



International Journal of Autism

E-ISSN: 2710-3927

P-ISSN: 2710-3919

IJRSE 2022; 2(1): 14-20

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www.rehabilitationjournals.com

Received: 11-01-2021

Accepted: 16-02-2021

Sumbul Akhlaque Khan

Assistant Professor,

HI Department, Ashtavakra

Institute of Rehabilitation

Sciences and Research, Delhi,

India

Management of children with autism spectrum disorder (ASD)

Sumbul Akhlaque Khan

Abstract

Pediatricians have an important role not only in early recognition and evaluation of autism spectrum disorders but also in chronic management of these disorders. The primary goals of treatment are to maximize the child's ultimate functional independence and quality of life by minimizing the core autism spectrum disorder features, facilitating development and learning, promoting socialization, reducing maladaptive behaviors, and educating and supporting families. To assist pediatricians in educating families and guiding them toward empirically supported interventions for their children, this report reviews the educational strategies and associated therapies that are the primary treatments for children with autism spectrum disorders. Optimization of health care is likely to have a positive effect on habilitative progress, functional outcome, and quality of life; therefore, important issues, such as management of associated medical problems, pharmacologic and non-pharmacologic intervention for challenging behaviors or coexisting mental health conditions, and use of complementary and alternative medical treatments, are also addressed.

Keywords: Management, educational strategies, alternative medical treatments, medical problems, interventions, tantrums

Introduction

Autism Spectrum Disorder' refers to a neuro-psychological condition typically appearing in the first three years of life that significantly affects a person's ability to communicate, understand relationships and relate to others, and is frequently associated with unusual or stereotypical rituals or behaviors. "Autism" means a condition of uneven skill development primarily affecting the communication and social abilities of a person, marked by repetitive and ritualistic behaviour.

Indicators: In the case of specific learning disabilities, the sub categories such as dyslexia, dysgraphia and dyscalculia each have certain similarities, although no two specific learning disabled persons are similar. While in the case of Autism, all persons who fall in this category have issues in the following three areas, namely

- Social impairment
- Communication difficulties
- Repetitive and stereotyped behaviors

Yet their intelligence may vary and the behaviour issues may also vary over a large range or spectrum. Hence now Autism is also referred to as autism spectrum disorder (ASD) as their symptoms vary over a large spectrum or range. The symptoms and the severity vary widely across these three core areas. Taken together, for some who are on the high functioning end of the autism spectrum, it may result in relatively mild challenges. For others, symptoms may be more severe, as when repetitive behaviors and lack of spoken language interfere with everyday life. In the case of severe autism the behaviors associated with autism are easily evident, yet those on the lower end of the spectrum do not necessarily have immediately identifiable symptoms. Thus those who have high-functioning autism may find life even more difficult. Their symptomatic behavior are often misunderstood as bad behavior.

- The main difficulties for people on the autism spectrum are social. They have difficulty reading social cues and thus often make mistakes in understanding the reactions of other people. For example they may stand too close, without realizing that the other person is uncomfortable. On the other hand they may not make eye contacts as they are uncomfortable with it. They do not realize the importance of eye contacts while interacting with people.

Correspondence

Sumbul Akhlaque Khan

Assistant Professor,

HI Department, Ashtavakra

Institute of Rehabilitation

Sciences and Research, Delhi,

India

Thus, people with autism are too often misunderstood and even bullied. In some cases, children with ASD, even before their first birthday become overly focused on certain objects, rarely make eye contacts, and fail to engage in typical back-and-forth play and babbling with their parents. Other children may develop normally until the second or even third year of life, but then start to lose interest in others and become silent, withdrawn, or indifferent to social signals. Loss or reversal of normal development is called regression and occurs in some other children with ASD.

Communication

Each person with ASD has different communication skills. Some people can speak well. Others can't speak at all or only very little. About 40% of children with an ASD do not talk at all. About 25%–30% of children with ASD have some words at 12 to 18 months of age and then lose them. Others might speak, but not until later in childhood.

Social Behavior

Social issues are one of the most common symptoms in all of the types of ASD. People with ASD do not have social "difficulties" like shyness. The social issues they have cause serious problems in everyday life. These social issues are very independent of the individual's age.

Repetitive and Stereotyped Behavior

Many people with ASD have unusual interests or behaviors. Repetitive movements are actions repeated over and over again. They can involve one part of the body or the entire body or even an object or toy. For instance, people with ASD might spend a lot of time repeatedly flapping their hands or rocking from side to side. They might repeatedly turn a light on and off or spin the wheels of a toy car. These types of activities are known as self stimulation or "stimming."

People with ASD often thrive on routine. A change in the normal pattern of the day—like a stop on the way home from school—can be very upsetting to people with ASD. They might "lose control" and have a "melt down" or tantrum, especially if in a strange place.

Some people with ASD also may develop routines that might seem unusual or unnecessary. For example, a person might try to look into every window of a building he or she walks by or might always want to watch a video from beginning to end, including the previews and the credits. Not being allowed to do these types of routines might cause severe frustration and tantrums.

- Gets "stuck" doing the same things over and over and can't move on to other things
- Shows unusual attachments to toys, objects, or routines (for example, always holding a string or having to put on socks before pants)
- Spends a lot of time lining things up or putting things in a certain order
- Repeats words or phrases (sometimes called echolalia [pronounced ek-oh-LEE-lee-uh])

Types of ASD (Autism Spectrum Disorder)

According to varying level of severity, some of the types of ASD include

- Autistic Disorder, sometimes known as "classic autism". This manifests as significant language delays,

social and communication challenges, and unusual behaviors. There may be additional learning difficulties and below-average intelligence as well.

- Pervasive Developmental Disorder – not otherwise specified (PDD-NOS), also known as "atypical autism" – these individuals meet some of the criteria for autistic disorder or Asperger syndrome, but not all. Symptoms may be fewer and milder. There may be social and communication challenges
- Asperger Syndrome (AS) – Symptoms are milder than classical autism. There are social challenges and unusual behaviors. There may be typically no language problems or intellectual disability. However, some areas of language development may be affected. They may typically have problems with understanding humor or figures of speech. Some children have particular skills in areas that require logic, memory and creativity, such as maths, computer science and music. The mildest form of autism, Asperger's syndrome (AS), affects boys three times more often than girls. Children with AS become obsessively interested in a single object or topic. They often learn all about their preferred subject and discuss it nonstop. Their social skills, however, are markedly impaired, and they are often awkward and uncoordinated
- Asperger's syndrome is mild compared to other ASDs. Also, children with AS frequently have normal to above average intelligence. As a result, some doctors call it "high-functioning autism." As children with AS enter adulthood, though, they are at high risk for anxiety and depression.

Educational Interventions

Education has been defined as the fostering of acquisition of skills and knowledge to assist a child to develop independence and personal responsibility; it encompasses not only academic learning but also socialization, adaptive skills, communication, amelioration of interfering behaviors, and generalization of abilities across multiple environments. Physicians and other clinicians are often in a position to guide families to empirically supported practices and help them evaluate the appropriateness of the educational services that are being offered.

Comprehensive Programs for Young Children

In the last 2 decades, research and program development in the area of educational intervention have focused largely on very young children with ASDs because of earlier identification and evidence that early intensive intervention may result in substantially better outcomes. Model early childhood educational programs for children with ASDs have been described in thorough reviews. These model programs are often categorized as behavior analytic, developmental, or structured teaching on the basis of the primary philosophical orientation. Although the approaches have important differences, they also overlap. For example, contemporary comprehensive behavioral curricula borrow from developmental or cognitive approaches (such as addressing joint attention, reciprocal imitation, symbolic play, and theory of mind and using indirect language stimulation and contingent imitation techniques), and some developmental models (eg, the Denver model) and the structured teaching approach of the Treatment and Education of Autistic and Related Communication

Handicapped Children (TEACCH) program use behavioral techniques to fulfill their curriculum goals.

Although programs may differ in philosophy and relative emphasis on particular strategies, they share many common goals, and there is a growing consensus that important principles and components of effective early childhood intervention for children with ASDs include the following:

- Entry into intervention as soon as an ASD diagnosis is seriously considered rather than deferring until a definitive diagnosis is made;
- Provision of intensive intervention, with active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate educational activities designed to address identified objectives;
- Low student-to-teacher ratio to allow sufficient amounts of 1-on-1 time and small-group instruction to meet specific individualized goals;
- Inclusion of a family component (including parent training as indicated);
- Promotion of opportunities for interaction with typically developing peers to the extent that these opportunities are helpful in addressing specified educational goals;
- Ongoing measurement and documentation of the individual child's progress toward educational objectives, resulting in adjustments in programming when indicated;
- Incorporation of a high degree of structure through elements such as predictable routine, visual activity schedules, and clear physical boundaries to minimize distractions;
- Implementation of strategies to apply learned skills to new environments and situations (generalization) and to maintain functional use of these skills; and
- Use of assessment-based curricula that address:
 - Functional, spontaneous communication;
 - Social skills, including joint attention, imitation, reciprocal interaction, initiation, and self-management;
 - Functional adaptive skills that prepare the child for increased responsibility and independence;
 - Reduction of disruptive or maladaptive behavior by using empirically supported strategies, including functional assessment;
 - Cognitive skills, such as symbolic play and perspective taking; and
 - Traditional readiness skills and academic skills as developmentally indicated.

Specific Strategies

A variety of specific methodologies are used in educational programs for children with ASDs. Detailed reviews of intervention strategies to enhance communication, teach social skills, and reduce interfering maladaptive behaviors have been published in recent years. Brief descriptions of selected methodologies are provided below

Applied Behavior Analysis

Applied behavior analysis (ABA) is the process of applying interventions that are based on the principles of learning derived from experimental psychology research to systematically change behavior and to demonstrate that the interventions used are responsible for the observable

improvement in behavior. ABA methods are used to increase and maintain desirable adaptive behaviors, reduce interfering maladaptive behaviors or narrow the conditions under which they occur, teach new skills, and generalize behaviors to new environments or situations. ABA focuses on the reliable measurement and objective evaluation of observable behavior within relevant settings including the home, school, and community.

Structured Teaching

The TEACCH method, developed by Schopler and colleagues, emphasizes structure and has come to be called "structured teaching." Important elements of structured teaching include organization of the physical environment, predictable sequence of activities, visual schedules, routines with flexibility, structured work/activity systems, and visually structured activities. There is an emphasis on both improving skills of individuals with ASDs and modifying the environment to accommodate their deficits. Several reports have documented progress in children who have received TEACCH services as well as parent satisfaction and improvement in parent teaching skills, but these reports were not from controlled studies of treatment outcomes.

Developmental Models

Developmental models are based on use of developmental theory to organize hypotheses regarding the fundamental nature of ASDs and design approaches to address the deficits. The Denver model, for example, is based largely on remediating key deficits in imitation, emotion sharing, theory of mind, and social perception by using play, interpersonal relationships, and activities to foster symbolic thought and teach the power of communication. This program has shifted from a center-based treatment unit to service delivery in homes and inclusive school environments. Several studies have demonstrated improvements in cognitive, motor, play, and social skills beyond what would be expected on the basis of initial developmental rates in children who are treated according to the Denver model, but controlled trials are lacking.

Speech and Language Therapy

A variety of approaches have been reported to be effective in producing gains in communication skills in children with ASDs. Didactic and naturalistic behavioral methodologies (eg, DTT, verbal behavior, natural language paradigm, pivotal response training, milieu teaching) have been studied most thoroughly, but there is also some empirical support for developmental-pragmatic approaches (eg, Social Communication Emotional Regulation Transactional Support, Denver model, RDI, Hanen model).

People with ASDs have deficits in social communication, and treatment by a speech-language pathologist usually is appropriate. Most children with ASDs can develop useful speech, and chronologic age, lack of typical prerequisite skills, failure to benefit from previous language intervention, and lack of discrepancy between language and IQ scores should not exclude a child from receiving speech-language services. However, traditional, low-intensity pull-out service delivery models often are ineffective, and speech-language pathologists are likely to be most effective when they train and work in close collaboration with teachers, support personnel, families, and the child's peers to promote functional communication in natural settings throughout the day.

The use of augmentative and alternative communication modalities, including gestures, sign language, and picture communication programs, often is effective in enhancing communication. The Picture Exchange Communication System (PECS) is used widely. The PECS method incorporates ABA and developmental-pragmatic principles, and the child is taught to initiate a picture request and persist with the communication until the partner responds. Some nonverbal people with ASDs may benefit from the use of voice-output communication aids, but published evidence for these aids is scant. Introduction of augmentative and alternative communication systems to nonverbal children with ASDs does not keep them from learning to talk, and there is some evidence that they may be more stimulated to learn speech if they already understand something about symbolic communication.

Social Skills Instruction

There is some objective evidence to support traditional and newer naturalistic behavioral strategies and other approaches to teaching social skills. A social skills curriculum should target responding to the social overtures of other children and adults, initiating social behavior, minimizing stereotyped perseverative behavior while using a flexible and varied repertoire of responses, and self-managing new and established skills, social skills groups, social stories, visual cueing, social games, video modeling, scripts, peer-mediated techniques, and play and leisure curricula are supported primarily by descriptive and anecdotal literature, but the quantity and quality of research is increasing. A number of social skills curricula and guidelines are available for use in school programs and at home.

Occupational Therapy and Sensory Integration Therapy

Traditional occupational therapy often is provided to promote development of self-care skills (eg, dressing, manipulating fasteners, using utensils, personal hygiene) and academic skills (eg, cutting with scissors, writing). Occupational therapists also may assist in promoting development of play skills, modifying classroom materials and routines to improve attention and organization, and providing prevocational training. However, research regarding the efficacy of occupational therapy in ASDs is lacking. Sensory integration (SI) therapy often is used alone or as part of a broader program of occupational therapy for children with ASDs. The goal of SI therapy is not to teach specific skills or behaviors but to remediate deficits in neurologic processing and integration of sensory information to allow the child to interact with the environment in a more adaptive fashion. Unusual sensory responses are common in children with ASDs, but there is not good evidence that these symptoms differentiate ASDs from other developmental disorders, and the efficacy of SI therapy has not been demonstrated objectively. Available studies are plagued by methodologic limitations, but proponents of SI note that higher-quality SI research is forthcoming. "Sensory" activities may be helpful as part of an overall program that uses desired sensory experiences to calm the child, reinforce a desired behavior, or help with transitions between activities.

Medical Management

Children with ASDs have the same basic health care needs

as children without disabilities and benefit from the same health-promotion and disease-prevention activities, including immunizations. In addition, they may have unique health care needs that relate to underlying etiologic conditions, such as fragile X syndrome or tuberous sclerosis, or to other conditions, such as epilepsy, that often are associated with ASDs. Those with pica or persistent mouthing of fingers or objects should be monitored for elevated blood lead concentrations, particularly if the history suggests potential for environmental exposure. These health care needs are most appropriately met within the context of a medical home.

To deliver appropriate and effective medical care, the history, approach to the patient, physical evaluation, and treatment options must be considered in the context of the patient's ASD. Familiarizing the patient with the office setting and staff, allowing ample time while talking before touching the patient, allowing the child to manipulate instruments and materials, keeping instructions simple, using visual cues and supports, slowing down the pace, exaggerating social cues, and having family and/or familiar staff available may be helpful in reducing the obstacles to health care provision presented by patients' difficulties with social interaction, communication, and accepting novelty. Often, more time is required for outpatient appointments. In a nationally representative sample, it was found that children with ASDs spent twice as much time with the physician per outpatient visit compared with children in control groups.

Evaluation of Challenging Behaviors

Problematic emotional reactions and behaviors such as aggression and self-injury are common in children and adolescents with ASDs. In some cases, medical factors may cause or exacerbate maladaptive behaviors, and recognition and treatment of medical conditions may eliminate the need for psychopharmacologic agents. For example, in the case of an acute onset or exacerbation of aggressive or self-injurious behavior, a source of pain or discomfort may be identified and treated. Sources of discomfort may include otitis media, otitis externa, pharyngitis, sinusitis, dental abscess, constipation, urinary tract infection, fracture, headache, esophagitis, gastritis, colitis, allergic rhinitis, and others. When behavioral deterioration is temporally related to menstrual cycles in an adolescent female, use of an analgesic or oral or injectable contraceptive may be helpful. Obstructive sleep apnea may contribute to behavioral deterioration and may be amenable to weight reduction, tonsillectomy and adenoidectomy, or continuous positive airway pressure. Extreme food selectivity has the potential to lead to protein-calorie malnutrition or specific vitamin or mineral deficiencies; however, most studies that evaluated nutritional status in children with ASDs have suggested that despite dietary selectivity, malnutrition is uncommon. Although the prevalence in children with ASDs is unknown, pica related to iron or zinc deficiency may respond to supplementation with the appropriate mineral. It should be noted that it is not clear how frequently medical factors cause or exacerbate serious maladaptive behaviors in children with ASDs, and the efficacy of these interventions is based on anecdotes, case reports, and conventional clinical practice rather than empirical support from clinical trials.

It is also important to consider environmental factors that

may precipitate challenging behaviors. Parents, teachers, or other caregivers may inadvertently reinforce maladaptive behaviors, and in such cases, the most appropriate and effective interventions are behavioral. In some instances, a mismatch between educational or behavioral expectations and cognitive ability of the child is responsible for disruptive behavior (eg, when the diagnosis of mental retardation has not been recognized), and adjustment of expectations is the most appropriate intervention. In both situations, a functional analysis of behavior, completed by a behavior specialist in the settings in which the problems occur, will identify factors in the environment that exacerbate or maintain the problematic behavior. A strategy for intervention through behavioral techniques and environmental manipulations can then be formulated and tested.

Family Support

Management should focus not only on the child but also on the family. Although parents once were viewed erroneously as the cause of a child's ASD, it is now recognized that parents play a key role in effective treatment. Having a child with an ASD has a substantial effect on a family. Parents and siblings of children with ASDs experience more stress and depression than those of children who are typically developing or even those who have other disabilities. Supporting the family and ensuring its emotional and physical health is an extremely important aspect of overall management of ASDs.

Physicians and other health care professionals can provide support to parents by educating them about ASDs; providing anticipatory guidance; training and involving them as co-therapists; assisting them in obtaining access to resources; providing emotional support through traditional strategies such as empathetic listening and talking through problems; and assisting them in advocating for their child's or sibling's needs. In some cases, referral of parents for counseling or other appropriate mental health services may be required. The need for support is longitudinal, although the specific needs may vary throughout the family life cycle. One of the chief strategies for helping families raise children with ASDs is helping to provide them with access to needed ongoing supports and additional services during critical periods and/or crises. Natural supports include spouses, extended family members, neighbors, religious institutions, and friends who can help with caregiving and who can provide psychological and emotional support. Informal supports include social networks of other families of children with ASDs and community agencies that provide training, respite, social events, and recreational activities. Formal supports include publicly funded, state-administrated programs such as early intervention, special education, vocational and residential/living services, respite services, Medicaid, in-home and community-based waiver services, Supplemental Security Income benefits, and other financial subsidies. The breadth and depth of services vary, even within the same state or region. Few services exist in many rural areas, and public programs may have long waiting lists.

Sibling support groups offer the opportunity to learn important information and skills while sharing experiences and connecting with other siblings of children with ASDs. Although the research on support groups for siblings of children with disabilities is difficult to interpret because of

study-design problems and inconsistent outcome effects on sibling adjustment, these groups generally have been evaluated positively by participating siblings and parents, and there is some evidence of beneficial effects for siblings of children with ASDs.

Because each state has organized its services and access mechanisms differently, physicians and families must learn their own state's unique rules to access supports by contacting the state or county offices of the states' Department of Health and Human Services or Mental Health and Mental Retardation or the state developmental disabilities organization. In addition, local parent advocacy organizations, national autism and related developmental disability organizations, early intervention administrators, and school district special education coordinators often are knowledgeable about various programs and their respective eligibility requirements.

Treatment

No cure exists for autism spectrum disorder, and there is no one-size-fits-all treatment. The goal of treatment is to maximize your child's ability to function by reducing autism spectrum disorder symptoms and supporting development and learning. Early intervention during the preschool years can help your child learn critical social, communication, functional and behavioral skills. The range of home-based and school-based treatments and interventions for autism spectrum disorder can be overwhelming, and your child's needs may change over time. Your health care provider can recommend options and help identify resources in your area. If your child is diagnosed with autism spectrum disorder, talk to experts about creating a treatment strategy and build a team of professionals to meet your child's needs. Treatment options may include:

- **Behavior and communication therapies:** Many programs address the range of social, language and behavioral difficulties associated with autism spectrum disorder. Some programs focus on reducing problem behaviors and teaching new skills. Other programs focus on teaching children how to act in social situations or communicate better with others. Applied behavior analysis (ABA) can help children learn new skills and generalize these skills to multiple situations through a reward-based motivation system.
- **Educational therapies:** Children with autism spectrum disorder often respond well to highly structured educational programs. Successful programs typically include a team of specialists and a variety of activities to improve social skills, communication and behavior. Preschool children who receive intensive, individualized behavioral interventions often show good progress.
- **Family therapies:** Parents and other family members can learn how to play and interact with their children in ways that promote social interaction skills, manage problem behaviors, and teach daily living skills and communication.
- **Other therapies:** Depending on your child's needs, speech therapy to improve communication skills, occupational therapy to teach activities of daily living, and physical therapy to improve movement and balance may be beneficial. A psychologist can recommend ways to address problem behavior.
- **Medications:** No medication can improve the core

signs of autism spectrum disorder, but specific medications can help control symptoms. For example, certain medications may be prescribed if your child is hyperactive; antipsychotic drugs are sometimes used to treat severe behavioral problems; and antidepressants may be prescribed for anxiety. Keep all health care providers updated on any medications or supplements your child is taking. Some medications and supplements can interact, causing dangerous side effects.

Conclusions

ASDs are chronic conditions that affect nearly 1 of every 150 children and require ongoing medical and nonmedical intervention. There is a growing body of evidence that supports the efficacy of certain interventions in ameliorating symptoms and enhancing functioning, but much remains to be learned. In addition to their important roles in identifying ASDs through screening and surveillance, establishing the diagnosis, conducting an etiologic evaluation, and providing genetic counseling after a diagnosis is made, pediatricians and other primary health care professionals are in a position to provide important longitudinal medical care and to support and educate families and guide them to empirically supported interventions for their children.

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