

Early intervention for children with autism



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Autism is a neurobehavioural disorder characterized by impairment of social relatedness, delayed and disordered communication, and restricted, perseverative and stereotypic behaviour patterns occurring in young children. It has a major impact on the lives of children and their families. The manifestations of this disorder vary between children and within an individual child over time. The current understanding of this disorder is of an autism spectrum with degrees of involvement from mild to severe. From a conservative analysis of existing data, the prevalence of autism spectrum disorder is reported at 27.5/10,000. This is comprised of a prevalence of 10/10,000 for autism, 15/10,000 for pervasive developmental disorder – not otherwise specified (PDD-NOS) and 2.5/10,000 for Asperger syndrome (1). These prevalence figures are higher than those reported 30 years ago. Current epidemiological data are insufficient to determine whether factors other than a broadening of the definition and better public awareness of autism disorders are responsible for this increase (1). The studies reviewed in this statement involve primarily children with autism, with four studies (2-5) involving children with autism and PDD-NOS. Autism or autism spectrum disorder is a disorder of abnormal brain development, the basis of which is largely genetic (6). The evidence does not suggest a causal association with measles-mumps-rubella vaccination (7).

Treatment for autism has become an important public policy issue, with parents advocating for funding of comprehensive treatment programs and challenging governments through the courts. Funding agencies and policy-makers should critically appraise the literature on early intensive teaching and behavioural programs for children with autism to make informed decisions about service provision.

OBJECTIVE

The objective of this statement is to briefly describe the main educational interventions (programs) that are intended to result in global improvement in autism and to review the status of the evidence regarding their effectiveness. Behavioural techniques that limit their aim to changing specific areas of functioning in autism will not be reviewed. There is ample evidence in the psychology literature that these focal treatments can decrease certain behaviours such as escape of self-injurious behaviours, and improve specific

skills such as eye contact, symbolic play or peer interactions (8). On the other hand, intensive educational programs are intended to result in global improvement and to improve the long-term outcome in children with autism. Early comprehensive intervention programs are intensive and costly, and most require significant parental commitment.

SEARCH STRATEGY

MEDLINE and PsychINFO databases were searched for the period of 1995 to September 2003 for human studies in English using the medical subject headings of autistic disorder, early intervention, education, behaviour therapy, Lovaas method, TEACCH (Treatment and Education of Autistic and Communication Handicapped Children) and applied behaviour analysis.

REVIEW OF THE LITERATURE

The use of the term early intensive behavioural intervention is somewhat variable but is usually intended to describe the Lovaas method of autism treatment. The Lovaas method is based on the field of applied behavioural analysis. The premise behind the Lovaas method is that behavioural intervention can build positive behaviours such as language, and suppress unwanted behaviours such as self-stimulatory or aggressive behaviours in young autistic children. Lovaas contends that the younger the child, the greater the likelihood that learning is generalized. Learning is maximized by intense treatment provided by the child's caregivers over most waking hours for two to three years. The Lovaas method is an operant-conditioning behavioural model in which desired behaviour is positively reinforced and unwanted behaviour is ignored or punished. The primary technique used is discrete trial training consisting of presentation of a stimulus, followed by the child's response and the consequence. The Lovaas study (9) followed 19 children with autism under 46 months of age who underwent a university-based two- to three-year program of 40 h per week of treatment administered by therapists and families. The experimental group was compared with a control group that received 10 h or less of one-on-one treatment and a second control group that did not receive any treatment from the intervention program. By the end of the study, the experimental group had a mean IQ gain of 30 points higher than

the control group. In addition, 47% of the early intensive behavioural intervention group were in regular school compared with none in either of the control groups. These gains were maintained over a seven-year follow-up (10).

There are several deficiencies in this study. Group assignment was not random, but was instead based on therapist availability. This raises the question of whether the experimental and control groups were indeed equivalent. The study did not compare two different therapies but rather different levels of intensity of the same treatment, and treatment implementation was inadequately documented. The children received a variety of different assessment tests rather than a uniform assessment protocol. In addition, selection IQ criteria may have been too restrictive, resulting in a group with an unusually favourable prognosis. Finally, follow-up measures were limited to IQ and classroom placement, which may have missed residual deficits. Therefore, the Lovaas study does not meet criteria for an empirically supported treatment. The results need to be interpreted cautiously.

Other researchers have studied the outcome of children treated with the Lovaas model and reported positive outcomes (for a thorough review see Rogers [8]). As a group, these studies show that the children who received intensive therapy for a minimum of 15 h to 20 h per week for one to two years had greater functional gains than controls who received no extra treatment. In Birnbrauer and Leach's study (2), the treated children had significantly higher nonverbal IQ scores and language levels after two years of treatment. The weaknesses of this study included nonrandom group assignment, nonrigorous diagnosis or description of diagnostic process, and lack of documentation of treatment fidelity. Sheinkopf and Siegel (3) showed in a retrospective case control study that the mean IQ of the treatment group was 25 points higher than the control group and that the treated group had lower symptom severity. There was no documentation of diagnostic criteria or treatment integrity. The observed IQ difference between groups was largely based on measures of nonverbal ability, which some argue to be inappropriate because nonverbal ability is a relative strength for many children with autism. Anderson et al's study (11) used a pre-post test design and did not have a comparison group. Results showed a significant increase in language abilities, social functioning and self care skills. Developmental rates during treatment were higher than pretreatment rates, but no tests of statistical significance were reported. In addition, the expected rate of developmental change was not considered. All children in these three studies continued to fall within the spectrum of autism.

The methodologically strongest study of the Lovaas method to date is Smith et al's (4) trial involving 28 young children (mean age of three years) with autism and PDD-NOS. This study had a true experimental design, with children randomized into intensive treatment or parent training groups, and it included more higher functioning children compared with Lovaas' original study. Children in

the treatment group received 30 h per week of discrete trial training over an approximate one-year period followed by more naturalistic teaching in a classroom for one to two years. Fewer requirements were placed on parents than in the original Lovaas study. Children in the parent training group received Lovaas treatment administered by their trained parents for 5 h per week and 10 h to 15 h of instruction in special education classes. At follow-up, at seven to eight years of age, the intensive treatment group outperformed the parent training group with a mean IQ gain of 16 points in the intensive treatment group versus no reported IQ gain in the parent training group. In addition, the treatment group did relatively better in visual spatial skills, language and academics, but not in adaptive functioning or behaviour problems. The treatment group had less restrictive school placements. The children with PDD-NOS had outcomes at least as positive as those obtained by the children with autism. The IQ gains of the treatment group as well as the proportion of children placed in regular classes without special services is about half of that reported in the children from Lovaas' study. The study does suffer from a small sample size, as well as a lack of a standardized diagnostic instrument and follow-up diagnostic assessment.

The optimal age for involvement in an early intensive treatment program is unclear. Most published studies that demonstrated treatment efficacy involved children younger than 48 months (3,4,6,9,11). One study (12) compared the outcome of children who entered a comprehensive treatment program at younger than 60 months to a group that started at older than 60 months of age. The researchers found that 67% of the early treatment group versus 11% of the late treatment group were able to reside at home with parents and attend public school. However there was no pretreatment data reported in this study to ensure that the groups were developmentally equivalent at the start. Another study (13) found that younger age (mean of 46 months) at treatment entry was predictive of being in a regular education class after discharge, whereas older age at intake (mean of 54 months) was predictive of placement in a special education classroom. The question of optimal age for involvement in a comprehensive treatment program requires further examination.

Parents are involved in treatment with most of the comprehensive programs for autism. However the effectiveness of parent-mediated treatment is not known. A recent review (14) identifies two methodologically-sound studies which address this question. One of these is the Smith et al study (4) in which an intensive treatment group receiving 30 h per week of Lovaas treatment was compared with a parent training group in which children received Lovaas treatment from their parents for 5 h per week in addition to 10 h to 15 h in special education classes. As noted, the intensive treatment group outperformed the parent training group on measures of intelligence, visual-spatial ability, language and academic achievement. The only results favouring the parent training group were that of parental perception that the children had less work

and less stress, and an increase in the parents' knowledge of autism. Another study (5) compared a parent group with training in behaviour analysis, empathy and problem behaviour training with community daycare of 20 h per week. The community daycare group had the support of a child care worker and the day-care centre received programming assistance for children with special needs. Results showed short-term language improvements in children in the parent group and an increase in the parents' knowledge of autism. Both studies have small sample sizes and are not directly comparable because of different intervention and outcome measures. Larger-scale, randomized, controlled trials comparing parent-mediated and therapist-mediated treatments are needed. Short- and longer-term outcomes should be used, and the emotional and economic impact of having parents administer treatment needs to be examined.

An alternative approach to Lovaas' discrete trial training is that of 'normalized teaching'. Discrete trial training involves highly structured sessions in which the child and teacher are seated and the pace is set by the teacher. The stimuli preceding a response opportunity are chosen by the teacher and presented repeatedly until there is the desired consistency of response. In contrast, 'normalized teaching' involves loosely structured sessions that occur during the child's play and are paced by the child. The child chooses which stimuli will precede a response opportunity, and thus, these vary from session to session. Delprato (15) has reviewed eight single case studies and two group comparison studies comparing discrete trial training and normalized interventions in language-impaired children with autism. Results show that in the eight studies with language criterion responses, normalized training was more effective than discrete trial training. It has been hypothesized that discrete trial training may be more effective at teaching the acquisition of language whereas normalized teaching may be more effective in achieving generalization of these skills or functional use of language (15).

Other models for intensive autism treatment include LEAP (Learning Experiences...An Alternative Program for Preschoolers and Parents), Floor Time and TEACCH. These programs will be briefly described here but not critiqued because of a paucity of controlled trials.

The underlying focus of the LEAP program is the child's social development. This is an inclusive classroom-based program which runs 3 h daily, year round. Developmentally appropriate practice and applied behavioural analysis techniques are employed and typically-developing peers are used in modeling and encouraging appropriate behaviour.

The Floor Time program centers around normalized treatment. Parents and therapists follow the child's play and interests while creating situations that will address their developmental goals. This program is home-based and intervention is typically made up of eight or more 20 min to 30 min sessions per day.

The long-term goal of the TEACCH program is for the child with autism to function optimally in society as an

adult. In contrast to other programs, it provides a lifelong continuum of services for individuals, families and service providers. The TEACCH program uses applied behavioural analysis and is based on a structured teaching approach in which environments are organized with clear, concrete visual information. Parents are co-therapists and home-programming is a cornerstone. These and other comprehensive programs for children with autism are thoroughly reviewed elsewhere (8,16).

The recommended amount of intervention with all of these programs ranges from 15 h to 40 h per week and programming is individualized. These treatment programs are in a preliminary phase of investigation. All of the studies lack control group comparison, with the exception of one study of the TEACCH program (17) in which children receiving structured teaching home programs were compared with matched peers receiving discrete trial training in a regular day treatment program. This study showed that the children with the TEACCH home program did better on all outcomes. The study was flawed by nonrandom group assignment and testers who were not blinded to group assignment. None of these treatment models have been compared with one another.

SUMMARY AND RECOMMENDATIONS

Autism is a lifelong neurobehavioural disorder that requires a specialized approach to treatment. The quality of the studies on educational treatment programs for children with autism are suboptimal. However the studies do show a trend toward showing a positive outcome from intervention. There is no evidence to support adopting a single autism treatment program as the gold standard.

Due to the complex nature of children with autism and the importance of defining the best interventions possible, there is a great need for well-designed and implemented studies in this area. Research is needed to further clarify the common effective elements of treatment programs. Studies should involve children across the full spectrum of autism. The optimal age and IQ range of children, optimal intensity, duration of treatment and parental involvement, as well as the magnitude of effectiveness of these programs, need to be determined. Consensus is required on the outcome measures that will most accurately reflect change in functioning. Direct comparison of the various intensive treatment programs is needed. The questions of whether gains will be long-term or whether there are multiple effective approaches or complementary approaches to intervention in autism need to be answered.

Although evidence of efficacy of educational treatment programs for autism is weak, the studies to date do suggest some guiding principles that may be of use in planning treatment. Given the available information, it would appear reasonable to set a target of a minimum of 15 h a week of structured, individualized teaching. The family should be involved in service provision, and there should be ongoing program evaluation and adjustment to meet the child's needs (16,18).

Physicians, educators and families should work together to plan rational, individualized treatment to enable the child with autism to reach his or her potential. Resources must be sufficient and accessible to address the complex issues related to this disorder.

Finally, funded programs for children with autism should include a research arm to address the questions that remain about early intensive intervention programs.

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The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate.