental concern, metabolic if indicated, sleep EEG if regression or seizures	EEG and imaging procedures not routinely recommended. (Also of unproven value: hair analysis for trace elements, celiac antibodies, allergy testing, immunological testing, micronutrients, intestinal permeability, urinary peptides, mitochondrial disorders, thyroid function, or erythrocyte glutathione peroxidase studies, chelation)

¹ See Appendix I – Reference Guide for Developmental & Diagnostic Measures

3.6. Assessment and Diagnosis of Asperger's Disorder

Unlike Autistic Disorder which can be reliably diagnosed by age 2, Asperger's Disorder is most often diagnosed when children reach school age, though when asked, parents are often retrospectively able to describe some signs apparent by age 3. This is likely due to the fact that children with Asperger's Disorder typically present with average or above average verbal skills and adequate early social development, and lack the developmental delays and behaviour problems associated with early referral for assessment services by parents, physicians, and early childhood educators. A number of children with Asperger's Disorder have been misdiagnosed with other labels (e.g., Autistic Disorder, Obsessive Compulsive Disorder) by well-meaning practitioners who are not aware of the symptom overlap among these disorders (Attwood, 1998).

There is considerable discussion in the literature as to the clinical differences, if any, between Asperger's Disorder and Autistic Disorder in individuals with higher cognitive achievement (Klin, Volkmar, Sparrow, Cicchetti, & Rourke, 1995; Szatmari, Archer, Fisman, Streiner, & Wilson, 1995). Klin (1994) notes that it is essential to avoid circularity and reliance on diagnostic criteria (which change periodically) in determining whether such distinctions exist. Instead, he suggests comparing the actual presentation of symptoms. Some of the major similarities and differences between groups with Autistic Disorder and Asperger's Disorder reported in the literature are summarized in Table 2. For a thorough review of the literature, see Klin, Volkmar, and Sparrow (2000).

Table 2. Comparison between Autistic Disorder and Asperger's Disorder

	Autistic Disorder	Asperger's Disorder
Symptom onset	between 1-3 years	after age 3
Early language development	impaired	proficient (even precocious)
Motor skills	consistent with developmental level	increased clumsiness
Overall intellectual skills	mostly well below average	mostly at or above average
Visual spatial skills	relative strength	relative weakness
Verbal skills (e.g., vocabulary & comprehension)	relative weakness	relative strength
Social pragmatic aspects of language (e.g., conversation, prosody, non-verbal)	relative weakness	relative weakness
Repetitive behaviour and interests	more physical mannerisms	more verbal/cognitive mannerisms

The major similarities are reflected in the overlap in diagnostic criteria in the social and behavioural areas. The major differences appear to be in the areas of cognitive and language development. As such, there is adequate information to suggest that Asperger's Disorder and Autistic Disorder are distinct (can be differentiated) but clearly related disorders. Further, the positioning of these disorders at opposite poles on the Autism Spectrum (due largely to their varying levels of cognitive impairments) appears to be warranted.

Another noteworthy characteristic of individuals with Asperger's Disorder (and high functioning Autism) is their failure to develop what researchers refer to as "Theory of Mind" (Baron-Cohen, Leslie, & Frith, 1985). Theory of mind refers to an individual's ability to understand that others have mental states (beliefs, intentions, etc.) that may differ from his or her own. It is typically developed between 3.5 and 4.5 years of age. The classic theory of mind task involves a scenario similar to this: Sally and Susie are playing dolls, when Susie is called away by the teacher. Before Susie leaves, she carefully places her doll in a stroller, under a blanket. After Susie has gone, Sally takes the doll from the stroller, and places it in a cradle. During the theory of mind assessment, the child is asked where Susie will look for the doll when she returns. A child who does not possess theory of mind will say that Susie will look in the cradle because he or she knows that is where Sally put the doll. A child with theory of mind will realize that Susie did not observe the doll being moved, and will know that Susie will look for the doll in the stroller where she left it. Theory of mind has implications for social development, especially social perspective taking. It also limits the degree to which individuals with Autism can demonstrate the use of irony or deceit.

It is important to be aware that some individuals with Asperger's Disorder present with a cognitive profile similar to that proposed by Rourke (1989) in his description of nonverbal learning disabilities (NLD). The core symptoms of NLD include:

- deficits in social interaction, social perception, and social judgement;
- difficulties in visual-spatial and visual-organizational skills; and
- well developed language skills (especially in rote/structural areas) (Rourke & Tsatsanis, 2000).

For example, these children are often quite verbose in their communication, but may have significant difficulty with mathematics and nonverbal problem solving. In addition to these typically observed clinical signs, there are often additional clinical manifestations that can be observed through careful neuropsychological examination, including tactile imperception and co-ordination difficulties. A study by Klin, Volkmar, Sparrow, Cicchetti, and Rourke (1995) found that 18 out of 21 individuals with Asperger's Disorder had features (strengths and limitations) consistent with the NLD profile, compared to only 1 out of 19 individuals with Autistic Disorder.

The assessment of Asperger's Disorder has received considerably less attention in clinical research than Autistic Disorder, and there is far less consensus on assessment procedures (for a complete review, see Volkmar & Klin, 2000). Most would agree that differential diagnosis between Autistic Disorder and Asperger's Disorder requires the assessment of cognitive, communication, and motor skills, as well as careful inquiry related to early history, current functioning, and observational measures of symptomatology. Whenever possible, a multidisciplinary assessment including participation as necessary from a psychologist, a developmental pediatrician, a psychiatrist, a speech and language pathologist, and an occupational therapist is warranted (Klin et al., 2000).

To assist in differential diagnosis between Autistic Disorder and Asperger's Disorder, the individual's cognitive profile must be considered. Standardized cognitive tests such as the WPPSI-III, WISC-III or WAIS-III, are recommended for use with this population. In addition to cognitive assessment, some detailed assessment of communicative skills might be useful for differential diagnosis, because the diagnostic criteria for Asperger's Disorder preclude significant language impairments. Instruments such as the Clinical Evaluation of Language Fundamentals – Fourth Edition (CELF-IV; Semel, Wiig, & Secord, 2003) are often useful. However, many individuals with Asperger's Disorder possess a relative strength in the basics of language (e.g., articulation, comprehension), so informal assessment is integral to differential diagnosis. Assessment should cover the more idiosyncratic forms of communication such as non-verbal skills, (e.g., gaze, gestures), prosody (tone, volume, cadence, pitch), social-pragmatics (e.g., responding to cues from communicative partner, taking turns), social reciprocity, empathy, and perseveration on preferred topics, and subtleties of communication such as use of irony and humour.

Individuals with Asperger's Disorder are often described as having some clumsiness, and unlike individuals with Autistic Disorder, their motor skills are often lower than expected given their cognitive abilities. In addition to a solid measure of gross and fine motor functioning, a measure of writing skills, perceptual skills, and hand-eye co-ordination such as the Beery Developmental Test of Visual-Motor Integration, 4th Edition (Beery VMI; Beery & Buktenica, 1997) are often useful motor screening tools. Beyond the standardized assessment tools, it is important to determine the degree to which any motor limitations impact upon functioning (e.g., lack of co-ordination affects ability to play with peers) or school learning (e.g., perceptual problems that affect handwriting). Neuropsychological testing might be beneficial for some individuals, to investigate underlying neuro-motor deficits and to address concerns about impaired executive functioning (i.e., the ability to integrate past experience and future anticipation into a plan for present action).

With the information gleaned from the other areas of assessment, the diagnostic assessment also requires specific information regarding the symptoms of ASDs to assist with differential diagnosis. A detailed history, using an instrument such as the Autism Diagnostic Interview –

Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) will provide the necessary information to determine if the early history and current presentation are consistent with a diagnosis on the Autism Spectrum. Further, an observational tool such as the Autism Diagnostic Observation Schedule, ADOS-G (Lord, Rutter, DiLavore, & Risi, 1999) can be very useful in providing opportunities to observe pro-social and idiosyncratic behaviours that assist in ruling in or ruling out an Autism Spectrum Disorder. While neither of the most commonly used instruments includes a specific algorithm for detecting Asperger's Disorder, both are widely used for such purposes. Clinical judgement is the essential ingredient in interpreting the scores of diagnostic instruments within the context of the broader assessment information.

Differential diagnosis between Asperger's Disorder and other psychiatric/developmental disorders must also be considered. Mesibov, Shea, and Adams (2001) suggest that clinicians give careful consideration to conditions that share some symptomology with Asperger's Disorder. For example, there is some overlap between the restricted and repetitive behaviours in Asperger's Disorder and the compulsions evident in Obsessive Compulsive Disorder (OCD). In addition to OCD, consideration should also be given to Schizoid Personality Disorder, Semantic-Pragmatic Language Disorder, and Non-Verbal Learning Disability.

During the diagnostic assessment, it is also essential to be vigilant for possible comorbid disorders, including Tourette's Disorder, OCD, Depression (in older children and adolescents), and Attention Deficit Hyperactivity Disorder (ADHD, in younger children) (Martin, Patzer, & Volkmar, 2000). Though ADHD cannot be diagnosed in an individual with a PDD, individuals with Asperger's Disorder frequently show significant symptoms of ADHD that are responsive to treatment. In a recent Ontario-based study, Kim, Szatmari, Bryson, Streiner, and Wilson (2002) found that children and adolescents with Asperger's Disorder (and those with high functioning Autism) showed a higher rate of problems related to anxiety and depression than a large community sample. Of 40 high functioning children with ASDs in their sample, 17% showed marked signs of depression, and almost 14% showed evidence of generalized anxiety. A number of these individuals also scored in the clinically relevant range across a number of measures related to mental health disorders, including internalizing (14%) and externalizing (9%) behaviours. Treatment for these comorbid conditions should follow best practices as outlined in other documents (e.g., CMHO, 2002a).

3.7. Assessment and Diagnosis of PDD-NOS

There is very little specific information regarding the appropriate way to assess and diagnose PDD-NOS. In general, use the procedures outlined in either or both of the previous sections.

Some professionals prefer not to use the term PDD-NOS at all, arguing that it is confusing to parents and not very helpful, and that distinctions among the subtypes of PDD either cannot be reliably made (at least in young children) or are not relevant for intervention planning (e.g.,

Mahoney et al., 1998). These clinicians would most likely use the term ASD(s) for these children, indicating that they are "on the spectrum." However, in a recent study of four groups of young children (Autistic Disorder, PDD-NOS, MR, and Other Disorders) groups of children with clinical diagnoses of Autistic Disorder and PDD-NOS represented relatively distinct distributions of symptom severity scores (based on the CARS) (Perry, Condillac, Freeman, Dunn Geier, & Belair, 2003). This supports the notion that PDD-NOS may be a valid entity on a continuum with Autism but milder in severity, as shown in Figure 1.

According to DSM-IV protocols, however, the diagnosis of PDD-NOS should be used when a child does not strictly meet criteria for either Autistic Disorder or Asperger's Disorder, but has difficulties in the three areas of social, communication, and repetitive behaviour, as stated earlier. The issue for diagnosticians who would like to use this classification is how many of these symptoms must be present, and which ones are most important. Buitelaar, Van der Gaag, Klin, and Volkmar (1999) examined the data from the DSM-IV field trials and found 7 of the 12 DSM-IV Autism criteria were related to a clinical diagnosis of PDD-NOS (all 4 of the social criteria listed earlier, impaired conversation, stereotypical language, and repetitive mannerisms). Their suggested scoring rule is a minimum of 3 criteria met, including at least 1 social item.

4. INTERVENTIONS

4.1. Pro-Social and Play Related Interventions

Many of the core deficits in ASDs fall within the domain of social development, regardless of the level of cognitive functioning of the particular child or adolescent. The goal of intervention in the social domain is to increase meaningful relationships by teaching skills that support the development of social interest, social initiation, social responsiveness, and empathy and understanding of the other's perspective. It is critical that intervention plans include strategies to enhance social understanding, social relating, and play skills, and that these strategies take into account the individual's cognitive and learning abilities (McConnell, 2002). Unfortunately, many individuals with ASDs (with varying cognitive abilities) are placed within integrated environments without adequate supports to scaffold the development of appropriate social interactions (Weiss & Harris, 2001). Under these sub-optimal conditions, some individuals with ASDs face further stigmatization from their peers based on their social awkwardness (e.g., misinterpreting social cues, lacking understanding of another's perspective; Church, Alisanski, & Amanullah, 2000). Consequently, some even develop anti-social behaviours in an effort to engage their peers.

Another concern is that the service delivery system tends to over-rely on short-term, generic, social skills groups. These tend to have little efficacy because most teach specific responses

that fail to generalize outside of the group context (Gresham, Sugai, & Horner, 2001). Well-designed social supports and several specific social interventions reviewed in this section can result in lasting increases in pro-social behaviour, and in some cases even result in dramatic decreases in problematic behaviour (Koegel, Koegel, Hurley, & Frea, 1992). Though the majority of research has focused on children with Autistic Disorder, many of the strategies outlined below show great promise for children with Asperger's Disorder.

4.1.1. Social Stories

These innovative stories, developed by Gray (1994), have been widely used to teach higher functioning individuals with ASDs (including those with Asperger's Disorder) how to understand and interact in a variety of social situations. The stories typically depict a social situation that an individual is likely to encounter, and include opportunities to learn appropriate ways to respond to the situation. The different types of sentences comprising the social stories are carefully balanced. They have more descriptive statements (give information), and perspective statements (provide information on others' likely reactions), and fewer directive statements (give a socially appropriate response) and affirmative statements (why this is important). The stories are presented to the individual as text, or as text with pictorial supports (Gray, 1995, 1998), and the individual is given a schedule for practising the social story until it is learned. They are also given opportunities to practise in real situations with appropriate supports. A few research studies have demonstrated that social stories can effectively enhance social interaction in higher-functioning individuals with ASDs (e.g., Gray & Garand, 1993; Norris & Dattilo, 1999; Swaggart et al., 1995). The effectiveness of social stories should be carefully evaluated for each individual with an ASD.

4.1.2. Peer-Mediated Instruction

Research over the past 30 years has shifted from adult-mediated strategies to enhance social skills to peer-mediated strategies. Adult-mediated strategies result in decreased generalization and increased reliance on adults in social interactions (Weiss & Harris, 2001). Currently, the literature emphasizes peer-mediated strategies, including instruction, prompting, and reinforcing of social interaction by peers (Kamps et al., 2002; Roeyers, 1996; Strain & Schwartz, 2001).

Pivotal Response Training (PRT), as described by Pierce and Schreibman (1995; 1997), is an effective naturalistic peer-mediated strategy to increase social initiations and maintenance of interaction in children with ASDs. In PRT, peers are taught to engage with, interact with, and reinforce their peers with ASDs in social situations. Unfortunately, generalization from peer-mediated strategies to initiations by individuals with ASDs does not occur without specific emphasis on generalization, including ongoing peer-tutoring and structured groups that permit relationships to be established (Chandler, Lubeck, & Fowler, 1992; Kamps et al., 2002). Specific supports to enhance skill development in children with Autism during peer-

mediated intervention will likely help to increase the generalization of social skills to natural situations, especially within school settings. When implemented with children and adolescents with ASDs, peer-mediated interventions should be systematically evaluated to monitor acquisition and generalization of skills.

4.1.3. Social Script Training

As many individuals with ASDs lack the imaginative skills necessary to engage in meaningful play with their same-aged peers, specific instruction in creative play has been useful in increasing the play skills of children with ASDs (Weiss & Harris, 2001). Social scripts can play an important role in this teaching for children with ASDs. A social script depicts roles for a child with an ASD and typically 1 to 2 peers in a conversation (e.g., invitation to play in the park) or an imaginative role-play activity (e.g., conductor, ticket seller, and passenger on a train). It is essential that scripts be carefully matched to the interest and ability level of the child with an ASD and his/her peers. In the case of conversational scripts, efforts should be made to fade scripts and teach alternative responses to increase the natural quality of interaction. A few small studies have demonstrated the effectiveness of scripts in teaching play to preschool and school-aged children with ASDs (Goldstein & Cisar, 1992; Krantz & McClannahan, 1993). In both studies, children engaged in elaboration of the scripts after adequate practice. Social scripts can be useful for enhancing interaction, but they require careful monitoring to determine their effectiveness for individual children with an ASD.

4.1.4. Theory of Mind Training

Several researchers have attempted to remediate the absence of "Theory of Mind" in individuals with ASDs (see section on Assessment and Diagnosis of Asperger's Disorder for an explanation) to improve empathy or social perspective taking (Klin & Volkmar, 2000). Despite results that show improvements on experimental theory of mind tasks, these results have not generalized broadly to conversational skills (Hadwin, Baron-Cohen, Howlin, & Hill, 1997) or social competence in real life situations (Ozonoff & Miller, 1995). In the Ozonoff and Miller study, intervention took place across 14 sessions (over a 4.5 month period) that each lasted an hour and a half. It is possible that generalizing theory of mind concepts to everyday social interactions might be achieved if the technology of generalization (Stokes & Baer, 1977), repeatedly demonstrated in behaviour analytic studies, was applied to this potentially exciting area of research. Systematic evaluation of skill development and impact on social and communication skills is highly recommended when delivering Theory of Mind training to individuals with ASDs.

4.1.5. Relationship Development Intervention

Relationship Development Intervention (RDI; Gutstein, 2000; Gutstein & Sheeley, 2002) is a series of techniques and strategies built upon the typical developmental processes of social competence. The goal of RDI is to increase motivation and interest in social relating in

individuals with ASDs, and provide activities and coaching to assist them to enjoy and become competent in social relationships. There are 6 levels in RDI: Novice, Apprentice, Challenger, Voyager, Explorer, and Partner, which are subdivided into a total of 24 developmental stages. Programming is individualized and based on the Relationship Development Assessment designed by Dr. Gutstein. Once a child's relationship level is determined, an individualized program is prepared, and coaches are trained to implement the program and support the acquisition of skills. To date there is no published research regarding the efficacy of this approach, though Dr. Gutstein suggests it might be a useful approach for higher functioning children and adolescents with ASDs, or for lower functioning children after they have learned some basic relating through IBI. This approach is regarded as promising, though its effectiveness should be carefully evaluated for the individual child, and it should be considered an adjunct to other interventions proven effective.

4.2. Language and Communication-Based Interventions

Individuals with Autism Spectrum Disorders can have a wide range of language and/or communication impairments, especially in the social and pragmatic areas of language development. As previously mentioned, some children have a total lack of language development, others may have a significant language impairment, still others may have idiosyncratic language difficulties including problems with prosody (tone, cadence, and quality of speech production), and some may not be able to conduct a conversation despite proficient language development. There is no single language/communication intervention appropriate for all children with ASDs; it depends very much on the child. Intervention choices should be made based on an individual assessment, preferably by a registered Speech and Language Pathologist who has experience supporting children with ASDs at the same functioning level as the individual.

4.2.1. Augmentative Communication

Augmentative communication approaches have been well established for the treatment of children and adolescents with language disorders and physical disabilities, and their use has been successfully generalized to those with ASDs. Based on assessment results, a modality (or modalities) of communication is selected that will best complement the individual's language level and learning abilities. Research has demonstrated the effective use of sign language, photographs, picture communication symbols (www.mayer-johnson.com), and various mechanical devices (e.g., tape recorders, voice output devices) to replace or augment the spoken language of individuals with Autism.

While some parents and professionals feared that the use of assistive devices would replace or inhibit the development of spoken language in children with ASDs, this has not been the case. In fact, many children have developed spoken language only after the implementation of an augmentative communication system (Mirenda & Erickson, 2000). One of the limits

of these approaches is that the emphasis tends to be on the use of the device, and not the act of communicating with a partner (Bondy & Frost, 1994). It is not unusual for some individuals with ASDs to attempt to use the communication device in the absence of a communicative partner (e.g., standing alone in the kitchen pointing to a picture of a cookie). It is therefore essential that professionals recommending intervention using augmentative communication systems emphasize the importance of the communicative partner in the social context.

The evidence supporting the use of assistive and augmentative communication systems with individuals with ASDs comes largely from research with children, adolescents, and adults with more generic developmental disabilities and communication disorders. However, many single subject and small group studies have demonstrated the efficacy of augmentative communication for individuals with ASDs. Augmentative communication can be implemented within the framework of many educational and treatment approaches in many settings.

4.2.2. Picture Exchange Communication System (PECS)

The Picture Exchange Communication System (PECS; Bondy & Frost, 1993) is a communication intervention developed by Bondy (a behaviour analyst) and Frost (a speech and language pathologist) in the early 1990s. This approach to augmentative communication differs from other approaches in that initial emphasis is placed on the communicative exchange between partners, not on expansion of the communicative repertoire. In this approach, the individual with an ASD is taught to:

- select a picture that represents a desired item, activity, or person;
- present the picture to a communicative partner; and
- receive the desired outcome (or learn when they can receive the desired outcome).

Later steps in the process teach sentence structure and move the communicative emphasis from requesting to answering questions to social commenting. PECS is most useful for children and adolescents with absent or severely delayed communication skills. However, it can be used to enhance sentence structure and responses to questions for individuals with only mild language impairments. Despite parental reluctance to use this augmentative approach (out of concern that it might inhibit language development), research has shown that use of PECS has preceded language development in many young children (Bondy & Frost, 1984). Many workshops are available through Pyramid Educational Consultants (www.pecs.com) to teach parents and professionals to effectively use this approach.

The evidence to support the use of PECS with individuals with Autism has been reported across research studies (Bondy & Frost, 1993, 1994, 1995) and independently replicated (Schwartz, Garfinkle, & Bauer, 1998). PECS is considered a useful and effective approach for individuals with ASDs that can complement many different educational and treatment options.

4.2.3. Verbal Behaviour Approach (VB)

The Verbal Behaviour approach is a method within applied behaviour analysis that has its roots in Skinner's (1957) analysis of verbal behaviour. Unlike other language approaches that stress the "receptive" (understanding) and "expressive" (production) aspects of language, Skinner's approach emphasizes the environmental variables responsible for language, the functional relationship between language and environment, and the structure of language. In typical development, children first use words to label people and items in their environment, and appear to thrive on the social response to their verbal behaviour. As many children with ASDs are not (at first) motivated by social interaction, Sundberg and Partington (1998) suggest that children with ASDs should first be taught to make requests (mands) using verbal or nonverbal means (e.g., words or sign language), and consequently receive immediate acknowledgement of those requests through reinforcement. Following the acquisition of several mands, the individual is taught to comment or label objects in the absence of desired objects (pure mands), with an emphasis on the social aspects of interaction. Some of the steps involved in teaching a child who is non-verbal to produce a verbal request include teaching basic motor imitation and vocal imitation of sounds (echoics) before trying to teach any full words. Behavioural analytic approaches using a verbal behaviour framework have been most effective in teaching children with severely limited language skills to develop or increase their verbal repertoire. They have also been successfully used to expand the social communication of children with ASDs at higher skill levels.

Evidence to support the use of a Verbal Behaviour approach has been repeatedly documented in single subject and multiple baseline small group designs for individuals with ASDs (e.g., Drash, High, & Tutor, 1999; Sundberg, Endicott, & Eigenheer, 2000). The emphasis on learning in the natural environment and generalization across responses, people, materials, and settings, makes this a good choice to complement educational and treatment programs for individuals with ASDs.

4.2.4. Developmental Social-Pragmatic Model (DPS)

The Developmental Social-Pragmatic Model (DPS; Wetherby, Schuler, & Prizant, 1997) focuses on developing language in the child's natural environment using existing (even if unconventional) communicative methods. This model emphasizes the initiation and spontaneity of communication while following the child's interests or lead. There is considerable developmental research supporting the premises of the DPS model and a definite need for intervention in the social and pragmatic aspects of communication. Unfortunately, there is a lack of direct empirical evidence demonstrating its efficacy with individuals with ASDs. The authors of the approach based the model on the developmental literature on language development, and on intervention research on component parts (e.g., Incidental Teaching, Hart & Risley, 1977 and Natural Language Paradigm, Koegel, O'Dell, &

Koegel, 1987). The DPS model is only recommended for children who have already learned some basic communicative skills through IBI, or for children without significant language delays. As there is no published research on the DPS model, it would be prudent to evaluate its efficacy on an individual basis.

The SCERTS Model (Prizant, Wetherby, & Rydell, 2000) is an individualized approach to communication intervention for individuals with ASDs. The authors claim this model draws its underlying theoretical framework from the DPS Model, the Floortime (DIR) approach (Greenspan & Weider, 1998), and Sensory Integration (Ayres, 1972). The goal of the approach is to simultaneously target core deficits, including:

- communication and language deficits;
- social and emotional deficits; and
- sensory processing deficits.

The model aims to provide customized support to individuals with ASDs and their families. As with the DPS model, there has been no research to date evaluating the entire SCERTS model. Unlike the DPS model, however, the component parts of the SCERTS model do not have adequate scientific evidence.

4.2.5. Facilitated Communication (FC)

Facilitated Communication (FC) involves a "facilitator" (staff, teacher, parent, etc.) holding the hand of or otherwise touching the person with Autism while he or she types or points to letters, words, or pictures. It was very popular in the early to mid 1990s in Ontario, and continues to be used in some settings. See Jacobson, Mulick, and Schwartz (1995) for a complete description of the history of FC.

FC is probably the most controversial of all the treatments for Autism, polarizing the field and sparking policy statements, lawsuits, and so on. Remarkable results were reported anecdotally (e.g., people who were severely impaired suddenly typing complex emotionally-laden messages), and many well-meaning practitioners and parents became highly invested in doing FC and promoting it. However, the hypothesized mechanism (touch counteracting apraxia) and proponents' assertions regarding its implications were contrary to accumulated knowledge about Autism, and there was a total lack of empirical evidence of its effectiveness.

Since that time, a large number of controlled studies of FC have been done (more than in many other areas of Autism treatment), including some quite large and methodologically sophisticated studies (see Shane, 1994, for a review), and including some done in Ontario (Bebko, Perry, & Bryson, 1996). The research does not provide support for the validity of FC. The more methodologically rigorous the research design, the more clear-cut the lack

of validity. Research has consistently shown that it is the facilitators (not the clients) who determine the content of the typed messages (though unconsciously). One study showed that, in fact, the more invested facilitators were, the more they influenced the clients (Perry, Bryson, & Bebko, 1998). Various professional organizations have issued policy statements essentially forbidding use of FC. In addition, consensus panels and reviewers have unanimously recommended that FC not be used (e.g., NYSDH, 1999), both because of the consistent findings of non-validity and because of the potential for harm of various kinds. This harm includes: a perceived abuse of clients, false allegations of sexual abuse by parents or staff, significant waste of time and resources of client, staff, and families, as well as significant emotional repercussions for all those involved.

4.3. Sensory and Motor Interventions

It is often reported clinically that individuals with Autism and other ASDs have unusual responses to sensory stimuli or "sensory issues" and/or motor apraxias. These are often among the earliest symptoms parents report (e.g., unresponsive to loud sounds, loved rubbing a certain texture, etc.). These sensitivities may be quite salient in some individuals, with implications for preventive approaches to structure their environment (as noted in the Challenging Behaviour section). However, it should be noted that these sensory differences are not unique to ASDs, are not universally present in clients with ASDs (though they are common), and are highly idiosyncratic when they do occur.

Gross and fine motor skills are often among the most well-developed domains in lower functioning children with Autism, but there are reports of motor planning difficulties and oral-motor apraxia in Autism and poor coordination in Asperger's Disorder. A wide array of interventions have been proposed to address these symptoms, but from an empirical point of view, they are among the most controversial of all treatments for ASDs.

4.3.1. Sensory Integration Therapy (SI)

Sensory Integration (SI) therapy and other sensory and physical approaches are very commonly used in Ontario in a variety of settings (homes, schools, child care settings, etc.). Classical SI has developed from the work of Ayres (1972), and is based on the premise that providing particular sensory and vestibular activities will improve the capacity of the child's nervous system to modulate arousal and organize and assimilate information coming in through the senses. This, in turn, is presumed to help the child attend, learn, and behave in more typical ways (King, 1987). The neurological theory behind SI is actually not well accepted (Baranek, 2002). SI typically takes place in a fairly child-directed and play-oriented 1:1 session, and thus includes many other (possibly beneficial) aspects besides the proposed critical features. Usually occupational therapists (OT) provide SI, but it should not be equated with OT (members of this profession may use a variety of techniques).

There is a conspicuous lack of empirical evidence for the validity of SI for children and adolescents with ASDs. Recent reviews found either no adequate studies at all (NYSDH, 1999), or a handful of studies showing only modest effects in poorly controlled studies (Baranek, 2002; Dawson & Watling, 2000). One of the largest and strongest studies (18 children with Autism in an alternating treatments design) found, in fact, that traditional fine motor activities resulted in slightly greater benefit to the development of appropriate speech than the vestibular/SI approach (Reilly, Nelson, & Bundy, 1983). Even studies in other populations (see Ottenbacher, 1982; Vargas & Camilli, 1999) are far from conclusive regarding the degree of efficacy of SI treatment.

Based on research available to date, practitioners are advised that sensory-based interventions are not essential components of a comprehensive intervention approach, and that investing large amounts of time in such approaches should be seriously questioned. However, the child or adolescent may enjoy these activities, and they may be effectively used as reinforcers. When used on an individual basis, SI programs should be designed with clear and measurable goals (e.g., symptom reduction) and a means of monitoring and evaluating its effectiveness.

4.3.2. Other Physical and/or Sensory Approaches

Several other sensory-based therapies have been proposed, some of which are in frequent use in Ontario, either individually or in combination. These include:

- Sensory Diet (sensory summation approach) — an approach that uses a wide range of tactile and vestibular experiences (e.g., brushing with a vegetable brush, joint compressions) several times per day (no empirical support);
- Alert Program — a combination of CBT approaches and sensory approaches for arousal modulation in individuals with Asperger's (no empirical evidence);
- Deep Pressure — applied by way of firm massage or joint compressions, using weighted vests and/or pressure gloves (no empirical support);
- "Squeeze machine" or "hug machine" — developed by Temple Grandin (some empirical evidence, possibly beneficial for anxiety and high arousal);
- Touch Therapy/Massage — (some empirical evidence of calming and possibly social responsiveness, but inconclusive because changes occurred in control group also);
- Patterning (Doman, 1974) — was introduced by Doman & Delacato in the 1960s. In this intervention, gross motor stages are recapitulated via many hours of exercises (creeping, crawling, etc.), ostensibly to create neurological reorganization (neurological theory disproven and no empirical evidence);
- Neurodevelopmental Therapy — a sensorimotor physiotherapy approach involving exercises and physical manipulation (no empirical support);
- Cranio-Sacral Therapy — an osteopathic or chiropractic treatment involving traction and decompression of the cranio-sacral area (no empirical support);
- Physical exercise — sometimes prescribed as a treatment for stereotypic behaviour

(several studies all showing short-term benefit on target behaviours, not necessarily global effects).

In summary, interventions designed to address sensory and motor difficulties should be viewed with caution. There is little empirical research, and what does exist is often methodologically weak and/or inconclusive. Control groups, where they exist, sometimes improved as much or more than treatment groups. These approaches are often specific, time-limited, and non-intensive. As a result, generalization and long-term benefits are doubtful. Baranek (2002) notes that "...the indiscriminate use of any sensory- or motor-based intervention is unethical...if necessary...must be prescribed in an individualized manner consistent with functional goals for each child" (p. 419).

However, this is not to say that particular interventions may not be helpful to particular individuals when warranted based on specific symptoms, or that future research will not provide better evidence. As noted earlier, these interventions may be effectively used as reinforcers or pleasurable leisure activities. If they are used as intervention, they should be monitored and their effects on specific goals empirically assessed, they should be discontinued if there is no evidence of effectiveness, and they should be integrated with other (proven) interventions.

4.3.3. Auditory Integration Training (AIT)

Auditory Integration Training (AIT) has also been controversial (Baranek, 2002; Gravel, 1994). The variation most commonly used in North America (Berard method) involves a course of 10 to 20 half-hour sessions of electronically modulated music played through headphones. The modulation is based on an audiometric assessment (filtering frequencies to which the child is hypersensitive) and thus the treatment is individualized for the child. AIT treatment is only available in a few places and costs several thousand dollars.

Two other variations of AIT are the Tomatis method (involves a combination of AIT and psychodynamic assumptions, and uses electronically filtered tapes of the mother's voice), and the Porges' Acoustic Intervention. There is currently no empirical support for either of these methods.

However, several empirical studies have been done on the Berard method, including some large studies with good methodology (including control groups who hear unmodulated music through headphones). Results have indicated some improvements in sound sensitivity or behavioural outcomes, though not necessarily concomitantly, suggesting extraneous factors may have led to improvements rather than the hypothesized mechanism. Some studies have shown equivalent or greater improvement in control groups and there have been occasional reports of negative side effects (Bettison, 1996). According to the New York Guidelines, AIT is in the "recommended not to be used" category (NYSDH, 1999).

4.3.4. Visual Therapies

Several optometric therapies have been proposed for children with ASDs, including the use of prism lenses, coloured filters (Irlen lenses), and oculomotor exercises. There is no empirical evidence to support the use of Irlen lenses for children with ASDs, nor for oculomotor approaches. There has been one series of studies on prism lenses suggesting some modest short-term effects on visual attending and orienting, but methodological issues preclude firm conclusions at present.

4.4. Intervention for Challenging Behaviour

Individuals with ASDs are clearly at increased risk for developing problematic behaviour (Horner, Carr, Strain, Todd, & Reed, 2002). Some of these behaviours fall under the category of restricted and repetitive behaviours and interests that are considered problematic because they interfere with opportunities for learning and social interaction. In particular, stereotypic behaviours tend to have an unusual quality, and may result in stigmatizing the individual with an ASD. Those with Autistic Disorder and some with PDD-NOS who also have significant cognitive deficits (developmental disabilities) are prone to increased risk of developing aberrant behaviours, including aggression, self-injurious behaviour, and many different forms of disruptive behaviours.

An Ontario-based study of aberrant behaviour in individuals with developmental disabilities (DD) found that, of 948 individuals, over 50% of children from 4 to 11 years of age, and over 45% of adolescents and adults aged 12 years and older, exhibited challenging behaviour. This behaviour included physical aggression, inappropriate verbal behaviour, self-injury, and non-compliance (Atkinson et al., 1994). These behavioural issues can increase the risk of social isolation, can decrease the quality of life experienced by individuals with developmental disabilities, are very stressful for families, and add an additional layer of difficulty in providing supports to those with ASDs.

For decades, behavioural interventions have been used in the education and treatment of individuals with Autism and developmental disabilities. The 1980s and '90s were fraught with debate over the use of intrusive (e.g., seclusionary time-out, mechanical restraint) versus non-intrusive treatment methods (Repp & Singh, 1990). Currently, there is consensus in the field that intrusive methods should not be used as first course treatments, and should only be used in the few situations when more pro-active, positive-based strategies have been given due course and demonstrated to not be effective for the presenting complaint (see further discussion below).

4.4.1. National Institutes of Health (NIH) Consensus Panel

A large NIH project examined the data on treatment effectiveness for severely problematic behaviours in individuals with DD (NIH, 1991). It included reviewing the literature on various forms of treatment for challenging behaviour in individuals with DD, and developing practice guidelines. Although this panel was not specifically charged with reviewing treatment for Autism, many of the studies included participants with ASDs, and most qualified practitioners have adopted their recommendations.

They found there was adequate scientific evidence to support the use of the following behavioural interventions:

- strategies that increase desirable behaviour (behaviour enhancement strategies);
- strategies that decrease undesirable behaviour (behaviour reduction strategies);
- strategies that teach adaptive replacement skills (educational strategies); and
- strategies that prevent problem behaviour by changing the environment (eco-behavioural strategies).

The panel carefully considered the issue of using medication for this purpose (see below). Despite a lack of empirical evidence for the use of medication in isolation as an effective treatment for this population, there was an alarming rate of use of psychotropic medication. The panel concluded that medication should be used, only when appropriate, to treat medical and psychiatric issues that are diagnosed by a qualified practitioner and that can potentially underlie the individual's problematic behaviour. As a treatment for problematic behaviour, medication should be used:

- as a last resort when less intrusive methods have been unsuccessful;
- as a temporary crisis intervention measure;
- only when monitored closely by a qualified physician; and
- in conjunction with a behavioural intervention program.

The final recommendations of this panel were that multi-elemental behavioural interventions, such as positive behavioural supports, are the treatment of choice for individuals with DD who exhibit severe problematic behaviours. Though frequently used, psychopharmacological intervention should usually be prescribed only to treat psychiatric or medical conditions. In some very serious cases, short-term use of behaviour control medication might be warranted to assist in implementing behavioural interventions and as a crisis intervention procedure. Finally, the panel reiterated that valid consent, which is informed, legal, and voluntary, must be obtained from the individual and/or the legal guardian with respect to the treatment plan (NIH, 1991).

4.4.2. Positive Behavioural Supports (Non-Intrusive Methods)

There has been extensive research and development of non-intrusive methods for treating challenging behaviour, known as positive behavioural supports (Jackson & Veeneman Panyan, 2002; Koegel, Koegel, & Dunlap, 1996). Research in Ontario has clearly demonstrated the effectiveness of these approaches in treating self-injurious, aggressive, and severely disruptive behaviour exhibited by children and adults with DD, including Autism, in community settings (Feldman, Condillac, Tough, Hunt, & Griffiths, 2002). Positive behavioural supports endeavour to change behaviour using strategies that avoid pain and loss of dignity (Jackson & Veeneman Panyan, 2002). A major research review of articles published between 1985 and 1996 on positive behavioural supports to treat individuals with developmental disabilities found that these approaches are effective for between one-half and two-thirds of reported cases (Carr et al., 1999).

Positive behavioural support strategies include changing environmental conditions (e.g., lowering noise levels), increasing positive reinforcement (e.g., differential reinforcement procedures), skill building (e.g., functional communication training), and planned natural consequences (Horner et al., 2002). These multi-elemental programs typify the types of interventions recommended by the NIH consensus panel reviewed above. Instead of relying on unpleasant consequences (punishers) to decrease problematic behaviour, positive behavioural supports attempt to decrease problematic behaviour by changing antecedents. Current treatment avoids "cookbook" style applications of behavioural procedures (e.g., if aggression, use time-out) in favour of comprehensive assessment of medical and environmental patterns and determining the function of the problem behaviour for the individual (Feldman & Griffiths, 1997).

When using positive behavioural supports, clinicians, in conjunction with trained health professionals, make every effort to determine underlying physiological and biomedical influences on the problematic behaviour. Careful assessment of the environmental situations and events associated with the problematic behaviour are pursued using a variety of interview and observational methods commonly referred to as a functional assessment. Once a working hypothesis is determined, efforts are made to make environmental changes (e.g., better match of curriculum to skill level, lower task demands, increase opportunities for interaction) that will circumvent the need for the individual with Autism to act out.

Another aspect of the assessment is called a functional analysis, the goal of which is to determine the variables maintaining the problem behaviour. Functional analyses can be performed using rating scales (Durand & Crimmins, 1988), naturalistic observations (O'Neill, Horner, Albin, Storey, & Sprague, 1990), or systematic experimental manipulations (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982). The four most common functions considered by clinicians include access to:

- escape (from people, demands, activities);
- attention (from adults or peers);
- tangibles (items or activities); and
- sensory stimulation or automatic reinforcement (internal reinforcement).

The goal of the functional analysis is to determine the purpose(s) the problematic behaviour serves for the individual, and then teach him/her to use an appropriate behaviour to serve the same purpose(s) (Carr & Durand, 1985; Carr et al., 1994). It is not unusual for a single behaviour to serve multiple functions, or for two behaviours to serve the same function (LaBelle & Charlop-Christy, 2002).

In addition to making environmental changes and teaching functional replacement skills, some effective, non-intrusive behaviour reduction strategies are also used within the context of positive behavioural supports. Functional extinction is a behaviour reduction strategy that involves withholding a previously established reinforcer that has become associated with the problem behaviour. Extinction procedures break the association of the problem behaviour with its previous reinforcer, and result in the eventual decrease of the problem behaviour. For example, if a functional analysis reveals that a child's tantrums typically result in increased attention, planned ignoring (not responding to the tantrums) would be an example of a functional extinction procedure.

When used in isolation, one drawback to functional extinction procedures is a potentially dangerous side effect known as an extinction burst, which is a dramatic increase in problem behaviour. Extinction bursts typically occur early in the extinction process when the reinforcer is first withheld. For example, when we first begin to ignore the child's tantrum, the child might begin to scream more loudly and kick his/her legs harder. To avoid or minimize an extinction burst, extinction procedures can be used in conjunction with differential reinforcement strategies. These strategies include reinforcing the absence of the problem behaviour, the presence of any other behaviour, or the presence of alternative or incompatible behaviour. For example, we would provide the child with attention every 30 seconds as long as the child did not tantrum (differential reinforcement of other behaviour). If the child did tantrum, we would not respond (functional extinction). This process is likely to avoid an extinction burst because the child can quickly learn other appropriate means of gaining attention.

Researchers have found that treatments based on the results of functional analyses are at least twice as effective as other treatments for individuals with Autism and developmental disabilities (Carr et al., 1999), and are less intrusive than interventions developed using other methods (Freeman, 1993).

4.4.3. Use of Medication

The use of medications in the treatment of challenging behaviour is a very controversial topic. Many agencies, clinicians, and families have strong philosophical beliefs about the appropriateness of treating children and adolescents with medication. There are different reasons to consider medication as part of the treatment protocol for a child or adolescent with Autism. If an individual presents with a comorbid condition (e.g., obsessive compulsive disorder or depression) that seriously impacts his/her quality of life, perhaps medication, in conjunction with behavioural treatment strategies and/or cognitive behaviour therapy, might be a suitable choice (see Biomedical Interventions section). If, on the other hand, an individual presents with aggressive behaviour, it would be prudent to attempt to treat the behaviour using positive behavioural supports (see below) before considering psychotropic medication. If medication is to be used, the standards set out by the NIH panel (1991) cited above should be followed, as well as applicable legislation (e.g., the *Child and Family Services Act*).

4.4.4. Crisis Intervention

Crisis intervention refers to emergency procedures that are used when unexpected behavioural issues arise. Crisis intervention procedures are NOT punishment procedures, in that they are applied in order to provide immediate safety and security, not with the intention of decreasing future problem behaviour. Unlike therapeutic interventions designed to solve behavioural problems and increase an individual's control over the environment, crisis intervention methods are designed to stop problems and allow care providers to take control from an individual in an emergency situation, until the individual is able to regain control of him/herself. A useful analogy for crisis intervention is putting out a fire. We have policies in place and equipment ready to fight fires, but we hope to use them infrequently. The same applies to crisis intervention. Organizations typically have policies relating to crisis procedures and staff are often trained in crisis intervention, but these are considered last resort efforts. The expectation is that clinical intervention should focus on positive behavioural supports (non-intrusive methods), de-escalation techniques, and preventing crisis situations.

Many different crisis intervention programs are used with individuals in mental health settings, however there is no published research comparing these methods. There are strengths and limitations associated with each commercially available crisis intervention program, therefore mental health settings should select the program most compatible with their policies and applicable legislation (e.g., residences licensed as children's residences under the *Child and Family Services Act* must comply with the training requirements set out in regulation 70). Further, there are no specific crisis intervention methods designed for use solely with individuals with Autism. Formal crisis intervention procedures typically include methods such as:

- chemical restraint;
- physical restraint; and
- secure isolation.

Though these methods can be considered intrusive, it is important to reiterate that they are NOT to be used as punishment. Staff training in prevention techniques (e.g., de-escalation) is essential to minimize the use of crisis intervention procedures in clinical settings.

One issue often facing staff from community mental health programs is consultation to families and educational settings (e.g., daycares, schools) regarding crisis management. In these situations, it is essential to involve qualified professionals in developing crisis prevention and intervention approaches, and to carefully monitor the use of crisis procedures.

4.4.5. Intrusive Behaviour Reduction Procedures

Intrusive behaviour reduction procedures must be distinguished from crisis intervention procedures in that they are typically applied:

- contingently in response to the occurrence of problem behaviour;
- for a fixed duration (can be independent of client response); and
- as a punishment procedure in an attempt to decrease the occurrence of problem behaviour.

Intrusive behaviour reduction procedures typically include strategies intended to decrease problem behaviour (punishment strategies). Mildly intrusive behaviour reduction procedures include techniques that are unpleasant, but not likely to be directly harmful or restrictive to an individual, such as response-cost (having to give back an earned reward or privilege), or over-correction (having to pick up 20 blocks after throwing only 1). Moderately intrusive behaviour reduction procedures are more restrictive and/or can be potentially harmful, such as mechanical restraints (wearing arm splints), noxious stimuli (lemon juice), or aversive stimuli (mild spanking²). Severely intrusive behaviour reduction procedures include those which are seriously restrictive and/or harmful, such as seclusionary time out (locked in secure isolation room) or faradic stimulation³ (contingent electric shock).

There is evidence that demonstrates the efficacy of some intrusive behaviour reduction techniques in the treatment of challenging behaviour in individuals with DD, including ASDs (Repp & Singh, 1990). However, less intrusive methods have proven to be equally efficacious, and should therefore be considered as the first course of treatment (Horner et al., 2002; NIH,

2. Corporal punishment, including spanking, is never to be used by staff, but is often a major concern that community-based staff have to work through when consulting to families.

3. Faradic stimulation is a controlled act that can only be performed by certain registered health professionals in Ontario (e.g., physicians & psychologists) under carefully controlled conditions.

1991). When less intrusive methods have been exhausted, it is important to consider that individuals have the right to effective treatment, and that intrusive procedures may have to be used judiciously (within the provisions of policies and legislations), and under careful supervision to treat problem behaviour (Van Houten et al., 1988).

Some of the most commonly used intrusive behaviour reduction procedures with individuals with ASDs include time-out procedures. Time-out is often perceived as an everyday approach to problem behaviour. However, technically it is on the continuum of intrusive procedures with seclusionary time-out (typically in a "time-out" room or bedroom) considered to be more intrusive and non-seclusionary time-out (in the hallway or corner) considered to be less intrusive.

There are several concerns regarding time-out. For example, consider a situation in which a child hits a parent each time he or she is asked to get dressed, and the parent leaves the child in his or her room for a period of 3 minutes in response to the hitting. Several problems can arise from this situation. First, if the function of hitting was to escape the task (getting dressed), then the child's hitting would be reinforced by time-out (parent leaves room; expectation is dropped), not punished by it. Second, if the child engages in stereotypic behaviour, being left alone in "time-out" would not technically meet the criteria of time-out from positive reinforcement. In fact, when sent to their rooms in response to problem behaviour, many children find activities to occupy their time that defeat the purpose of the time-out procedures, and potentially strengthen the problematic behaviour (e.g., hitting).

4.5. Biomedical Interventions

There is no specific or universal medical treatment or cure for the core symptoms of ASDs (Gillberg & Coleman, 2000). However, a number of biomedical approaches have been tried in an effort to treat particular symptoms or comorbid disorders, and/or to increase the likelihood that the individual will benefit from concurrent educational or behavioural interventions (McDougle, 1997). The use of medication in connection with severe problem behaviour is reviewed above in the Challenging Behaviour section.

While a detailed review of the psychopharmacological literature is beyond the scope of this document, some potential benefits of various medications will be briefly noted. Some approaches may be more effective for clients of different ages or different subtypes of ASDs, and it is important to consider side effects. There is very little research on certain drug combinations and on long-term side effects, especially for children. There are also a number of controversial biological approaches being proposed, most of which have little empirical evidence.

4.5.1. Medications

Neuroleptics/antipsychotics such as Haloperidol, the most studied in this category, have been shown to reduce stereotypies, hyperactivity, affective lability, temper outbursts, and social withdrawal. However, side effects include sedation and irritability, and long-term use can be associated with serious side effects such as tardive and other dyskinesias (i.e., abnormal or involuntary movements).

Risperidone, an atypical neuroleptic/antipsychotic, is the subject of considerable professional interest, and is considered promising at the present time (Tanguay, 2000). A recent large double-blind placebo-controlled study (McCracken et al., 2002) found 70% of children with Autism responded favourably, showing decreases in aggression, self-injury, and agitation. The primary side effect is significant weight gain (especially in children), but can also include secondary side effects (e.g., sedation, and tremors). It is important to note that atypical neuroleptic agents are associated with a lower incidence of extrapyramidal symptoms (e.g., tremor, stiffness) than are typical neuroleptics. There have been recent concerns that Risperidone can induce hyperprolactinemia (elevated serum prolactin). The long term health consequences of this are not clear, however monitoring of prolactin levels should be considered. This information should be factored into the decision-making process around medication options (Sanders et al., 2002).

Clomipramine, a non-selective Serotonin Reuptake Inhibitor, may be effective for stereotypies, rage, and ritualistic behaviours, but has serious side effects (including, possibly, seizures) and is not recommended for young children (McDougle & Posey, 2002).

The Selective Serotonin Reuptake Inhibitors (SSRIs; fluvoxamine, fluoxetine), however, show considerable promise (Tanguay, 2000). Some open label studies and some recent double-blind studies suggest possible benefits in ritualistic behaviours, obsessive-compulsive symptoms, and reduced depressive symptoms (McDougle, Kresch, & Posey, 2000). In a recent double-blind study of fluvoxamine, about half of adults with Autism were considered responders, showing improvement in repetitive thoughts and behaviours, inappropriate language, and aggression (McDougle et al., 1996). Side effects included nausea and sedation. However, a study of children found lack of effectiveness and more problematic side effects, suggesting these drugs are more appropriate for adolescents and adults, possibly because of changes in serotonin functioning at puberty (McDougle & Posey, 2002).

People with higher functioning Autism or Asperger's Disorder may develop depressive symptoms, if not major clinical depression. Although this may manifest atypically, especially in children, and thus antidepressants (imipramine, desipramine) might appropriately be considered, there are few empirical studies in this specific population (AACAP, 1999; Klin & Volkmar, 1997). There is very little literature on the use of lithium or other mood stabilizers,

and they are not recommended unless there are strong indications of bipolar mood disorder in the client (and possibly other family members).

Stimulant medications (e.g., methylphenidate) may help children with Autism if they are hyperactive and inattentive, although there are reports of exacerbated agitation and stereotypies (AACAP, 1999). There may be greater benefit in adolescents with Asperger's Disorder (McDougle, 1997). Side effects include social withdrawal, sadness, and irritability (McDougle & Posey, 2002). Some years ago, fenfluramine was extensively investigated as initial reports suggested effectiveness, but many subsequent studies have failed to find positive effects and serious side effects have been reported. Fenfluramine is contraindicated according to the AACAP Practice Parameters.

Naltexone, an Opiate Antagonist, was thought to be promising and has shown modest behavioural improvement in hyperactivity, but not self-injurious behaviour as hypothesized (Willemsen-Swinkels, Buitelaar, Nijhof, & van Engeland, 1995).

Anticonvulsants (e.g., Depacote) are appropriately prescribed for the approximately one-third of children and adolescents with Autism who develop seizures (Minshew, Sweeney, & Baumann, 1997). Seizures may be present early in life (infantile spasms), but often do not develop until puberty. Seizures can be of various types, but partial complex seizures are probably the most common (Olsson, Steffenburg, & Gillberg, 1988) and are not necessarily easily recognized. Parents, teachers, and other staff working with children with Autism need to be on the alert for absences and other less obvious signs of potential seizures.

4.5.2. Other Biomedical Approaches

Secretin, a digestive hormone secreted by the pancreas, has received considerable media attention of late. However, there are now a number of controlled clinical trials, including some conducted in Ontario (e.g., Dunn Geier et al 2000; Roberts et al., 2001; 2002) showing no evidence of effectiveness. There have also been reports of some serious behavioural side effects. Some researchers continue to explore multiple doses and synthetic hormones for subgroups of responders, especially children who display chronic GI problems. At this point, secretin cannot be recommended, based on the empirical evidence that it is ineffective and may be harmful in some cases.

Adrenocorticotrophin hormone (ACTH), a growth hormone produced by the pituitary gland, has some empirical support for reducing social withdrawal and improving sleep and anxiety (Buitelaar et al., 1992). However, it also has potentially serious side effects in terms of affecting children's growth and development and is not recommended.

Corticosteroids have been recommended but show little evidence of effectiveness (Volkmar, Klin, Marans, & Cohen, 1996).

Various immune system tests and related treatment approaches have been proposed, including intravenous immune globulin (IVIG). There have been a few methodologically weak and inconclusive studies. Given that IVIG is a blood product, there is a potential risk of blood-borne diseases and allergic reaction. Thus, it is not recommended (AACAP, 1999) and the immune system tests are also not recommended (Filipek et al, 1999; NYSDH, 1999)

Vitamin and dietary supplements, in particular megadoses of Vitamin B6 and magnesium, have been proposed as a treatment for Autism (Rimland, 1988), and there have been a number of studies done showing modest positive effects (Martineau, Barthelemey, Garreau, & Lelord, 1985; Pfeiffer, Norton, Nelson, & Short, 1995). However, in most cases the methodology has been problematic. There are concerns about possible toxicity of long-term exposure to very high dosages of these vitamins (AACAP, 1999).

Exclusion diets, in particular the casein and gluten-free diet, which is quite popular in Ontario, requires parents to completely eliminate all milk and gluten products from the child's diet. It is based on the (controversial) hypothesis that these foods do not break down properly in the child's digestive system and leave opiate-like peptides circulating in the bloodstream, which "cause" autistic symptoms. According to the New York Guidelines (NYSDH, 1999), there are no methodologically sound studies of this or any other dietary approach to Autism, and thus they are not recommended. However, other researchers continue to explore these theories and treatments.

Anti-yeast therapies include orally administered anti-fungal medication as well as special anti-yeast diets (including grapefruit and garlic). There is not adequate evidence to evaluate this approach (NYSDH, 1999).

The DAN! (Defeat Autism Now!) Protocol involves a variety of unusual screening tests (not recommended in Filipek et al., 1999; see Medical Investigations section, Table 1) by way of assessment. The treatment includes several unproven approaches: the elimination of gluten, dairy products, and refined sugar, and the ingestion of a number of vitamin and nutrient supplements. Secretin is often prescribed as well. These approaches individually or together are unproven and not recommended.

4.6. General Skill Building

Service providers are frequently faced with adapting existing approaches or technologies to support individuals with ASDs. When participating in traditional group interventions, for example, these individuals often require constant reminders about the social rules in group situations. In other situations, individuals with ASDs require additional skills to be able to participate in traditional programs. For example, individuals with serious cognitive deficits might require instruction in basic life-skills, while those with well-developed cognitive skills

might require assistance to stay on topic or learn an unfamiliar routine. The following strategies can be used to enhance learning of communication and social skills, as well as assist with redirecting, replacing, or otherwise decreasing problematic behaviour.

4.6.1. Behavioural Teaching

Behavioural teaching methods have been demonstrated to effectively increase communication skills, social skills, activities of daily living, and academic skills in community settings (Repp, Favell, & Munk, 1996). Behavioural teaching describes a wide range of techniques based on learning theories. These theories focus on observable environmental events that prompt, increase, and maintain appropriate behaviours. Behavioural teaching is the application of applied behaviour analysis (ABA) to skill development. It differs from IBI in that it is NOT necessarily intensive, and can be effectively implemented for individuals of all ages from both clinical and typical populations.

These methods for skill development can be used to develop target skills identified by the individual or by professionals such as speech and language pathologists, occupational therapists, teachers, and other clinicians. Skill development can have a positive impact on the quality of life of individuals with ASDs (Horner et al., 2002). Regardless of cognitive skill level, several components of behavioural teaching can be used to enhance skill development. First, it is essential to identify key behaviours to teach in conjunction with the individual and/or family members. Second, the behaviours to be taught need to be broken into manageable learning steps (task analysis). Third, appropriate technical strategies need to be applied to the teaching of the new skill (e.g., modelling, prompting, reinforcement, and error correction). Finally, maintenance strategies need to be implemented to enhance generalization and build life-long skills (Martin & Pear, 1999).

4.6.2. Environmental Supports/Structure

Environmental supports can play an important role in the lives of individuals with ASDs. For those with specific adherence to non-functional routines, changes to these routines can cause a great deal of distress unless properly supported. For others with skill deficits, unstructured time can pose a significant challenge, and without proper supports is likely to be associated with increased problem behaviour. In her review of environmental supports for individuals with ASDs, Dalrymple (1995) suggests four types of environmental supports:

- temporal supports to sequence events over time;
- procedural supports to outline steps of an activity or the relationship of items to events or people;

- spatial supports to provide information about environmental organization; and
- assertion supports to help initiate interactions or assert control over the environment.

Research has demonstrated the effectiveness of various environmental supports for individuals with Autism. Studies about the effectiveness of temporal and procedural supports are reviewed below within the context of Picture Activity Schedules (McClannahan & Krantz, 1999).

Assertion supports (e.g., choice making, and communication training) have been reviewed in countless studies on functional communication training (Carr et al., 1999) and communication training in general (Hodgdon, 1995). Spatial supports (e.g., signs or physical barriers) can be useful in teaching individuals with ASDs about personal space and/or privacy. Any of these environmental supports can be enhanced through the used of visual cues (Quill, 1997; 2000).

Transitional strategies can be very effective tools to increase co-operation with daily routines (Dalrymple, 1995). Individualized assessment should consider the needs of each child or adolescent, and make reasonable accommodations to meet those needs. For example, if an adolescent regularly becomes upset when walking from history class to the cafeteria through a noisy and busy corridor, allow early (or late) dismissal to accommodate his or her needs and promote independence. For younger children, strategies that warn of pending changes (e.g., count-downs that promote readiness for termination of preferred activities) can contribute to successful transitions.

4.6.3. Picture Activity Schedules

Picture activity schedules were designed to teach individuals with ASDs to follow routines or complete tasks without adult assistance. Activity schedules have been used for individuals with ASDs with and without accompanying cognitive deficits (Bryan & Gast, 2000; Morrison, Sainato, Benchaaban, & Endo, 2002). It is important to note, however, that some individuals with Asperger's Disorder who have visual-perceptual weaknesses might prefer written schedules to pictorial ones. Individuals with significant cognitive delays might do better with actual photographs than with picture symbols. The most important feature of these schedules is that adult prompts are systematically faded and the individual with ASD gains increasing levels of independence. This has been especially useful in fading supports of teaching assistants in classroom settings (Hall, McClannahan, & Krantz, 1995). Another important use for picture activity schedules is to assist children and adolescents to get through routines independently at home. Parents have been successfully taught to increase their children's participation in household routines using picture activity schedules (Krantz, MacDuff, & McClannahan, 1993). Research has also demonstrated that the use of these schedules can generalize across people and settings (MacDuff, Krantz, & McClannahan, 1993).

4.7. Expressive Psychotherapies

Many mental health services offer a variety of expressive therapies to treat children and adolescents with a wide range of mental health needs. There is a lack of scientific evidence to support the extension of these services to the majority of individuals with Autistic Disorder, likely due to the large proportion of individuals with significant cognitive impairments. For individuals with Asperger's Disorder and those with better developed cognitive skills, there is some evidence to support the use of problem solving-based (e.g., cognitive) therapies and counseling techniques as an adjunct to more direct strategies for skill development (Gillberg & Ehlers, 1998; Stoddart, 1999). On the other hand, insight-oriented and creative therapies have not been found to be useful (Klin & Volkmar, 2000).

4.7.1. Cognitive Behaviour Therapy (CBT)

Cognitive Behaviour Therapy (CBT) is a form of psychotherapy that helps individuals change their behaviour (how they think, feel, or act) as a means of reducing stress or anxiety, improving affect, and achieving other relevant goals (Kendall, 2000). There is considerable support in the literature for the use of CBT (alone or in combination with medication) to treat mood disorders, anxiety disorders, and specific phobias in children and adolescents (Hare, 1997; Hare & Paine, 1997; Kazdin, 1994). Attwood (2003) describes modifications to CBT that may be useful for individuals with Asperger's Disorder, including adding visual supports (if appropriate), specific education about emotions, and expressing feelings and social perception.

Another important area includes scaffolding surrounding cognitive restructuring to help the individual become less rigid or more flexible in his/her thinking. Lord (1996) describes a case study in which she used CBT to assist a high functioning 19-year-old man with Autism to gain control over his obsessions and decrease his frustration using standard CBT strategies (e.g., cognitive re-structuring, affective education, self-monitoring). While the evidence for using CBT to treat individuals with ASDs is limited, its efficacy is well-documented in other related populations (Kazdin, 1994). Given the communicative and cognitive skills required to engage in the process, CBT is only recommended for individuals with an ASD who have adequate skills to benefit from the process.

4.7.2. Other Expressive Therapies

The following expressive therapies were reviewed and found to lack adequate empirical evidence for use with individuals with Autism at this time. Though there have been many papers published describing the potential benefits of these treatments and offering theoretical rationales for their use, none have demonstrated adequate efficacy in studies using sound research methodologies. Some individuals might enjoy the activities (e.g., music and art) and might benefit from their inclusion as leisure activities. However, professionals and families need to be aware that: (a) there has been no demonstrated therapeutic benefit; (b) these

therapies should be considered experimental; and (c) they should not be allowed to interfere with treatments that are proven effective.

- Music Therapy involves the child with Autism in either listening to or participating in music. A variety of approaches and influences on Autism have been postulated (Wigram, 2000). The current research lacks a consistent definition of the therapy, and research studies have not demonstrated its efficacy, but there is no evidence of harmful effects (NYSDH, 1999).
- Holding Therapy is a psychodynamically-oriented treatment that was popular in the 1970s and 1980s (Welch, 1984). There is not adequate scientific evidence to support its use, and the potential for harm (long periods of prone restraint) is self-evident.
- Sand Tray Therapy is a Jungian approach made popular by the Jung Society in the late 1970s and early 1980s. The combination of moisture in the sand, colours in the box, and selection of toys result in the child entering a very relaxed state believed to allow inner psychic conflict to become apparent, and therefore amenable to therapy (Bradway, 1981). There has been no empirical evidence that demonstrates efficacy of this approach for individuals with Autism, though some individuals might enjoy the sensory feedback from playing in sand.
- Art Therapy involves the use of different media to allow clients to create art and explore the process of creating art as a means of gaining greater understanding of their inner states. There are no current published studies that demonstrate the effectiveness of art therapy in individuals with ASDs. There is concern that the need for imagination and insight might limit the utility of this mode of therapy for most individuals with ASDs.

4.8. Comprehensive Programs

The term "comprehensive programs" is used here to refer to ASD-specialized, intensive intervention programs (usually for many hours per week), involving a combination of the approaches and strategies described in other sections of this paper. They typically include an educational or skill development orientation, together with therapeutic intervention(s) for problem behaviour, often using a multidisciplinary team (including the parents). Multiple systems are usually involved, and intervention likely takes place in various settings (home, school, agency).

Most comprehensive programs described in the literature focus on early intervention, and the well-known published outcome data are from young children. However, most of these programs serve a wide range of ages (NRC, 2001), although programs may be configured differently for children or adolescents of different ages and different functioning levels. There are different theoretical underpinnings to these programs which have been described as behavioural, developmental, or eclectic (NRC, 2001), although the vast majority are behaviourally-oriented.

The New York Guidelines provide recommendations to parents and professionals regarding selecting an appropriate comprehensive program (see Table 3).

Table 3. New York guidelines for sound comprehensive programs

New York Guidelines for Sound Comprehensive Programs (NYSDH, 1999)
<p>Curriculum:</p> <ul style="list-style-type: none"> • Specifically designed for Autism, extra focus on attending to environment, imitation, social and play skills, language and communication • Individualized for child's strengths and needs <p>Settings/environment:</p> <ul style="list-style-type: none"> • Highly structured and supportive • High degree of routine, predictability • Families highly involved in intervention planning, delivery sometimes • Progression from 1:1 to group settings • Progression from more restricted to more natural settings • Long-term planning for as great a degree of independence as possible <p>Skill building:</p> <ul style="list-style-type: none"> • Includes strategies to assist in transitions (short- and long-term) • Includes strategies for generalization to more natural settings <p>Reduction of problem behaviour:</p> <ul style="list-style-type: none"> • Functional approach (understanding function of behaviour), changing antecedents to prevent, teaching replacement skills

Similarly, the National Research Council (NRC, 2001) report includes a chapter summarizing the research on 10 comprehensive model early intervention programs documenting evidence of effectiveness, published in peer-reviewed journals. They recommended that all children with an ASD diagnosis should receive education/intervention which:

- begins as early as possible (i.e., pre-school);
- is intensive in nature (25 hours/week 12 months/year);
- is individualized and systematically planned to address specific measurable objectives;
- uses a curriculum focusing on communication, engagement, social, play, cognitive, self-help, behaviour, and motor goals;
- uses data-based decision-making processes;
- provides sufficient individualized 1:1 attention;
- uses only empirically-supported approaches to problem behaviour (see Intervention for Challenging Behaviour section);

- includes planning for generalization and transition planning to next settings;
- has families actively involved; and
- teaches specific goals in settings with typical peers (see Peer-Mediated Instruction section) whenever possible.

Not all children or adolescents with ASDs necessarily need such a comprehensive approach. It depends upon the individual's level of functioning, symptom severity, age, and progress made. Many children and adolescents (especially higher functioning ones) may do quite well in an appropriate school placement with some consultation and specific services as needed (using approaches described in this paper).

Bearing in mind these general guidelines, several somewhat more specific types of comprehensive approaches will be described and evaluated below.

4.8.1. TEACCH

TEACCH is a large, statewide program in North Carolina (TEACCH stands for Treatment and Education of Autistic and related Communication Handicapped Children), which provides a comprehensive spectrum of services to children, youth, and adults with Autism, their families, and communities (Marcus, Schopler, & Lord, 2001). Professionals from TEACCH pioneered many assessment and intervention approaches, have an empirical orientation, have been actively involved in journals, edited books, and manuals which have impacted the field significantly, and have been staunch advocates for the perspective and experience of families.

The TEACCH comprehensive intervention includes, when appropriate for the child, a specialized school-based program, which could perhaps be described as an eclectic combination of special education and structured behavioural teaching (Schopler, Mesibov, & Hearshey, 1995). Environmental manipulations and visual cues (such as picture schedules) are used extensively in an individualized, developmentally-ordered and comprehensive curriculum. The learning environment is organized to provide necessary structure to the child or adolescent, but encourages as much independence as possible. Behaviour problems are dealt with according to a functional approach with an emphasis on prevention and use of cognitive and behavioural strategies. TEACCH does extensive teacher training locally, and has provided many training workshops for broader audiences. A number of "day treatment" classrooms in Ontario operated by children's mental health centres, sometimes jointly with education, operate rather similarly to a TEACCH program.

Research on children and adolescents from the TEACCH program has not explicitly tested the effectiveness of specific interventions relative to controls, but various program evaluation studies, including long-term follow-up studies, indicate low rates of institutionalization and better academic functioning in adolescents than expected from previous research (Schopler, 1997).

4.8.2. The Denver Model

The Denver model is based on an Autism-specific adaptation of Stern's model of interpersonal development in infancy and dynamic systems theory (Rogers, Hall, Osaki, Reaven, & Herbison, 2001; Rogers & Pennington, 1991). The intervention focus is on placing the child in social situations (whether at home, classrooms, or preschools) which provide opportunities and demands for imitation and nonverbal, affective, and pragmatic communication, as well as intensive teaching to remediate learning deficits. The model uses a functional, communication-oriented approach to behaviour management.

There is some published evidence of the effectiveness of the Denver model in producing significant developmental gains (increased rate of developmental progress during intervention versus prior to it) in children with a range of ASDs, with program implementation in centre-based and community-based settings (Rogers & DiLalla, 1991; Rogers, Lewis, & Reis, 1987). Although these were pre-post designs (no comparison to other conditions or groups), the researchers compared the rate of progress made in different subgroups within their sample. They found a greater rate of improvement in children with Autism as compared with PDD-NOS and other developmental problems (though not necessarily a better outcome; Rogers & Lewis, 1989). Thus, these approaches can be regarded as promising, at least, and they illustrate many of the features listed earlier of good comprehensive programs.

4.8.3. The Developmental, Individual Difference, Relationship (DIR) Model

The DIR model (Greenspan & Wieder, 1997) is a currently popular approach that takes the child's developmental level into account (although avoiding standardized assessment methods), and emphasizes individual differences in the child's processing and expression of emotion, as well as cognitive and sensory-motor domains. Affect is given considerable prominence in this model, based on child psychiatry models applied in other populations, on the assumption that the child's core deficit is a biologically-based emotional problem. Intervention occurs in the context of the child's relationship with the therapist or parents, which is believed to stimulate cognitive and other forms of development. Intervention based on the DIR model may be quite intensive (i.e., taking place for many hours per week) and includes a significant amount of time spent in semi-structured play sessions (several hours per day in 6 to 10 short sessions). These sessions are referred to as "floortime" as the adult and child often play together on the floor. Alternately, and quite commonly, it may be informally incorporated into a behaviourally-oriented home program and/or school-based educational intervention.

Greenspan and Wieder (1997) have provided a descriptive paper based on a large number of case studies, published in a non-peer-reviewed journal they founded, but there have been no systematic or controlled studies of the DIR approach. Although they note that the DIR approach potentially shares some elements consistent with other effective programs, the

New York Guidelines (NYSDH, 1999) do not recommend use of the DIR model as a primary approach because there is no evidence of its effectiveness, and because it is time-consuming and may detract from or even interfere with an intensive behavioural/educational approach.

4.8.4. Intensive Behavioural Intervention (IBI)

Intensive Behavioural Intervention (IBI) is an intensive, comprehensive form of early intervention designed for young children with ASDs. It is based on the principles and techniques of applied behaviour analysis and empirically-based practices from the Autism literature. This intervention may be thought of as an intensive form of teaching children to address skill deficits, together with approaches to improve behaviour. In Ontario, IBI is implemented by trained instructor therapists supervised by senior therapists, under the clinical supervision of registered psychologists. IBI makes use of a wide variety of specific techniques (including many discussed in earlier sections of this document). It may include a one-to-one discrete trial approach (often useful initially), as well as more naturalistic approaches which may take place in home-based programs, specialized small group settings, or integrated settings.

Some people use the terms IBI and ABA synonymously, but this is inaccurate. Applied Behaviour Analysis (ABA) is traditionally defined as "... the science in which procedures derived from the principles of behaviour are systematically applied to improve socially significant behaviour to a meaningful degree and to demonstrate empirically the procedures employed were responsible for the improvement in behaviour" (Baer, Wolf, & Risley, 1968). ABA is an approach that includes a large variety of specific methods of assessment and intervention which are based on objective, empirical evidence, and which may be applied to individuals with a wide variety of diagnoses (or no diagnosis). It is not necessarily restricted to Autism or to young children, does not necessarily involve one-to-one teaching, and is not necessarily intensive.

Consensus Panels (as described in an early section of this report) have universally endorsed early intensive structured intervention, or specifically ABA and IBI, for young children with Autism. The National Institutes of Health State of the Science in Autism report (McIlvane, 1996) states that it is clear that individualized, comprehensive educational/behavioural intervention should be the primary approach for all children with Autism, supplemented by a developmental approach, medical approach, and others as needed. The New York Guidelines also make a general recommendation that IBI should be the primary intervention of choice for young children with Autism, along with a number of specific recommendations and qualifications, as shown in Table 4.

Table 4. New York State Department of Health guidelines

New York State Department of Health Guidelines for Children with Autism/PDD Aged 0–3 (NYSDH,1999)
<ol style="list-style-type: none">1. Use ABA as important element of any intervention program for young children with Autism2. Minimum 20 hours/week of ABA3. Precise number of hours based on clinical considerations: age, severity, health, tolerance, family participation4. Optimal intensity impossible to state (but literature demonstrates between 18 and 40 hours/week effective)5. Intensity should be monitored and potentially increased or decreased6. Consider altering program if child showing significant improvement or lack of7. All therapists should receive regular supervision from qualified professional8. Parent involvement9. Parent training to ensure consistency and extend intervention hours10. Parents to have regular consultation with qualified professional11. Physical aversives not to be used

Research evidence for IBI is considerable (Green, 1996). There are more studies and better quality studies for IBI than for most areas of intervention in ASDs, although the literature is not totally conclusive on certain issues and the samples are quite small. In brief, the research suggests that some children (probably 40–50%), though not all, can improve so substantially that they would no longer be considered to have Autism or a developmental delay, and are described as indistinguishable from their peers (sometimes referred to as "recovery"). However, recovery should not be viewed as the only goal, since the majority of children will likely not "recover," and this vision, while inspiring great effort, can also be emotionally counterproductive for families (see Practices for Families section). Low functioning children can be expected to improve significantly with IBI (perhaps more likely than with other forms of intervention; Smith, Eikeseth, Klevstrand, & Lovaas, 1997), but not so dramatically.

Lovaas (1987) originally demonstrated 47% of children who had received IBI (for about 2 years beginning about age 3) had "best outcomes" when followed up at age 7. Best outcomes were defined as successful completion of kindergarten and grade one without being identified, and removal of diagnoses of Autism or MR. These results were maintained at follow-up about age 13 (McEachin, Smith, & Lovaas, 1993). However, this was a small sample and there were methodological critiques (e.g., Gresham & MacMillan, 1998), although these have been competently addressed (Eikeseth, 2001; Smith & Lovaas, 1997).

Most of the existing studies from the 1980s and 1990s (except Lovaas') were uncontrolled.

However, there are now controlled studies emerging (and a number currently underway; Smith, 2002) which indicate superior outcomes, even if not necessarily recovery, in IBI groups versus comparison groups receiving either equivalent amounts of special education or "generic" community intervention (Eikeseth, Smith, Jahr, & Eldevik, 2002; Eldevik, Jahr, & Eikeseth, 2002; Sallows & Graupner, 2002; Sheinkopf & Siegel, 1998) or minimal amounts of IBI (Lovaas, 1987; Smith et al., 1997; Smith, Groen, & Wynn, 2000).

The factors that predict which children will have more positive outcomes are not fully understood, but several have been investigated. To date, the literature shows:

- Age at onset of intervention is clearly one important predictor, with much better outcomes when IBI is started before age 5 (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris & Handleman, 2000).
- Higher initial IQ is associated with greater rate of improvement (Harris & Handleman, 2000).
- Effectiveness has been documented based on programs providing anywhere from 20 to 40 hours of IBI per week, but, within that range, it does not appear that the number of hours is very predictive of outcome (Sheinkopf & Siegel, 1998).
- Settings for IBI (home, segregated centre-based, integrated child care setting, etc.) have varied across and within studies, with virtually all programs including some home-based component and aiming to progress to more naturalistic settings over time. These parameters need to be based more on philosophical and clinical considerations, as there have been no direct empirical comparisons among them. There have, however, been some demonstrations of effectiveness of parent-directed IBI programs (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2001; Sallows & Graupner, 1999; Sheinkopf & Siegel, 1998).
- The duration of intervention is usually one or two years, but this varies widely depending on the program model (i.e., a 2-year program with transition to school built in) and/or empirical factors (i.e., whether the child has mastered certain skills deemed necessary for the next environment or, alternatively, the child has essentially not improved and intervention is discontinued). Some researchers have found bigger gains in the first year of intervention (e.g., Sallows & Graupner, 1999), others in the second year (Anderson et al., 1987). In the Lovaas (1987) study, intervention was discontinued or decreased in intensity as the child moved into regular school, but was continued longer for children who had been slower to progress (usually without major additional gains after two years; McEachin et al., 1993). Research does not yet permit us to determine an optimal duration of IBI.

5. PRACTICES FOR FAMILIES

Having a child with an ASD is one of the most difficult things that can happen to a family. Although most families cope remarkably well most of the time, they have some tough challenges along the way. The needs of families are quite variable depending on:

- the particular characteristics of their child (age, level of functioning, particular symptom severity, response to intervention, and so on);
- the parents' own intrapsychic and interpersonal resources; and
- the availability and effectiveness of supports and services.

This section reviews several theoretical frameworks for thinking about families and their clinical implications, along with the existing empirical evidence for family-based interventions.

Historically, parents (especially mothers) were held responsible for their child's Autism (Bettelheim, 1967; Kanner, 1943), based on psychodynamic formulations prevalent at the time. This mistaken notion has left an unfortunate legacy which has been very hurtful to parents. Many studies have been done which indicate parental warmth and competence of parents of children with ASDs is no different from that of other parents (see Bristol, 1984). This myth should be dispelled by professionals at every opportunity. It is crucial for professionals working with families to take a nonjudgmental, collaborative stance (Marcus & Schopler, 1989).

5.1. Family Stress

Having a child with Autism can have a devastating impact on parents' mental health (most of this research is based on Autism; little has been done on other forms of ASDs). In fact, family stress research has repeatedly demonstrated that parents (especially mothers) of children with Autism experience greater stress, depression, and mental health difficulties than parents of children with other types of disabilities or no disability (Bristol, Gallagher, & Schopler, 1988; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Dyson, 1997; Konstantareas, 1991; Sanders & Morgan, 1997).

Family stress may be related to the specific diagnostic features of Autism, such as behavioural difficulties of the children and their lack of communication and relationship skills (Bebko, Konstantareas, & Springer, 1987; Freeman, Perry, & Factor, 1991; Konstantareas & Homatidis, 1989; Weiss, 1991), among other more generic factors, such as the developmental level of the child, the caretaking burden in terms of activities of daily living, and chronicity of the disorder (Freeman et al., 1991; Koegel et al., 1992; Sharpley, Bitsika, & Efremidid, 1997).

Different aspects of life with the child with an ASD may affect mothers as opposed to fathers (DeMyer, 1979; Trute & Hiebert-Murphy, 2002). It has also been shown that mothers bear the greater burden (Bebko et al., 1987; Bristol et al., 1988; Freeman et al., 1991; Milgram & Atzil,

1988; Minnes, 1988), although fathers' experiences have been much less studied (Rodrigue, Morgan, & Geffken, 1992). Also, the family's culture is an important factor in the meaning they attribute to having a child with an ASD and their tendency to seek help outside the family (e.g., Bailey et al., 1999). Other significant stressors include the poor understanding of Autism in the community, inferences or outright accusations of improper parenting when the child "looks normal" but acts "strangely" in public (Gallagher, Beckman, & Cross, 1983; Perkins & Wolkind, 1991), difficulty experienced in the process of obtaining a diagnosis, the exhausting process of advocating for scarce intervention and educational programs, and the financial strain of certain therapies (Bristol, 1985; Norton & Drew, 1994).

Needless to say, in families with other major stressors, such as family violence, poverty, addiction, and so on (which, for the most part, are not present in families who participate in research studies), the situation is very much more complicated.

5.2. Models of Family Impact

5.2.1. Grieving Models

Although there is little empirical research, it is common clinically to use a grieving model in understanding the experience of parents of children with developmental disabilities, including Autism (e.g., Fortier & Wanlass, 1984). It is assumed that parents "grieve" the loss of the expected or hoped-for child and go through stages of grieving similar to those associated with other losses or bereavements. These stages are named and grouped differently by different authors in the clinical literature, but typically consist of denial, anger, bargaining, working through, and acceptance. Most parents are seen as progressing through these stages within a reasonable time, although a few may experience more serious difficulties akin to "pathological grieving." While serious mental health problems may emerge in certain parents at various stages which may require intervention, it is important to realize that a certain amount of psychological processing is necessary and appropriate and to help normalize rather than pathologize that for parents. Table 5 shows Siegel's (1997) framework illustrating what she calls "normal" and "complicated, intensified" responses which may occur in parents at various stages.

Table 5. Stages of family response (Siegel, 1997, p. 760)

Stage	Normal Responses	Complicated, Intensified Responses
Outcry	Crying; intense feelings of loss; protective action toward child in response to "threat"; "why me?" questioning of etiology	Numbing/shutdown in response to news; "kill the messenger"; invalidate credibility of diagnostician; clinical distancing from child; abandon spouse and child
Denial	Continue to seek further diagnostic opinions; avoid situations where child may look "different"; try not to think about child's future; don't tell siblings	Avoid contact with helping professionals; resist recommended early intervention/special education; persist in belief that child will outgrow it; refuse a "label" for child even if dealing with professionals
Intrusion	Fear that child will worsen (e.g., develop self-injury); fear for child's future; imagined re-enactment of possible "causal" events; wishing child were dead; re-experiencing moment it was realized child had an ASD or receiving diagnosis; bad dreams about child	Recurring and intense shame; guilt at negative thoughts and feeling about child; real fear of harming child and/or self (uncontrollable rage); uncontrollable and diffuse anxiety about child; anger/irritation at success of siblings, relatives' children; recurring nightmares about child
Working through	Realization that child can improve but that hard work is needed; realization that intrusive fears can be mastered; recognition of situations that trigger sadness; ability to seek and accept support from family, friends, and system	Continued hope for "cure"; pursuit of illogical, long-shot, "miracle" cures; child may become "feral" from lack of intervention; confirming worst fears; feeling that no one is helping; system is out to thwart parents
Stasis vs. Chronic sorrow	Acceptance of Autism as part of child's personality; enjoyment of "quirks"; realistic expectations for child's future; rational balance between child and other aspects of life; sadness but acceptance of how child's future will differ from others	Inability to feel that child is doing as well as can be expected; unable or unwilling to use social support offered, "martyr"; devotes self entirely to child with an ASD; can accept other family members only if devoted to child with ASD too; numbness in response to other children

If parents are "stuck," it may be appropriate to direct therapeutic efforts at facilitating the adjustment process. However, it is generally recommended that defenses (e.g., denial, which can come in many forms) not be challenged until people are "ready," unless it is clear that the defenses are interfering with necessary and appropriate intervention for the child or adolescent (e.g., parents continuously searching for a miracle cure and not engaging the child in a structured educational/behavioural program). As families "...contend with reckless promoters of faddish therapies and the pressure to find a cure, both of which reinforce the natural tendency to doubt or deny the chronicity of the disorder, professionals must remain sensitive to the vulnerable situation parents are placed in and their need for support and for sound, empirically-based interventions " (Marcus, Kuncze, & Schopler, 1997, p. 646).

It should be noted that there have been critiques by both parents and professionals of the grieving analogy and of particular stage models (Blacher, 1984). Clearly, the continuing physical and psychological demands placed on parents by the presence of the child with an ASD make the situation different from a loss through death. It is frequently reported that parents experience cyclical revisiting of these stages (or some of them), often at life transition points in the family, which has been termed "chronic sorrow" (Olshansky, 1962; Wikler, 1986). It is important for clinicians to realize this pain can ultimately not be taken away by all the best techniques and intentions.

5.2.2. Family Systems and Functions Model

Harris (1983) describes a number of subtypes of families using structural family therapy models. One of the most common patterns encountered in clinical practice is that of maternal enmeshment with the child with an ASD, while father is either absent or peripheralized with other siblings. A variation on this is for the mother and oldest (parentified) daughter to be enmeshed. Another phenomenon is for parents to be strongly allied at the parental subsystem level, and united in fighting for services for their child as a way of avoiding dealing with their own (marital subsystem) issues. Having a child with an ASD or any disability is, naturally, a strain on the marriage. Although the evidence is mixed, it appears that a sound marriage is maintained or even strengthened by the experience, but a vulnerable one is not likely to survive. It is important for professionals to make every effort to include fathers in activities and meetings, to assist families in maintaining good generational boundaries, and to consider family structural issues when prescribing parent-administered interventions.

Various family functions are impacted by the presence of a child or adolescent with an ASD (Bristol & Schopler, 1983, 1984). These include economic, physical, and recreational functions. For mothers in particular, there are often career implications. The need to care for the child, take him or her to many appointments, and so on, often necessitates women quitting their jobs, turning down promotions and transfers, working part-time only, etc. There are obvious financial issues for families, both because of opportunity costs and costs of various therapies and programs for the child or adolescent. The recreational function

of the family is often severely curtailed, depending on the appropriateness of the child's behaviour in public. It may be difficult for the family to get babysitters, visit friends, engage in hobbies, or go on vacations (Bristol, 1984; DeMyer & Goldberg, 1983). Encouraging parents to use respite care or take advantage of other opportunities to maintain healthy balance is an important function for clinicians working with families.

On the other hand, parents do report some positive effects on certain family functions (Turnbull, Summers, & Brotherson, 1986; Wilgosh & Scorgie, 2000), and a recent study indicated that positive and negative family impacts were not inversely correlated (Trute & Hiebert-Murphy, 2002). Although this research was done with parents of children with broader developmental disabilities (not ASDs specifically), it suggests the difficulties and joys of having a child with disabilities are not mutually exclusive.

There are certain issues or needs that parents and siblings (and sometimes extended family members) may have at various times throughout their lives with a child with Autism, and these have important implications for family support services and case management. Some family functions have greater priority or are expressed differently at different family life cycle stages, and transitions between these stages are difficult for all families, especially if they happen in a non-normative way (Minuchin, 1974). Given that transition from one stage to another requires changes in family structure and function, which is stressful anyway, having to maintain two life cycle stages simultaneously can be a source of considerable tension for families of children with ASDs (Turnbull et al., 1986). The "launching" stage, when siblings are moving out, going away to school, and so on, is especially difficult for these families (Wikler, Wasow, & Hatfield, 1981), partly because it is readily apparent by then that the child with an ASD has a different future, and because many supports and services discontinue at that time. The process of seeking out-of-home placement for their son or daughter (which may take place over a long time or rather suddenly in crisis situations) is a particularly upsetting time which may trigger various emotional reactions (Perry & Black, 1997). In summary, it is important for mental health professionals to help families work actively on transition-planning at two main junctures: from preschool to school (about age 5 or 6) and from high school to early adulthood (about age 18–21). Intensive case management and concurrent emotional support may be needed at these times.

Table 6 briefly illustrates common child difficulties, possible family issues, and appropriate clinical responses (often the focus of case management activities needed) during different developmental stages.

Table 6. Family issues and needs through the lifespan

Child Difficulties	Family Issues and Needs	Clinical Recommendations
<p>Infancy (Pre-diagnosis)</p> <ul style="list-style-type: none"> • Difficult child behaviours (e.g., excessive screaming, hyperactivity, aloofness, lack of sleeping, very picky eating, etc.) • Lack of typical social-communicative behaviours (e.g., no joint attention, eye contact, social sharing, no speech, does not use speech socially, etc.) • Regression in language skills (in some cases) 	<ul style="list-style-type: none"> • Beginning to wonder if something wrong • Ambiguity regarding child's behaviour (seems skilled in some areas, serious difficulties in others) and "normal" appearance of child • Critical attitudes of extended family around child-rearing, possibly self-blame, blaming between spouses • Concerns first voiced to professionals – often told not to worry, wait 	<ul style="list-style-type: none"> • Take parent concerns seriously • Be knowledgeable about "red flags" indicating possible Autism • Empathize with worries, feelings of blame, guilt • Refer as soon as possible for full diagnostic assessment, don't wait
<p>Preschool Years</p> <ul style="list-style-type: none"> • Behavioural concerns persist and can no longer be denied, ignored • Classic autistic symptoms noted (e.g., lining up toys, echolalia, spinning, flapping, etc.) • Social difficulties become apparent (e.g., no interest in other children, no reciprocity even with familiar adults, though may enjoy self-initiated social/physical contact) 	<ul style="list-style-type: none"> • Further consultation with professionals, referrals for diagnostic assessment, etc. • Stress of ambiguity and waiting • Obtaining second opinion • Perceived or actual discrepancies between professionals • Perceived or actual insensitivity of professionals in providing assessment feedback and delivering the diagnosis • Emotional impact of diagnosis on parents – grieving process – need to call on coping strategies and supports • Difficulty explaining diagnosis to siblings, extended family, friends • Need to mobilize resources to research the disorder, treatments • Need to learn the social service system, advocate for child • Roller coaster of optimism (e.g., as child seen to respond well to IBI) and pessimism/anxiety for future 	<ul style="list-style-type: none"> • Do early developmental and diagnostic assessment according to best practices • Provide parent education regarding Autism, treatment options, importance of empirically supported approaches • Refer parents to Autism Society, other local sources of information • Refer child for early IBI • Enroll child in some integrated social setting, part-time if possible (may need to provide consultation & support) • Assist parents in coming to grips with reality of diagnosis • Help parents apply for funding (e.g., SSAH, etc.) • Assist with medical, community service referrals as needed • Provide parent support (often via parent groups) • Help plan for transition to school

Table 6. Family issues and needs through the lifespan (continued)

Child Difficulties	Family Issues and Needs	Clinical Recommendations
<p>School Years</p> <ul style="list-style-type: none"> • Form(s) of communication usually established – verbal, picture, sign, etc. • Behavioural issues may be relatively well understood and dealt with or may continue to be problematic • Social difficulties persist and become more obvious (e.g., no friends) • Asperger's may not be recognized until school age • Skills taught mostly at school (e.g., academic skills) usually improve • Skills taught mostly at home (e.g., toileting, dressing, etc.) usually improve 	<ul style="list-style-type: none"> • Ambiguity caused by unusual developmental profile of strengths, weaknesses, sometimes "peak skills" in generally low functioning child • Need to deal with school system, IEP procedures • Need to struggle with ideological and practical issues regarding different school placements (integration, special classes, etc.) • Need to learn to work with teacher and school personnel 	<ul style="list-style-type: none"> • Encourage parents to use respite care • Provide information and support to siblings (often via sibling groups) • Refer siblings for psychoeducational assessment if warranted • Provide consultation to school regarding specific ASD issues • Assist family in obtaining other needed supports and services (e.g., recreational programs, summer camp, etc.)
<p>Adolescence</p> <ul style="list-style-type: none"> • Academic and self-help skills of adolescent continue to increase, though maybe slowly • Social difficulties become more apparent • Mental health difficulties may emerge • Behavioural concerns may improve or worsen • Behavioural excesses, if present, more problematic as adolescent is bigger, more difficult to manage • Onset of seizures (in some cases) • Emerging sexuality and lack of skills or understanding of appropriate behaviour 	<ul style="list-style-type: none"> • Reality of child's limitations becoming more clear – loss of hopes for "recovery" – new round of grieving • Feelings of burnout and exhaustion from caring for child and "fighting the system" • Consideration of medications may be difficult • Need to begin future planning regarding adult issues, possible residential care, etc. • Need to do financial planning for future (wills, guardianship, etc.) 	<ul style="list-style-type: none"> • Assist families in dealing with changing emotional needs • Assist in seeking other services and supports (e.g., vocational training programs, supported employment, residential placement) • Assist adolescent in obtaining appropriate intervention for social difficulties (e.g., social skills groups) and mental health difficulties (e.g., CBT, supportive counseling, etc.)

5.2.3. Family Coping Model

Coping theory (Folkman, Schaefer, & Lazarus, 1979; Lazarus & Folkman, 1984) is a useful theoretical framework for describing families' experiences. The child with an ASD is viewed as a stressor, which, along with other potential stressors that can occur in any family, if left unchecked lead to depression, distress, and other negative mental health outcomes for parents. However, coping resources, including intrapersonal variables (such as hardiness and ambiguity tolerance), interpersonal skills, information resources, religious and other beliefs (e.g., optimism), social support (formal and informal), health/energy, and economic resources may ameliorate the negative impact of the stressors. These coping resources may be seen as buffers or "protective factors," a concept which is driving a new wave of family stress research (e.g., Dunn, Burbine, Bowers, & Tanteleff-Dunn, 2001; Hastings & Johnson, 2001).

It is important to realize that a number of studies have shown no overall group differences on standard measures of stress and marital adjustment between parents of children with Autism and other parents (Dyson, 1997; Koegel, Schreibman, O'Neill, & Burke, 1983). This finding is presumably because of good coping skills and effective supports and services. Thus, it is not appropriate to assume all parents are highly distressed and dysfunctional.

A coping framework can guide supportive intervention efforts with families in a rather broad way. Family supports and therapeutic interventions can be directed toward a number of domains in this model, such as:

- interventions aimed at directly improving the child's symptoms (although this will not necessarily have a direct correspondence to alleviating parent distress because of the other components involved in parents' experiences);
- supports directed toward reducing other family stressors (e.g., other family problems, housing, financial issues, etc.);
- interventions aimed at changing the parents' appraisal of the stressor and/or confidence in their ability to cope, as well as their skills in handling the child (such as parent training);
- interventions aimed at teaching skills directly to parents, including advocacy skills, behaviour management skills;
- strengthening individual and family resources and supports (via individual, marital, or family therapy);
- encouraging the use of informal sources of support (friends, family, community) which are often more effective than formal supports (although they may be sources of additional stress in some cases); and
- facilitating access to (and assisting parents to advocate for) formal support services such as respite care.

5.3 Siblings

Early clinical literature on siblings of children with Autism (again, most studies deal with Autism and not other ASDs) suggested high rates of psychopathology and emotional distress, especially in oldest girls. This distress was ostensibly because of parental neglect, additional household responsibilities, and social embarrassment (Lobato, 1983; Simeonsson & McHale, 1981). However, systematic studies of siblings of children with Autism, compared to siblings of children with other disabilities or no disabilities, have provided mixed results. Some studies have suggested higher rates of emotional and behavioural problems in siblings (Bagenholm & Gillberg, 1991; Fisman, Wolf, Elison, Gillis, Freeman, & Szatmari, 1996; Hastings, 2003; Rodrigue, Geffken, & Morgan, 1993), but others have found no difference and/or some positive effects (Gold, 1993; Kaminsky & Dewey, 2002). Current sibling research emphasizes examining more positive outcome measures in siblings (Hannah & Midlarsky, 2001; Hastings, 2003) and the effects of parental stress and adjustment on siblings' adjustment longitudinally (Fisman, Wolf, Elison, & Freeman, 2000).

From a practical point of view, the most likely interpretation of these findings is that a minority of siblings experience clinically significant internalizing and/or externalizing disorders, and may benefit from the social support of sibling groups (e.g., Lobato, 1983), accurate information about ASDs (Glasberg, 2000), and/or individual therapeutic intervention. However, many do not display such disorders and do not necessarily require formal supports (Bristol & Schopler, 1989).

It is also important to realize that because of the genetic factors involved in the etiology of ASDs, a sizable number of siblings can be expected to show some signs of learning or language disorders and concomitant school achievement difficulties which may require support and remediation (Fonbonne, Bolton, Prior, Jordan, & Rutter, 1997). These are often misinterpreted as being emotionally-based or the result of the family's systemic issues. Siblings referred for social-behavioural difficulties should receive a psychoeducational assessment to rule out this possibility or determine to what extent such difficulties are part of the clinical picture for the child.

5.4. Family-Based Interventions

5.4.1. Parent Education

After the child is diagnosed, parents need access to ongoing, current information about ASDs, specific therapies and approaches (reputable websites, books, etc.), and information about local supports, services, and resources. Many agencies provide information sessions (or series) for new families or on an ongoing basis, which may include reading materials, videos, guest speakers from different services, other parents, and so on. These are often beneficial for

extended family and friends as well, and may serve a support function as well as a strictly informational one.

5.4.2. Parent Support Groups

Parent support groups (sometimes combined with information and sometimes also with parent training approaches) are commonly provided for parents of children with ASDs. They may operate according to various theoretical models (more group-therapy oriented vs. more informal), but are typically intended to be facilitative and empathic, to provide parents a safe place to discuss feelings and issues and gain the invaluable perspective of other parents who have "been there." Consideration needs to be given to group composition with respect to age of child (and thus time since diagnosis) and level of behavioural and developmental difficulties. Too much diversity in these characteristics may limit the usefulness of the group. There are few published evaluations of these kinds of groups (but see Perry, Factor, & Freeman, 1992), but they are widely used and are typically very much appreciated by parents. They likely have a positive impact on family functioning, at least temporarily, however it is not clear whether they alleviate stress or what lasting effects they have.

5.4.3. Communication/Relationship Parent Training

Communication interventions are likely to be more effective when implemented consistently by parents and family members in natural settings. Early Language Intervention courses for parents, such as the "More Than Words" program delivered by the Hanen Centre, have been custom-tailored to enhance communication and parent-child relationships in families with a child with an ASD (Sussman, 1999). This program is built on the social-pragmatic approach to language, though some aspects of the natural language paradigm (Koegel, O'Dell, & Koegel, 1987) are also embedded. The goal of the training is to teach parents to increase their responsiveness to their children and create motivating opportunities for their children to communicate. This training is meant to supplement other interventions the child is receiving and to assist parents to embed language instruction into functional routines and activities. To date there are no published studies on the effectiveness of this program, but preliminary program evaluation research shows some promise (Le Couteur et. al., 2002).

5.4.4. Behavioural Parent Training

Marcus et al. (1997) summarize various approaches to parent training. Behavioural parent training is, of course, a common approach in many childhood disorders (Kazdin, 1997; Schaefer & Briesmeister, 1989) and generally has a solid empirical basis. It is particularly important in ASDs because it helps combat the well-known generalization difficulties seen in these children. Parent training also has a number of other benefits, including:

- providing a sense of partnership between parents and other intervention agents;
- helping parents know empirically the child's abilities and difficulties;

- involving parents directly in selecting target behaviours for intervention;
- providing additional intervention hours in a cost-effective way;
- enhancing maintenance and generalization of gains;
- teaching different skills;
- being more relevant to home environment and community;
- providing parents with a sense of control and self-efficacy, which may decrease parent stress;
- improving parents' interactions and relationship with their child; and
- preventing the development of more severe problem behaviours.

Training methods include didactic instruction, demonstration of mastery of content, role plays, videos, feedback and/or live coaching, and homework assignments. Training may take place in either group or individual formats, with obvious pros and cons to each approach (Kolko, 1984; Kozloff, 1973). Some limitations of parent training are that the degree of real fidelity in the home is unknown, long-term implementation is often difficult to sustain, and personal problems may render it ineffective (Plenis, Robbins, & Dunlap, 1988; Scotti, Evans, Meyer, & Walker, 1991).

Although the principles taught are similar regardless of the child's specific diagnosis (reinforcement, task analysis, consistency, etc.), it is important that the training be geared specifically to ASDs, and roughly to the functioning level of the child. For example, the use of delayed and abstract contingencies such as stickers may not be effective for a low-functioning child. Similarly, the use of time-out, a staple in many parent training programs, is not always advisable in children with ASDs if they prefer to be alone or engage in repetitive behaviours while in time-out (see Intervention for Challenging Behaviour section).

Many IBI programs and other comprehensive programs include a parent training component, although they vary in the degree to which it is required or emphasized (see Handleman & Harris, 2001). Parents may be asked to do 6 to 10 hours of additional IBI similar to what the child receives from therapists, engage in specific generalization activities related to the child's IBI program, teach different goals more relevant to home (e.g., self-help skills), and so on. Parents are, of course, not always interested, willing, or able (for a variety of reasons) to take such an active role in their child's program.

Research on parent training models in families of children with ASDs has shown benefits both for children and for parents. For example, a parent training program implemented by TEACCH was evaluated by Ozonoff and Cathcart (1998), who compared two groups of children with Autism aged 2 to 6, all of whom were receiving school-based behavioural intervention. Children whose parents were also trained improved significantly more on

several developmental domains, including cognitive and motor development, especially those who were higher functioning and less severely autistic.

A few studies have examined whether parent training increases or decreases parents' stress and family functioning, both of which have been hypothesized. Koegel et al. (1983) showed improved family functioning in a parent training group versus a clinic-treated group, although parents' preferences were for the (free) clinic treatment. Koegel, Bimbela, and Scheibman (1996) compared two different models of parent intervention for families of children with Autism (aged 3 to 9): the Individual Target Behaviour approach (similar to discrete trial training); and Pivotal Response Training, which emphasizes responding to multiple cues, sharing task and stimuli selection with child to improve motivation, and using natural reinforcers, in addition to the basic behavioural techniques. Results showed significantly better family outcomes (happiness, stress, interest, and communication style) for the Pivotal Response Training approach. Another creative and effective approach, the Individualized Support Project (Fox, Dunlap, & Philbrick, 1997) combines training in social skill development, positive behavioural supports, parent training, and comprehensive family supports in integrated settings (Dunlap & Fox, 1996).

A recent study focusing on families of children with Asperger's Disorder found training to be equally effective whether done individually or in small groups. Both trained groups reported improvement in the children, and mothers (but not fathers) felt better able to handle difficult behaviours in their child, relative to an untrained waitlist comparison group (Sofronoff & Farbotko, 2002).

In summary, behavioural parent training is likely a valuable intervention for many families, but should be tailored to ASDs, and should be considered in the context of family systems issues and the larger context of services the child or adolescent may be receiving (Moes & Frea, 2000).

5.4.5. Respite Care

Respite care provides parents with a break from the child with an ASD and is frequently listed as a service families need (e.g., Cutler & Kozloff, 1987), although it may not be seen as acceptable to some families. Some respite programs do not admit children with ASDs or severe problem behaviours. There are several models of respite care, including in-home and out-of-home. Published studies of respite care indicate that parent satisfaction is high for those who have access to it and choose to use it. Several studies have shown parents of children who are lower functioning or more difficult are more likely to use out-of-home respite care (Factor, Perry, & Freeman, 1990; Marc & MacDonald, 1988). There is also some evidence that regular, planned use of respite care can decrease stress, and possibly prevent it increasing over time (Intagliata, 1986; Rimmerman, 1989; Wikler et al., 1986). Clinicians are encouraged to assist

families in considering the regular use of respite care in the larger family context and how the time can be spent in ways which strengthen the family.

5.5. Summary Regarding Family Research and Intervention

In summary, there is a great deal of variability in the experiences of families who have a child with an ASD, depending upon family factors and characteristics of the child, and these can and do vary considerably over time, even in the same family. Many of the issues faced are not dissimilar to those faced by other kinds of families, and the intervention approaches are also similar. Other needs are unique to their experience of having a child with an ASD. Services and supports families may need include:

- early, accurate diagnosis with clear explanations of assessment;
- intensive early intervention (strongly evidence-based);
- case management, future planning;
- professional therapeutic supports (e.g., supportive counseling, family therapy);
- information and education regarding Autism for parents and siblings, including assistance evaluating new treatment approaches;
- parent training regarding social/communication skill development and behaviour management (evidence-based and can be specialized for ASDs);
- respite care to decrease or prevent family stress (evidence-based);
- parent support groups and sibling support groups (somewhat evidence-based);
- appropriate and effective interventions and supports for child;
- appropriate programs and supports for adolescents and adults; and
- appropriate residential placements when needed (children and adults).

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Section 3

Evidence-Based Practices for Children and Adolescents with Autism Spectrum Disorders:

Appendices

- Reference Guide for
Developmental and
Diagnostic Measures
- Acknowledgements

APPENDIX 1

REFERENCE GUIDE FOR DEVELOPMENTAL AND DIAGNOSTIC MEASURES

ABC	Autism Behavior Checklist (Krug et al., 1980)
ABLIS	The Assessment of Basic Language and Learning Skills (Partington & Sundberg, 1998)
ADI-R	Autism Diagnostic Interview—Revised (Lord et al., 1994)
ADOS-G	Autism Diagnostic Observation Schedule—Generic (Lord et al., 2000)
Bayley	Bayley Scales of Infant Development II (2nd ed.) (Bayley, 1993)
Beery VMI	Beery Developmental Test of Visual-Motor Integration (4th ed.) (Beery & Buktenica, 1997)
Brigance	Revised Brigance Diagnostic Inventory of Early Development (Brigance, 1991)
CARS	Childhood Autism Rating Scale (Schopler et al., 1988)
CELF-IV	Clinical Evaluation of Language Fundamentals (4th ed.) (Semel et al., 2003)
CHAT	Checklist for Autism in Toddlers (Baron-Cohen et al., 1996)
CSBS	Communication and Symbolic Behavior Scales (Wetherby & Prizant, 1993)
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders (4th ed.) (American Psychiatric Association, 1994)
MacArthur	MacArthur Communicative Development Inventories (Fenson et al., 1993)
Mullen	Mullen Scales of Early Learning (Mullen, 1997)
Nipissing	Nipissing District Developmental Screen (2002)

PDDST	Pervasive Developmental Disorders Screening Test (Siegel, 1998)
Portage	Portage Guide to Early Education (Bluma, 1994)
Rosetti	Rosetti Infant-Toddler Language Scale (Rosetti, 1990)
Rourke	Rourke Baby Record (Rourke, Rourke, & Leduc, 2000)
SIB-R	Scales of Independent Behavior–Revised (Bruininks et al., 1996)
SICD	Sequenced Inventory of Communication Development (Hedrick et al., 1984)
SB-IV	Stanford-Binet Intelligence Scale: Fourth Edition (Thorndike et al., 1986)
VABS	Vineland Scales of Adaptive Behavior (Sparrow et al., 1984)
WAIS-III	Wechsler Adult Intelligence Scale 3rd ed. (Wechsler, 1997)
WISC-III	Wechsler Intelligence Scale for Children 3rd ed. (Wechsler, 1991)
WPPSI-III	Wechsler Preschool and Primary Scale of Intelligence 3rd ed. (Wechsler, 2002)

APPENDIX II

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Project Advisory Committee

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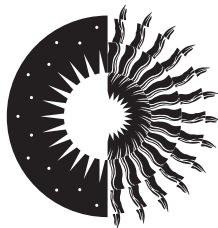
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