



Autism

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<http://www.child-encyclopedia.com/EN-CA/child-autism/perspectives.html?RId=CA>



Synthesis on autism

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How important is it?

Autism is a [developmental disorder](#) of unknown origin. Once considered rare and almost always severe, it is now understood to be more common and varied in its occurrence. Autism begins in infancy, affecting one in 200 children. Usually detected by the age of three and in some cases as early as 18 months¹ rates of occurrence are unequally divided between the sexes with it being four times more likely to manifest in boys than girls.

Autism is characterized by impairments in socialization, communication, and behaviour and play. Children affected with this disorder “demonstrate deficits in 1) social interaction, 2) verbal and nonverbal communication, and 3) repetitive behaviours or interests. In addition, they will often have unusual responses to sensory experiences, such as certain sounds or the way objects look.¹” The cognitive abilities of individuals with autism vary widely. While the rate of [mental retardation](#) in autism is approximately 70%, a significant percentage of individuals fall within the average to above-average range of intelligence. Between 15% and 30% of autistic children experience a [period of regression](#) at the age of 12 to 20 months in speech and social behaviour.

While no susceptibility gene has yet been identified, evidence of inheritability exists. The recurrence rate of autism in siblings is known to be between 2% and 8% and milder impairments of social communication skills or language are found in as many as 20% of relatives.

What do we know?

Autism is an organic condition that affects development very early in life. Autistic children have [social/emotional difficulties](#) with the use of non-verbal behaviours, such as eye-to-face gaze, and the communicative use of gestures, facial expressions and body posture. Demonstrating joint attention and empathy seems to be a challenge as they are likely to prefer isolated activities.

The ways in which social and communicative problems are manifested vary widely among autistic children. However, the presence of [early social orienting impairment](#), which is demonstrated prior to 24 months of age, has led researchers to conclude that it is the primary impairment in autism.

Diagnosis of autism is difficult prior to 30 months of age because of the [instability of diagnoses](#) before that age period. A [key indicator](#) is impaired social processing of faces, emotions and mentalizing skills, and difficulties acquiring communication skills. But because there is no biological marker or medical test for the condition, and early indicators of social behaviour are harder to measure and analyze than developments

in language or motor skills, diagnosis of young children can be hard to achieve. Instead, [autism diagnosis](#) relies on parental report information and on behavioural observation.

What can be done?

Treatment of autism is complicated by the wide range of [individual differences](#) among children with the disorder. As a result, effective intervention is difficult. Despite these difficulties, different types of early intensive interventions have been found to lead to significant gains in cognitive, social and language functioning for children with autism. For instance, early intensive [Applied Behaviour Analysis \(ABA\)](#) intervention – an approach to understand, assess and change behaviours and to teach new skills using a variety of methods based on individual needs – have led, in some children, to increased levels of educational and intellectual functioning. However, age and IQ of the children receiving ABA seem to affect their outcomes greatly. Other types of early intervention, which provide to preschool children with autism visual cues and structure that they find difficult to generate themselves, have also been associated with increased levels of social functioning in some of them.

Early intervention for children in [inclusive school settings](#) has been shown to help improve specific social skills. For instance, ABA teaching methods help children with autism learn how to initiate and respond to other children. These methods also teach children specific play skills and other behaviours to help them interact with their peers. Other specific [instructional methods](#) that are beneficial for learning social behaviours include pivotal response training (teach key behaviours); script-fading (follow a written, auditory or pictorial script); and time delay (wait before offering a response to the child).

It is possible to isolate some [important elements](#) of intervention programs for autistic preschoolers. These include

- development of communication skills (verbal or non-verbal)
- joint engagement and joint social activities
- promotion of emotional engagement and regulation
- help for parents to manage behavioural problems

Parents play a pivotal role in the outcomes of early intervention and researchers are beginning to identify parent characteristics or skills that could help a child's progress. [Parent education](#) can serve as a way to relieve stress and empower parents, which could help enhance the impact of early intervention. Parental sensitivity – following the child's focus of attention – has also been identified as influential.

A vital [social policy issue](#) is to develop training programs to help more impaired children with autism to transition into adaptive adult roles in society. Early intervention is cost-effective relative to the [cost](#) of autism to individuals, families and society when early treatment is not received. Policy-makers should support early identification and treatment to minimize the negative consequences of late diagnosis. To increase the potential for positive developmental and social progress in children with autism, researchers should focus on improving methods for the reliable identification of autism and on understanding what form of treatment is most [effective](#) for the type of child, the developmental stage and the outcomes. Moreover, research needs to address the possible causes of this disorder such as genetic transmission and brain development.

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Autism and Its Impact on Child Development

TONY CHARMAN, PhD

Institute of Child Health, UNITED KINGDOM

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Topic

Autism

Introduction

Autism and related pervasive developmental disorders are more common than previously recognized, affecting up to one in 100 individuals.¹ Although symptoms and accompanying functional impairments can improve with development and as a result of specific interventions, the condition is lifelong and results in considerable morbidity and cost to the individual, his or her family and society.

Subject

The term “autism spectrum disorders” is now commonly used to describe a range of neurodevelopmental conditions that differ in underlying etiology and vary in manifestation.² What they share in common with Kanner’s description of classically “autistic” children is a primary impairment in social relatedness and reciprocity.³ Once considered particular characteristics of rare individuals in the population, these impairments are now more commonly understood as a broad spectrum of individual differences that are widely distributed in the general population.⁴

Problems

The primary impairment in social reciprocity, peer relationships and emotional engagement is accompanied in different individuals by varying degrees of language and communication impairment, mental retardation and patterns of non-functional restricted, repetitive and stereotyped behaviours. Sensory abnormalities, including either hyposensitivity or hypersensitivity, and unusual interests in some sensations are common. A lack of imaginative play indicates an underlying difficulty with generation of ideas that is highly relevant in the development of understanding, and thinking about, other people and other situations. All of these characteristics can be seen in varying degrees of severity.

Both the DSM-IV⁵ and the ICD-10⁶ classification systems include diagnostic categories for individuals who show some but not the full complement of impairments necessary to meet criteria for autism: Asperger’s syndrome, atypical autism and pervasive developmental disorder (“unspecified” in ICD-10; “not otherwise specified” in DSM-IV).

This group is a mix of those with greater severity in one area than others, mild impairments in several areas or late onset (after three years of age).

Research Context

While it has been established that autism is an organic condition and that the condition is highly heritable, in only a minority of cases can a specific neurologic or genetic cause be identified.² As a result, considerable research activity is currently focused on identifying the genetic and neuro-pathological basis. However, as the autism phenotype may be arrived at by a number of pathogenic routes that overlap somewhere in brain development and function, as yet unidentified biological or genetic markers will not necessarily be present in all cases and case definition will continue to be reliant on the behavioural picture alone. Targets for behavioural research include establishing the neuropsychological processes that are impaired, earlier identification and establishment of accurate and reliable diagnosis in toddlers, and testing the efficacy and effectiveness of various intervention programs and approaches.

Key Research Questions and Recent Research Findings

Although etiology can be established in a few cases (e.g. children with fragile-X syndrome or tuberous sclerosis), there is evidence for complex polygenic inheritance. However, while attempts to identify susceptibility genes by association studies have produced several candidate genes on different chromosomes, no gene has yet been identified.⁷ The recurrence risk for subsequently born siblings is approximately 5-10%, although milder impairments of social communication skills or language are found in as many as 20% of relatives. Familial susceptibility to the “broader phenotype” of autism has implications for genetic counselling. Autism is more common in boys than girls (4:1), but no explanation for this discrepancy has been substantiated.⁸ Between 15% and 30% of children with autism experience a period of stasis or regression, most commonly in speech and social behaviour, usually between 12 and 20 months of age, although the causes of this regression are not well understood.⁹

There is agreement that social processing (of faces, emotions, mentalizing skills) is impaired and there is evidence that the brain systems that subserve such cognitive functions are structurally and functionally disrupted. However, the developmental cause of such impairments may be earlier disruptions in the development of brain circuits that underlie the social reward and social orienting systems.^{10,11}

There has been progress in the earlier identification and diagnosis of cases, in part via efforts to develop prospective screening instruments¹² and the prospective study of “high-risk” samples, such as younger siblings of already diagnosed children.¹³ However, this presents clinical challenges: establishing the reliability of early diagnosis, modification of treatment approaches for toddlers, use of assessment tools with younger children and the ability to indicate prognosis.¹⁴

There is some evidence for effectiveness of intensive applied behavioural analysis approaches to early intervention, but there are also limitations with respect to outcomes and the generalization of cue-dependent behaviours.¹⁵ There is also evidence for benefits

from social and communication-based approaches¹⁶ and approaches that provide visual cues and structure that many preschoolers with autism find difficult to generate themselves¹⁷. Important elements of intervention programs for preschool children with autism include a focus on the development of pragmatic and functional communication skills (whether verbal or non-verbal), joint engagement and joint social activities, promotion of emotional engagement and regulation, and helping parents to manage behavioural tantrums and maladaptive routines.¹⁵ For the most treatment-resistant children with the poorest prognosis (e.g. those with no verbal communication by mid-school years, accompanied by extreme social aloofness and mental retardation), there is a need to determine whether augmentative communication approaches might help adaptation.

Depending on family resources and access to support and services, the impact on the family can be considerable, especially at times of important transition (diagnosis, school entry, school transfer, entry to adulthood). Research into the effectiveness and acceptability of support services for families and for adults with autism is scant. One emerging trend is the identification of comorbid psychopathology (e.g. anxiety, OCD) in adolescents and adults, most notable in individuals with average IQs, that can lead to additional challenging behaviour.

Conclusions

Our understanding of autism, once considered a rare and almost always severe childhood disorder, has undergone a revolution in the past 20 years. It is not a rare disorder. Its manifestations can vary widely and it can present in high- as well as in low-IQ individuals. Together with increasing evidence of the positive benefits of early intervention, these changes in conceptualization and application of the diagnosis mean that our notions of outcome and likely progress are also undergoing a revolution. Alongside advances in genetic and neuro-scientific research, a reconceptualization of autism has led scientists to ask fundamental questions regarding social behaviour and communication that have relevance for populations of children in general and not just those relatively rare children who have impairments in these abilities sufficient to meet diagnostic criteria for autism.

Policy Implications

The costs of autism to individuals, families and society are considerable. Internationally, there is an impetus to improve early identification and treatment in order to minimize the impact and to ameliorate the negative secondary sequelae of late diagnosis and ineffective treatments. Community health practitioners and kindergarten staff require training in the identification and management of autism. Basic research into the etiology and underlying psychological impairments that characterize autism are required alongside more applied research into early identification, effective interventions and support for families. At a broader societal level, the recognition that aspects of autism are connected more generally to individual differences in social behaviour (for example, between males and females¹⁸) challenges the notion of autism as a distinct and necessarily “impaired” way of processing and understanding the social world. This calls for greater societal acceptance of differences in social engagement and social behaviour.

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The Impact of Autism on Child Development

WENDY L. STONE, PhD

LAUREN TURNER, PhD

Vanderbilt Centre for Child Development, USA

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Topic

Autism

Introduction

Autism is a developmental disorder characterized by impairments in social reciprocity and communication, and the presence of restricted or repetitive activities. Onset of autism is before the age of three. The etiology of autism is organic, though no single pathologic event has been identified as uniquely or universally associated with the disorder. The diagnosis of autism can be made accurately at two years of age, with social and communication impairments presenting as primary impairments.^{1,2} Treatments that are specialized for autism and begin at young ages have been found to contribute to significant gains in cognitive, social and language functioning.³⁻⁸ Thus, several different professional practice parameters emphasize the importance of both early identification and early intervention in promoting more positive outcomes for children with autism.⁹⁻¹¹

Current prevalence estimates suggest that approximately three to five children per 1,000 are affected with an autism spectrum disorder.¹² These estimates are higher for first-degree relatives; the recurrence rate of autism in siblings has been reported to be between 2% and 8%.¹³ Individuals with autism span the entire range of cognitive ability, with more than half functioning in the range of mental retardation, and a substantial proportion functioning within the average to above-average range of intelligence.

Subject

This review examines the early behavioural features of autism, with particular focus on the social and emotional sequelae of autism under 24 months of age.

Problems

There are many challenges to studying autism during infancy. First, there is no biological marker or medical test for autism. Therefore, the diagnosis is based on behavioural observation and parental report information.¹⁴ Second, the DSM diagnostic criteria for autism were not developed for young children, and some criteria, such as problems with conversational language, are not appropriate for infants and toddlers. As a result, definitive diagnoses of autism are often not made until children are over three years of age. To learn about very early behavioural features, then, studies must either be retrospective or must follow children prospectively until diagnoses are certain. Third,

early milestones for social behaviour are less well defined than those related to motor or language development (i.e. walking and talking). Thus, early deviance in social development, which is the core feature of autism, can be challenging to detect. Fourth, some symptoms of autism overlap with those seen in other developmental disorders, such as language disorders and developmental delays, which makes diagnostic determination – as well as selection of appropriate comparison groups – more difficult. Finally, autism presents differently in every child. The expression of symptoms varies greatly across children as well as within each child throughout development.

Research Context

The most common research methodologies used to study early social/emotional development in infants with autism have been retrospective parental reports and analysis of home movies of infants who were later diagnosed with autism. A newer methodology involves the prospective study of high-risk infants, such as younger siblings of children with autism or children who have failed early social-communication screenings.

Key Research Questions

This review will address the social and emotional markers of autism in children under 24 months. An emphasis is placed on studies that have compared the early behaviours of children with autism to those of children with developmental delays, as these studies are more likely to provide information about autism-specific behaviours, rather than behaviours resulting from concomitant developmental delays.

Recent Research Results

Retrospective parental report: Retrospective parental reports have provided important information about the early development of children with autism prior to their first referral for diagnosis. However, retrospective reporting is prone to several types of distortions, such as inaccurate recall and reporter bias, which require that their results be interpreted cautiously. Compared with children with non-autistic developmental delays, children with autism have been described as less likely to demonstrate early social-communicative behaviours such as making eye contact,¹⁵ looking at others,¹⁶ greeting others,¹⁵ offering and giving objects,¹⁵ showing and pointing to objects,¹⁵⁻¹⁷ raising arms to be picked up,¹⁵ imitating,¹⁵⁻¹⁷ and using non-verbal vocalizations communicatively.¹⁵ They are also described as less likely to understand or respond to the communication of others, such as following the point of an adult to an object,^{15,16} or responding to their names being called.¹⁶ Parents of children with autism also reported that their infants were less likely to play with them during lap games or turn-taking games,^{15,16} were less responsive to parents' attempts to join in their play,^{15,16} and were more likely to prefer to be alone^{16,17} than children with non-autistic delays. Finally, parents reported that infants with autism were less likely to smile at others^{16,17} and more likely to exhibit an expressionless face than non-autistic infants.¹⁶

Home movie studies: Retrospective home movie studies have examined video clips of infants with autism in their home environments as young as six months of age. This method has allowed researchers to judge infant behaviours objectively, without the bias

of knowing their later diagnoses. Only results from studies that used observers who were blind to children's later diagnoses are summarized below.

In general, more behavioural differences have been found when comparing infants with autism to those with typical development, than for comparisons between autism and developmental delays. Compared to typically developing infants, infants with autism spend less time looking at people,¹⁸⁻²⁰ vocalizing toward people,¹⁹ orienting toward people,¹⁹ responding to their name,^{18,21-23} seeking contact with people, smiling at others,^{19,20} and showing anticipatory gestures in response to adult actions.^{18,19,23} However, when compared to infants with developmental delays, differences are apparent only for behaviours indicating social responsiveness, with infants with autism looking at others less frequently,²³ responding to their names less frequently,²³ and requiring more prompts from their parents when calling their names.²¹

Prospective studies: A newer research approach has been to study high-risk infants prospectively. Prospective studies have an advantage over retrospective studies in that researchers can present standard situations to elicit and measure behaviour. One prospective approach has been to follow children who are at risk for autism because of having failed early screenings for autism or for language delay. In two studies,^{24,25} the high-risk group consisted of children who failed the Checklist for Autism in Toddlers (CHAT),²⁶ a screening measure administered at 18 months of age. Both studies compared children receiving a subsequent diagnosis of autism with those receiving a subsequent diagnosis of developmental delay. Results revealed that at 20 months of age, the children with autism spent less time looking at adults during free play,²⁵ were less likely to look at the face of an adult feigning distress,²⁴ showed less gaze switching between people and objects,^{24,25} and showed less imitation²⁴ than children with developmental delays.

Wetherby et al.²⁷ took a different approach, following a group of children who had failed language/communication screenings from the Communication and Symbolic Behavior Scales Developmental Profile (CSBS).²⁸ Videotapes of the CSBS Behavior Sample were obtained at a mean age of 18 to 21 months for children who received later diagnoses of autism or developmental delay, and children with typical development. Specific social-communication behaviours, such as eye gaze, coordination of gaze with other non-verbal behaviours, directing attention, responding to name, and unusual prosody were found to differentiate the children with autism from the other two groups.

A more recent prospective approach has been to study later-born siblings of children with autism because of their elevated risk for developing the disorder. The only published study to date employing this methodology found that siblings later diagnosed with autism demonstrated several social differences from typically developing controls by the age of 12 months;²⁹ these differences included eye contact, social interest, affect and imitation.

Conclusions

In sum, the results from retrospective and prospective studies are similar in their findings that infants with autism demonstrate many social impairments before 24 months of age. Early social orienting and joint attention behaviours are the most consistently described

impairments in these young children in the domain of social development, while expressing and sharing positive affect and responding to the affect of others may be most impaired in the domain of emotional development. What makes these findings most remarkable is that these symptoms are apparent up to two years before many children are diagnosed with autism. These findings have led many researchers to consider early social orienting impairments as a primary impairment in autism.³⁰ Although this is beyond the scope of the present review, it should be noted that infants and toddlers who develop autism may display deviant development in non-social domains as well, such as sensory-motor and attentional functioning.

Implications for the Policy and Services Perspective

These findings have several implications for policies and services. First, it is clear that autism can affect development very early in life, before a definitive diagnosis can be made. Therefore, continuing support for research on early identification is sorely needed. New questions about ethical obligations and professional responsibilities have arisen with this focus on very young children, because the implications of early social delays for individual children are not yet known. For example, it is not clear whether all infants who display risk markers for autism at 12 months should be referred for early intervention services, or exactly which services they should receive. Could the full expression of autism be prevented by intervening early in life? Further research is needed to determine which services are appropriate for at-risk infants, and whether these services have the potential to prevent the full expression of autism. Second, there is ongoing parallel research being conducted on early brain development in autism. Collaborative work between researchers studying the early behavioural manifestations of autism and those studying early brain development could facilitate our understanding of how the disorder develops and when developmental deviations begin. Finally, collaboration across centres studying high-risk infants will be critical for obtaining sufficient samples to allow more complex questions about the early development of autism to be asked – and answered.

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Autism and Its Impact on Young Children's Social Development

MARIAN SIGMAN, PhD

SARAH J. SPENCE, MD

*Center for Autism Research and Treatment
UCLA School of Medicine, USA*

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Topic

Autism

Introduction

Autism is a disorder originating in early childhood that has extremely debilitating effects on social and communicative development.¹⁻⁵ Because the causes of autism have not yet been identified, it cannot be prevented, nor do we have a cure or even particularly effective treatments. The symptoms of autism are quite heterogeneous but must involve deficits in social relatedness and communication, as well as the presence of restricted interests and repetitive behaviours.⁶

Subject

The investigation of autism is important because of its very serious consequences for life adjustment. Moreover, because autism involves deficits in social abilities that are manifested very early in typical development, the disorder serves as a model for understanding the prerequisites for communicative and emotional interactions.

Problems

Individuals with autism invariably have difficulties in social engagement and the acquisition of communicative skills. However, the ways in which these difficulties are manifested vary widely from person to person. Many individuals with autism do not develop functional language skills^{7,8} and show deficiencies in non-verbal communication.⁹ Those who do acquire language have problems in communicating because effective communication requires the ability to share perspectives with others, a major deficit in autism.¹⁰ The rate of mental retardation (MR) in autism has long been cited as approximately 75%, and a current review paper summarizing surveys with IQ data gave a median of 70%. However, recent studies have reported lower estimates, largely because of the inclusion of individuals with Pervasive Developmental Disabilities (PDD) and Asperger's syndrome, who typically have lower rates of MR.¹¹

Research Contexts

Because autism was discovered relatively recently, there has been a great deal of change in the contexts in which autism is researched. Only in the last five to 10 years has there been sufficient consensus over the core symptoms of autism to enable reliable and valid diagnostic instruments to be created, a major research improvement. The demonstration by epidemiological studies of a greater prevalence than previously thought has also altered the research context.

Key Research Questions

One key research question concerns the psychological and physiological manifestations of autism and the factors responsible for these characteristics. Psychological theories of autism focus on problems in social and symbolic understanding,^{12,13} executive functions including attention shifting,^{14,15} and central coherence.¹⁶ Physiological manifestations are assessed with measures of head circumference, structural and functional imaging techniques (this can include magnetic resonance imaging [MRI], positron emission tomography [PET], and magneto encephalography [MEG]), electroencephalography, evoked potentials, and post-mortem anatomical studies of brain tissue. Most studies compare psychological and physiological characteristics of individuals with autism with the characteristics of non-autistic individuals of similar age, gender and frequently, developmental or language level. More recent studies have addressed the genetic basis for these characteristics as well as for the diagnosis itself.

A second research aim is to develop early identification measures for the syndrome of autism. The diagnosis of autism is now generally not made before a child reaches 30 months of age because of instability in diagnoses made before that age period. Early diagnosis studies use three approaches: the coding of behaviours from birthday party videotapes of children who are later diagnosed with autism;¹⁷ the assessment of two- to three-year-old children who have behaviours characteristic of autism; and the longitudinal follow-up of siblings of children with autism, who are at higher risk than siblings of non-autistic children.¹⁸

Investigations of the effectiveness of interventions with children with autism have been increasing over the last few years. This is fortunate because, until this time, there have been very few randomized control studies of interventions with children with autism.^{19,20} Current studies improve on previous investigations in that the aims of the interventions are often based on theoretical considerations or empirical evidence of areas of deficits or environmental mediators of developmental progress. In the past, since less was known about autism specifically, interventions were less tailored to the problems of children with autism or characteristics of the children or their environments that are associated with improved development.

Recent Research Results

There is research evidence supporting most of the psychological theories of autism, but no single theory that explains all the symptoms and developmental aspects of the disorder. Many studies replicate the identification of specific and unique deficits in social and symbolic domains that are manifested as early as the second year of life. However, it

is possible that these deficits arise from earlier problems in attention regulation or in social orientation and engagement. Moreover, deficits in social communication and play in early childhood do not explain the presence of repetitive behaviours and obsessive concerns or problems in decision-making that mar the functioning of more highly able individuals with autism. Theories of executive function and central coherence deficits explain these latter problems more adequately, but are limited in their application to problems with social communication and play.

While psychological studies have been quite successful in terms of replication, this has been less true for findings of differences in brain structure and/or function. Perhaps the strongest evidence is for a neurodevelopmental disorder in brain growth, in that the most common physical abnormality found in children with autism is large head size.

Genetic transmission is the most broadly supported causal mechanism. The higher rate of autism in monozygotic as opposed to dizygotic twins, as well as the increased sibling recurrence risk and the presence of the broad phenotype in family members support this theory. A number of regions on different chromosomes have been identified in various studies and a variety of candidate genes are being investigated. Unfortunately, there has been only limited replication to date. Recently, the description of specific subgroups with similar physical or behavioural profiles (endophenotypes) has been shown to increase the power to detect linkage for autism susceptibility gene regions. Research on environmental teratogens (stimuli that disrupt normal development by damaging cells, altering chromosomes structure, or acting as abnormal inducers) that might contribute to autism is just beginning.

Conclusions

Autism is a developmental disorder of unknown origin that severely compromises the social development of children whose behaviour meets the diagnostic criteria. Most individuals with autism are sufficiently socially isolated and intellectually impaired that they have difficulties with employment and do not marry or have children. Research is needed that addresses the causes of the disorder as well as the causes of variations in its manifestations. Such research is likely to lead to more effective interventions that are created with two aims: 1) where possible, to treat and even prevent the disorder; and 2) to optimize the developmental progress and level of functioning of individuals with the disorder.

Implications for the Policy and Services Perspective

There is a great need for therapeutic and educational services for individuals with autism. School systems and social services are largely unable to provide the resources that are required to educate and treat the problems faced by people with autism at all age levels. At the same time, families are over-burdened by the challenges involved in rearing and supporting family members with autism. Currently, there is an emphasis on early detection so that interventions can be implemented that prevent the development of problems secondary to the social deprivation often elicited by the children's social difficulties. At the same time, we need many more programs designed to help older individuals with autism to adapt to their life circumstances.

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Autism and Its Impact on Child Development: Comments on Charman¹, Stone and Turner, and Sigman and Spence

PETER MUNDY, PhD

University of Miami Center for Autism and Related Disabilities, USA

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Topic

Autism

Introduction

Autism first emerges in infancy and is characterized by chronic impairments in social development, along with disturbances in communication and restricted or repetitive patterns of behaviour.¹ Genetic and neurodevelopmental processes are evident in its etiology; it occurs four times more frequently in boys and may be associated with mental retardation.^{2,3} An improved understanding of some of the social features of autism and related disorders has led to advances in diagnosis and early identification over the past 20 years.⁴ These advances may have contributed to the increased ascertainment and prevalence of autism that has been noted worldwide.⁵ Behavioural, psycho-educational treatments are most often recommended for autism; however, research suggests the effectiveness of these treatments is currently limited.⁶ Individual differences in the presentation of autism are clear and constitute one element of complexity that complicates efforts to understand and treat this disorder.⁷ The prototype of the child with autism as “unresponsive and aloof” describes only one subgroup.⁸ Some children and adolescents with autism may be quite interactive, have well developed language skills, and be accomplished in the classroom, but still suffer from significant and debilitating social impairments.⁹

Research and Conclusions

Charman, Stone and Turner, and Sigman and Spence have provided cogent summaries that highlight many of the essential elements of current research and theory on this syndrome. Each of these eminent scientists notes the importance of research in improving methods for identifying children with autism at the earliest possible age. Progress in understanding the early non-verbal social-communication deficits of autism has facilitated the development of assessments for autism in children as young as 18 to 36 months of age (see Stone and Turner). However, these methods remain imprecise. In addition to the identification of deficits (negative symptoms), the identification of positive symptoms of autism in young children, such as atypical vocalizations, may help

¹ Comments on original paper published by Tony Charman in 2005. To have access to this article, contact us at cedje-ceed@umontreal.ca

to improve these methods.^{4,10} The discovery of biological or genetic markers of autism may also be critical to future improvements in early identification.³

Early identification enables early intervention, which may be most effective in treating the developmental nature of autism. A “constructivist” theory of autism suggests that:

a) the active participation of infants in social interactions with other people is necessary for typical social-communication and neurobehavioural development in early childhood; and b) social-communication impairments prevent children with autism from being active participants in social interactions from early in infancy. Therefore, social communication disturbance may be both an early *symptom of autism* and also a contributing factor in an atypical developmental process that leads to symptoms, such as social cognitive deficits that develop later in the lives of children with autism.^{11,12} The early treatment of social communication disturbance¹³ may be one of the more effective means of reducing the pernicious development component of pathology in autism.

As noted in the previous summaries, hope for the development of effective treatments for autism has been hampered by too few randomized control trial studies of treatments.¹⁴

These types of studies are needed to ensure that experimental bias, such as critical group differences among children presented with comparison treatments, does not compromise conclusions that may be drawn regarding the effectiveness of treatments. This is important because even treatments that have the best-documented evidence of efficacy appear to be less effective with children with more intense symptom presentation and more effective with those with less intense symptom profiles.⁶ Understanding how to intervene effectively with all children with autism remains a fundamental challenge. One approach is to identify and understand the individual differences that are related to treatment responsiveness. For example, Bono, Daily and Sigman¹⁵ reported that children with autism who have better developed joint attention, and are more active in paying attention to what others look at, may be more responsive to early intervention.

Another approach may be to combine behavioural, psycho-educational therapy with pharmacotherapy, or the use of medicine to target the symptoms of autism.¹⁶ However, after children have experienced many months, or years of atypical interactions and development, it could be difficult for medication, by itself, to lead directly to the acquisition of critical developmental milestones such as language or social cognition. Medication may boost the ability of children with autism to participate in social learning by addressing some of the symptoms of autism, or by reducing secondary complications that may impede learning (e.g. gastroenterological disturbance). However, for longer-term effects a period of psycho-educational developmental remediation may be needed in conjunction with pharmacotherapy. Understanding the synergism of behavioural and medical treatments for autism, while very carefully considering the risks of pharmacotherapy in young children, is an important goal for future research.

The previous summaries also did an excellent job of describing the outstanding contemporary work on identifying the core psychological and neurodevelopmental processes involved in autism. In conjunction with these summaries, it may be useful to distinguish several additional issues. First, since autism is often associated with mental retardation and social learning processes, there remains a considerable need to understand

the associations among autism, IQ and learning. Second, because autism occurs much more frequently among boys than girls, it is important to pursue theory and research linking autism to gender-related neuro-hormonal and neurodevelopmental processes¹⁷ while recognizing that similar gender-related processes may also contribute to other forms of developmental pathology.¹⁸ Finally, understanding individual differences in autism may lead to greater clarity in genetic, neuro-anatomical, early identification, and intervention research. Here, it may be important to consider not only the possibility that autism may have varied etiological paths, but also that moderating factors may refract autism into important bio-behavioural variations.¹⁹

Implications for Policy and Services

Given the number and talent of the research teams now working on autism worldwide, it is likely that advances will continue in understanding, identifying and treating this disorder. These advances will have social-policy and related service provision implications. For example, it makes little sense to improve early identification methods without also systematically improving access to appropriate early intervention programs. The numbers of children referred to such programs may well exceed the current highest prevalence estimate for autism (1:200) because optimal early identification systems tend to over-identify (accept errors of commission) rather than use too narrow a definition and miss children in need (accept errors of omission). Providing the supports for such services will require considerable political will and resources within all nations. Early service provision may be cost-effective, though, relative to the tremendous expenditures associated with the long-term care of children and families affected by autism who do not receive early treatment. For example, the lifetime costs of medical, behavioural and education treatment for children with autism in the United Kingdom have been estimated at up to 2.4 million Pounds Sterling for many children or more than \$4 million U.S.²⁰ However, the cost savings of early intervention have been estimated at between \$656,000 and \$1,082,00 per individual with autism between the ages of three and 55 years.²¹

Rather than a cure, it is likely that a significant shift toward higher IQs and verbal abilities may be among the best outcomes of early identification and intervention for autism.²² Although we do not yet know enough about these higher-functioning children with autism (HFA), many will likely continue to require services in the elementary and secondary school years to maintain progress in social development and avoid maladaptive social emotional outcomes.²³ Research leading to the development of services for these children may become an important new focus for the field. Finally, the need to develop the types of training that allow more impaired children with autism to make the transition to adaptive adult roles in society remains unmet and constitutes a vital social policy issue.²⁴

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Autism Intervention

SANDRA L. HARRIS, PhD

Rutgers, The State University of New Jersey, USA

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Topic

Autism

Introduction

Early intensive intervention has a significant impact on the functioning of many young children with autism. It enables some to be full participants in the regular education system, while others, despite substantial progress, are still left with significant symptoms. Although educational and language gains are easier to achieve than social/emotional skills, there has been important progress in modifying complex interpersonal behaviours as well. Research has documented significant improvements in social/emotional behaviours for young children with autism following intensive treatment.

Subject

Difficulties in social/emotional functioning are intrinsic to the diagnosis of autism. These include problems with the use of non-verbal behaviours such as eye-to-face gaze and the communicative use of gestures, facial expressions and body posture. Young children with autism have problems developing age-appropriate friendships and may have minimal motivation to do so. They are challenged in demonstrating joint attention (using coordinated vocalization, eye contact and gesture to draw someone's attention to an object or responding to these behaviours by another), and may not bring, show or point out objects that interest them. Recent research indicates it is possible to measure and track some of these behaviours in infants and toddlers at risk for autism¹. As a group, young children show a limited capacity for empathy or understanding that their view of the world differs from others².

Problems

Difficulties in the social and interpersonal attunement of the young child with autism make interactions with others a stressful challenge. They seem to prefer isolated activity, standing by and watching others, or engaging in problematic behaviours rather than in social interaction.² Children with autism interact less with, and keep a greater distance from, their peers. They also spend more time in seemingly purposeless behaviour than do other children.² Appropriate social behaviour does not come without active teaching and even then, their social skills may retain a lack of ease that distinguishes them from their peers.

Research Context

Studies of the effects of intervention on the social/emotional behaviour of young children with autism have employed two approaches. One uses group designs with a comparison of two or more different treatments to assess the impact of intervention. The other uses single-subject designs, most often a reversal or multiple baseline design, in which a small number of participants are systematically exposed to two or more different conditions to examine the impact on skill acquisition. In a reversal design, a baseline condition is followed by the treatment, then a return to baseline and, if it was effective, a return to the treatment condition. In a multiple baseline design, a treatment is systematically evaluated across several different children, settings or behaviours, one at a time. Studies of social/emotional behaviour are most often done in small group settings or classrooms appropriate to the skill being taught, although some private “coaching” may occur prior to entering the group.

Key Research Questions

The first tier of research questions concerns techniques to teach the fundamentals of the broad gamut of social skills to young children with autism. The more complex questions concern how to teach these skills to ensure their generalized use with many people in many contexts, to enhance the child’s ability to use the skills fluently and to learn new skills from observation of peers.

Recent Research Results

Lovaas³ performed the most influential group study of the outcome of early intensive Applied Behaviour Analysis (ABA) intervention of children with autism. Although that study did not describe systematic assessment of social/emotional functioning, it did report that among children who received ABA intensive treatment, nearly half achieved normal educational and intellectual functioning. A long-term follow-up of participants who had achieved this good initial outcome was done in early adolescence and examined social and emotional functioning.⁴ Nine children who were classified as “best-outcome” during the initial study continued to show average levels of intelligence and adaptive functioning and, with the exception of one youngster, were described as “normal-functioning.” This research suggests that some, but not all, children receiving intensive behavioural intervention showed major social gains.

One important thread of social-skills teaching has focused on the role of peers. This work shows that physical proximity alone is insufficient to support interactions, but when peers learn to encourage social behaviours from the children with autism, there are beneficial effects.⁵ McGee⁶ et al. taught typical preschoolers to request responses from the child with autism and to praise appropriate behaviours during free play. Initial adult support can be used to teach children with autism to begin an interaction^{7,8} or teach a peer to initiate to the child with autism⁶ and then adult intervention is faded because continued intrusion has an adverse impact on the child-to-child exchange.⁹ In a kindergarten-wide intervention, Laushey and Heflin¹⁰ arranged a peer buddy system that included two children with autism such that each child in the class had a different “buddy” every day. The children, including the youngsters with autism, were taught to stay close to, talk to and play with their buddy each day. This system, which eliminated the stigma that might

be attached to being the only child with a buddy, increased positive social interactions of the children with autism and increased the likelihood that they would generalize their behaviour with all of their peers, rather than a select few.

Among the factors that impact on social behaviour are ensuring that the child has the necessary skills for a particular play activity, teaching the child with autism how to initiate and respond to a peer, and training peers to persist in efforts to join with the child with autism². Beyond the basic teaching methods for young children used in ABA, other specific instructional methods that are beneficial for learning social behaviours include pivotal response training,¹¹ in which key behaviours like social initiations or independent responding are taught, and script-fading, in which a child is given a written, auditory or pictorial script to follow.¹² Hwang and Hughes,¹³ in a review of the literature on social interactive training with young children, found that the use of time delay in which an adult waits a few seconds before offering a prompt to respond, environmental arrangement in which materials are arranged to facilitate interaction, the use of naturally occurring reinforcement inherent in the activity, and contingent imitation (copying) of the child may all serve to enhance the child's interaction with an adult. Bernard-Opitz and colleagues¹⁴ demonstrated the feasibility of computer-assisted instruction to teach preschool-aged children with autism to generate increasing numbers of alternative solutions to social problems.

Conclusions

There is modest evidence to document the benefits of early intensive intervention for the acquisition of generalized use of appropriate social and emotional skills by children with autism. Many group studies have failed to include social and emotional functioning as an outcome measure, perhaps because of the complexity of measuring these skills. Most of the single-subject research looking at discrete social skills has found ABA teaching methods helpful in teaching children with autism initiations and responses to other children, specific play skills and other behaviours that lend themselves to behavioural measurement. Regardless of the theoretical orientation of the intervention, there is a need for long-term, rigorous studies tracking the development of social and emotional skills in young children who participate in intensive treatment.

Implications

Early intensive treatment should include a social/emotional component integrated through the day, as well as having specific planned "lessons." Much of toddlers' early interaction is with adults, but intervention should include systematic involvement with children the same age or slightly older who are able to follow simple directions for engaging the child with autism. For preschool-aged children, such exposure should be expanded as rapidly as possible given the child's level of functioning. Multiple peers should be used, and supported in making social approaches as well as teaching the child with autism how to initiate to peers and reciprocate their social bids. Not every child with autism will be ready for extended child-to-child interaction, but issues of communication, management of challenging behaviours and increasing awareness of others may be precursors to peer-related play.

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AUTISM

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The Effect of Early Intervention on the Social and Emotional Development of Young Children (0-5) with Autism

***YVONNE E.M. BRUINSMA, M.A., ROBERT L. KOEGEL, PhD
& LYNN KERN KOEGEL, PhD***

University of California at Santa Barbara, USA

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Topic

Autism

Introduction

Autism is an increasingly common severe developmental disability that affects three major areas of development: communication, socialization and behaviour/play. Child outcomes vary from child to child and may depend heavily on the age at which intervention begins, since children who start intervention prior to or at age three have significantly better outcomes compared to older children.^{1,2,3}

Subject

A growing body of literature suggests that early intensive intervention may greatly enhance outcomes for children with autism. Studies on the effects of behaviourally oriented interventions with preschoolers with autism have documented positive short- and long-term effects.^{1,4-9} These outcomes have ranged from partial to nearly complete remediation of symptoms^{1,6,7,10-13} (the most optimistic figures suggest approximately a 50% complete recovery with intensive early intervention), with progress sometimes defined in terms of gains on standardized pre-post test scores and sometimes in terms of behavioural outcomes. Furthermore, although early estimates suggested only half of all children would learn to use functional speech,¹⁴ more recent estimates based on children who participated in early intervention indicate that at least as many as 85 to 90% of children with autism can learn to use functional speech if intervention begins in the preschool years.¹⁵⁻¹⁷

Problems

Difficulty with reciprocal social interactions lies at the heart of the autism disorder and is therefore an important goal of early intervention. However, since most interventions focus on child-adult interactions, relatively few studies to date have focused on improving social competence in peer groups and with siblings.¹⁸ A second issue emerging from the literature is that early intervention outcome measures need to better reflect a child's true functioning in his or her natural environment. Some studies have included only changes in IQ scores and post-intervention placements, but these obviously would be of more value if they included social and behavioural measures.¹⁹ Finally, relatively

few studies on the effects of early intervention have been published to date that include children under three years of age, since it has only recently become more common for practitioners to diagnose autism prior to age three.

Research Context

The effects of early intervention are usually studied through single subject design studies. To date, few controlled group studies have been published.^{20,21} Recently, some studies that have begun to follow children over longer periods of time have depicted children's developmental trajectories during baseline and intervention, possibly providing supplemental valuable information.^{22,23}

Key Research Questions

One of the key questions emerging from the literature is the identification of child characteristics that predict not only outcomes, but which type of intervention is the best match for that particular child.²⁴ Similarly, some researchers are beginning to identify parent characteristics or skills that may be more conducive to child progress.²⁵ Finally, as more children are included in regular education preschools, researchers are beginning to identify early intervention target behaviours reflective of child functioning within inclusive school settings, and to compare these behaviours to those of typically developing peers in similar settings.^{6,20}

Recent Research Results

Child characteristics that have been most frequently studied in terms of outcome are age and IQ at entry into program. These studies suggest that an earlier age and a higher IQ at the beginning of intervention may be predictors of better outcomes.^{26,2} More recently, the child's level of peer social avoidance (meaning how often the child actively avoids being near peers) was identified as a significant predictor of intervention outcome in terms of language use and peer avoidance after six months of intervention.²⁷ Other studies have shown significant associations between a child's use of joint attention behaviours (such as eye gaze alternation and pointing) and later expressive language development.²⁸ Finally, Koegel and colleagues²⁹ demonstrated that child initiations (defined as the child beginning a new interaction or changing the direction of an interaction) at program entry predicted highly favourable treatment outcomes. Interestingly, these last three target behaviours, peer avoidance, joint attention and initiations, could be viewed as highly similar in nature. Such studies may further help to identify important, even pivotal, intervention target behaviours.

The current literature is also beginning to identify parental characteristics and skills that could augment the impact of early intervention. A large body of literature exists that supports the use of parent education as a way to relieve stress and empower parents. Parental optimism, as well as the amount of stress a parent is experiencing as a result of the child's disability,³⁰ may be important factors in a child's outcome. Another parental behaviour that has been identified as influential is parental sensitivity in terms of following the child's focus of attention.²⁵ This study showed that higher levels of following the child's lead were associated with better joint attention and better language use. Finally, research shows that it may be important to teach parents in a partnership

model rather than in a clinician-directed format.³¹ For example, Brookman-Frazee showed that parent affect is higher and parental stress lower during parent education sessions that use a partnership model.³⁰

Several studies have begun to investigate early intervention outcomes for children in inclusive school settings. Stahmer and Ingersoll²² report comprehensive outcomes on standardized assessments as well as communication skills, social interaction skills and play skills of 20 children with autism in an inclusive setting, with 90% of children using a functional communication system at exit compared to 50% at entry. McGee and colleagues³² reported on improvements in proximity of the child with autism to typical peers, with 71% of children showing improvement on this measure. A recent study by Koegel and colleagues¹⁸ showed that compared to typical peers, children with autism interacted just as much with adults in the classroom, but that they rarely interacted with other children. However, Koegel and colleagues²⁹ showed that children with autism could be taught to initiate interaction with adults and peers and that overall outcomes for these children were much better than for children with autism who initiated at low levels.

Conclusions

Research is beginning to identify child and parent variables related to outcomes for very young children with autism. These studies are important because they may provide us with valuable information about possible pivotal child behaviours, such as child initiations. It appears from the current body of literature, for example, that it is extremely important to teach a child to initiate interaction with peers and adults so that the child can create his or her own learning opportunities throughout the day. Furthermore, the current literature suggests support for parent education and parent empowerment in a partnership model to help relieve stress and help parents feel more optimistic about their child's outcome. Finally, the current data lend support for an inclusive school model, even for very young children with autism. Over time and with intervention, these children benefit from typical peer proximity, especially if they are taught to initiate towards them.

Implications

The primary implication for policy-makers is the need to support early intervention. Diagnosis at 18 months, or shortly after, increases the likelihood that intervention can begin earlier and that outcomes will improve. The fear of labelling a child less than three years old is understandable; however, withholding much needed specialized treatment may have extensive and long-term consequences for not only the child, but also the child's family and community. Moreover, the current outcome research for children with autism suggests that with appropriate and specialized intervention, children with autism can thrive in their families, communities and regular education preschools. It is up to us as a community to make it possible.

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Autism Intervention: Comments on Harris¹, and Bruinsma, Koegel and Kern Koegel

PETER SZATMARI, MD

JO-ANN REITZEL, PhD, C. Psych

*Offord Centre for Child Studies
McMaster University, CANADA*

(Published online February 2, 2005)

Topic

Autism

Introduction

The autism spectrum disorders are among the most serious of all childhood conditions and include autism, Asperger Syndrome and Pervasive Developmental Disorder (not otherwise specified). The condition is more common than previously thought and affects one in 165 children between birth and six years of age.¹ The outcome is poor² and the cost to both society and the family is enormous.³ In addition, the stress experienced by parents is considerable,⁴ especially as they search for a cause for their child's disability and an effective treatment that can alter that long-term outcome.

It is encouraging to note that there is now evidence that there are behavioural treatments for children with Autism Spectrum Disorders (ASD) that can lead to improvements in socialization, communication and cognitive abilities. The two reviews by Harris, and Bruinsma, Koegel and Kern Koegel nicely summarize and build upon data that are consistent with the National Research Council Canada's⁵ recommendations for educating young children with autism. Both papers emphasize that early intervention for ASD children is needed and must start as early as possible. There is good scientific evidence that behavioural and educational intervention lead to gains in cognitive and language development and help compensate for some of the core deficits associated with the disorder. The outcome measures employed in studies have included cognitive, language and adaptive behaviour and behavioural measures and to a lesser extent, social and emotional measures.

However, these two reviews also emphasize that many questions remain unanswered. It is known that children's outcomes are variable in response to treatment; some children make substantial gains while others make slow progress. Very little is known about the child or family characteristics associated with this variation in outcome. Age and IQ seem

¹ Comments on original paper published by Sandra L. Harris in 2004. To have access to this article, contact us at cedje-ceecd@umontreal.ca

to be important, but beyond that little is known. Harris and Bruinsma et al. recognize the difficulties with social-emotional functioning that children with autism experience. There are some single-subject design studies indicating that children with autism are able to learn to respond to and initiate social interactions with others, including peers, but the impact this will have on their development is yet unknown.

Harris emphasizes that children with autism need direct teaching in social and interpersonal skills. She clearly advocates for social inclusion programming with typical peers. Single-subject research has shown that specific social skills can be taught. Harris highlights the work of McGee, who taught young peers to request responses from children with autism, and Laushey and Heflin, who designed a peer buddy program to increase positive social interactions and increase the opportunities to generalize the skills to others. Specialized instructional methods such as script-fading, time delay and pivotal response training have been studied and used to teach necessary skills for play activities and found to be effective with some children. It is good to see an emphasis on social-emotional functioning as an outcome for SD children that is not mentioned in the reviews and that can have an impact on the implementation of these programs on a community-wide basis. It is important to remember that there is only a single Randomized Control Trial (RCT) that shows that approximately 25 hours per week of early Intensive Behavioural Intervention (IBI) is more effective than parent training. This study, by Smith Groen and Wynn,⁶ had a small sample size (N=28) and did not include children with ASD who also had severe developmental disability (i.e. IQ less than 35). This means that it is impossible to calculate the actual degree of treatment effect from the other studies. In the absence of an RCT, any estimate of increase in IQ points in response to treatment is likely to be biased by the assignment of children to treatment or control groups. It is also not possible to compare this level of intensity or duration with other levels of intensity since only one level was compared to little or no treatment. Finally, it is not possible to generalize the findings to ASD children with severe developmental disability – that is, those with IQ below 35. Bruinsma et al. base their conclusions on the efficacy of early intervention on the several cohort studies and many single case studies that have been published, which is perfectly acceptable. But the lack of randomized controlled trials leads them to rely on these studies in an attempt to identify many child and parent characteristics associated with a better outcome. To be fully confident about the validity of these conclusions, these variables need to be tested as a priori hypotheses in RCTs.

It is also extremely important to draw a distinction between efficacy and effectiveness.⁷ Efficacy refers to evidence that a treatment works in the highly confined conditions of a lab setting, where there is strict control over who is admitted to the study, how well-trained the therapists are and how well the treatment is implemented. Effectiveness refers to how well a treatment works in community settings, where the conditions are very different. In effectiveness studies, inclusion criteria are very broad, therapists are trained as usual, and the treatment is implemented as it would be under normal circumstances. In this context, it may not be possible to ask a family to participate in 40 hours of treatment a week for four years. Neither review makes this important distinction.

Many questions remain; most studies lack measures that are sensitive to changes in social and emotional functioning. There is also a need for longitudinal studies of the impact of Intensive Behavioural Intervention across the lifespan. It is also important to emphasize that there are a range of interventions for children with ASD with strict ABA type discrete trial training that focus on teaching across all developmental domains at one end and more child-initiated developmental interventions that focus on social-communication skills at the other. Both are behavioural in the sense that complex cognitive and social skills are broken down into their component parts and are taught, but the methods of teaching are different. There is less evidence that these developmental methods are effective at present, but for some higher-functioning children this may be more cost-effective treatment than 40 hours a week of ABA for three to four years.

Implications

It is important to realize that children with ASD have a very severe developmental disability. Policy-makers must be aware that they have complex needs that may require a range of treatments and these must be distributed across the lifespan, not just concentrated in the early years so that there are no funds left over for school-aged children, adolescents and adults. Admittedly, there are fewer studies of interventions at older levels and these must be a priority for researchers.

It is certainly true that the field is progressing and it is no longer an issue whether intensive early intervention based on behavioural methods makes a difference. One of the key research goals must be understanding what form of treatment is most effective for what type of child at what developmental stage for what outcome goals. We have made a start in achieving this understanding but we have a long way to go. In the mean time, clinical judgment should rest on the solid foundation of available evidence and guide public policy while we wait for the new research to come in.

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