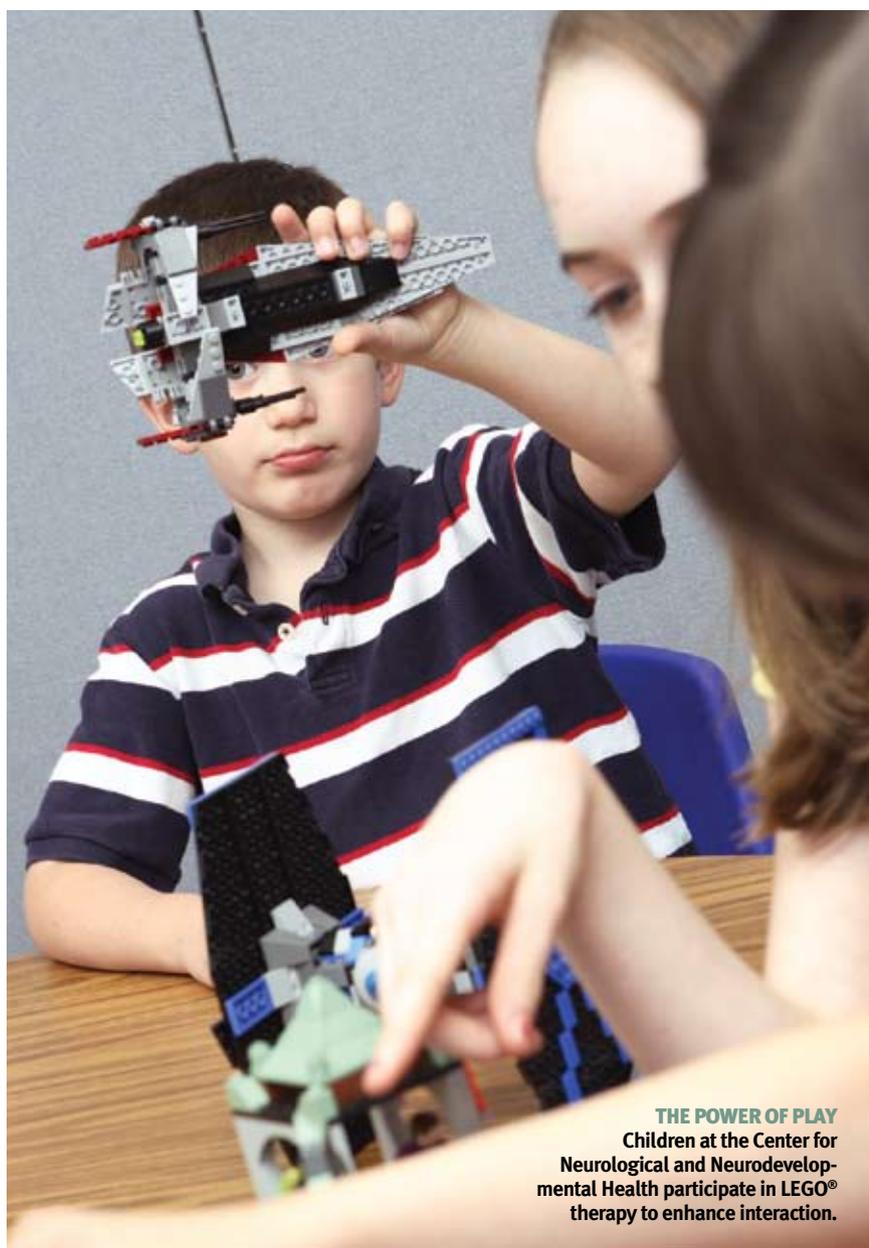


Early Intervention in Autism

Researchers are finding that early diagnosis and treatment of autism spectrum disorders can help children flourish.

BY DEBRA GORDON, M.S.



THE POWER OF PLAY
Children at the Center for
Neurological and Neurodevel-
opmental Health participate in LEGO®
therapy to enhance interaction.

By the time the girls were 18 months old, Matt Cherry and his wife knew something wasn't right. Their twin daughters Lyra and Sophia were severely delayed in their language development. Sometimes Lyra exhibited strange behavior, like flapping her arms. The girls couldn't complete simple tasks such as taking off their socks or using a fork. They began speech and occupational therapy four times a week each. A few months later, the twins were formally diagnosed with autism spectrum disorder (ASD). Autism spectrum disorders are characterized by three core deficits: problems with relating socially; difficulty communicating and with language; and restrictive, repetitive patterns of behavior, activities, or interests. The disorders occur along a spectrum, with variability within and across the three areas of deficit.

Lyra and Sophia began attending a special pre-school for children with ASD. There, they receive intensive support through applied behavior analysis (ABA), an evidence-based therapy that uses a reward system to encourage appropriate and discourage inappropriate behavior (see box, "Early Intervention: What's It All About").

One year later, both girls have progressed significantly in terms of their speech and ability to listen, cooperate with instruction, and learn. They are even ahead of their non-autistic peers in some areas, such as reciting the alphabet, and counting to 40. "We are so relieved that the girls received early intervention," says Cherry, who lives in Albany,

CHARACTERISTICS OF AUTISM BY AGE

OBSERVABLE AT 6-12 MONTHS

- ▶ Poor eye contact
- ▶ Passive in social interactions
- ▶ Little facial expression, smiling, and/or emotional control when interacting with others
- ▶ Delayed babbling, infrequent vocalization, and decreased object manipulation
- ▶ Abnormal movements, little variety of movement in exploring new objects, poor muscle tone and motor coordination

OBSERVABLE AT 9-14 MONTHS

- ▶ Infrequent or delayed response when name is called
- ▶ Infrequent monitoring of the direction of other's gaze
- ▶ Infrequent response to others' pointing gestures
- ▶ Infrequent attempts to point out or show objects of interest
- ▶ Infrequent smiling at others paired with eye contact
- ▶ Low variety of speech sounds and gestures during communication attempts
- ▶ Delayed language development
- ▶ Low variety of actions on toys
- ▶ Infrequent vocalization paired with eye contact
- ▶ Repetitive behaviors and interests
- ▶ Unusual sensory responses, such as being unable to tolerate the feel of grass on bare feet

OBSERVABLE AT 20-24 MONTHS

- ▶ Infrequent imitation of others' actions
- ▶ Minimal display of interest in other children
- ▶ Infrequent attempts to share with others
- ▶ Limited range of facial expression
- ▶ Infrequent offering of comfort to others
- ▶ Low variety of words produced
- ▶ Repetitive behaviors
- ▶ Restricted interests
- ▶ Unusual sensory responses

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NY. "It has made a huge difference. They may both overcome this early disadvantage to a significant degree."

When it comes to kids with ASD the operative word these days is "early": early diagnosis—possibly as young as 1—and early treatment. The cost of intervention is typically covered under the Individuals with Disabilities Education Act.

The average age of diagnosis for autism is 6, even though the American Academy of Pediatrics recommends that all 18- and 24-month-olds be screened for ASD and other developmental delays. Later diagnosis doesn't preclude treatment and progress; says Catherine Lord, Ph.D., who directs the University of Michigan's Autism and Communication Disorders Center and chaired the Early Intervention in Autism Committee for the National Academy of Science. But the reality is that the earlier they start, the better.

THE "PLASTIC" BRAIN

The reason for the emphasis on early intervention is simple: neuroplasticity, or the ability of the brain to form new connections. While this ability remains throughout life, "there are sensitive periods in brain development where the brain is most ready and has the greatest capacity to alter the way it designs itself based on the kinds of experiences the child is exposed to," says Rebecca Landa, Ph.D., director of Kennedy Krieger Institute's Center for Autism and Related Disorders in Baltimore, MD.

"We know that experience can change brain function and brain development," explains Dr. Lord. "So the idea is that a child with autism has underlying deficits that affect the information they take in from the world; and if we can modify that, we may be able to minimize the effects of ASD."

Studies have found that 13-year-olds who received 20 or more hours of therapy

during early childhood were likely to be closer in age-equivalent scores than their peers who received little or no treatment. In addition, verbal skills for children who received one form of speech therapy through age 5 improved at a faster rate over the following seven years than children who received little or no such therapy.

Dr. Landa and her group are following a group of children who began intervention at age 2 and are now 6. "The findings are so striking," she says. "Good intervention definitely alters the course of development."

It may even erase the signs of autism altogether. A 2007 study evaluated children who were diagnosed around age 2 and received any of a variety of early interventions, including speech, behavioral, occupational, and special education. By age 4, just slightly more than half the children met the diagnostic criteria for autism and just seven out of 10 remained on the autism spectrum. However, notes Dr. Lord, it is not typical of what has been seen in other studies. In one study her team conducted, one out of 80 children with autism at age 2 had moved higher on the ASD spectrum by age 9, and about 20 percent of those had moved out of the spectrum.

Another researcher tracking what she calls "optimal outcomes" in children with autism is University of Connecticut Professor Deborah Fein, Ph.D., who presented research at the Annual International Meeting for Autism Research in Chicago on children with autism who by age 9 no longer met the diagnostic criteria for autism. "What Debbie Fein presented are the best-outcome cases," says Dr. Landa. "Everyone working in the field has kids like this in their caseload. We know this phenomenon exists, but it is not linked to any specific intervention."

"We can't say one is better than the other," says Dr. Lord, because there are no well-designed studies comparing the different approaches to each other.

STARTING EARLY
As part of the 1-year-old intervention program at Kennedy Krieger, specialists regularly use outdoor equipment for teaching a variety of play, social, and communication skills. Here, two girls were encouraged to join their friend on the see-saw.

AUTISM PREVENTION?

“Everyone believes that the earlier we identify autism, the more we can change it,” says Dr. Lord.

But how early is early? To find out, Drs. Lord, Landa, and others are focusing their efforts on the siblings of children with autism, who have a nearly 20-fold increased risk of the disease compared to siblings of children without autism.

What if you could track those siblings from birth and diagnose them around 1 year of age? Would early intervention at 12 or 14 months slow or even reverse the disease’s progression?

Using home videos of infants and toddlers later diagnosed with ASD, researchers developed a set of criteria that can be used to evaluate babies as young as 6 months old (see box, “Autism Characteristics By Age”).

Some siblings of children with autism who later develop autism themselves show signs of ASD—passivity, an inability to sit independently, low muscle tone, problems with fine and gross motor ability—as young as six months of age. Others, as Dr. Landa’s research demonstrates, show no unusual signs up to nine months (and sometimes later). However, at the one-year-old mark, the behavioral signs become more apparent. Children with ASDs begin to have readily apparent problems socializing and communicating. They also demonstrate repetitive patterns of behavior and interest. Using the criteria discussed earlier, Dr. Landa and other researchers have correctly diagnosed autism in children as young as 14 months.

But diagnosis is just the first step. What type of intervention do you design for a 1-year-old?

One that incorporates teaching for both child and parents. At Kennedy Krieger, the program for one-year-olds has three primary goals: strengthen parents’ emotional ability to cope with a special needs child;



Early Intervention: What’s It All About?

Autism experts agree that intervention should begin early, but not on what form it should take. The bottom line is that the intervention should be designed to fit the child rather than forcing the child into a specific model, says Mark Mintz, M.D.

BEHAVIORAL APPROACHES: The core behavioral approach to intervention is applied behavior analysis (ABA). It involves structured teaching, often on a one-to-one basis, in which children are rewarded for achieving certain goals, such as learning to look people in the eye or using a word to ask for an item instead of crying. Rewards range from M&Ms to a few minutes of playtime with a treasured toy. Carol Greenburg—a special-needs consultant and the mother of a 7-year-old boy with autism—explains: “In classic ABA, you want a certain behavior, so you give the child a couple of chances and then you reward the positive behavior.” Recordkeeping is crucial to the program. Therapists maintain detailed notes on everything from how long it took the child to exhibit the behavior to how long until he exhibits it with 80 percent reliability.

Forms of ABA include discrete trial training, in which tasks are broken into their smallest parts and taught individually; analysis of verbal behavior, which focuses on language as the core to all further learning; and pivotal response training, which focuses on certain key behaviors such as motivation, self-initiation, and responsiveness.

DEVELOPMENTAL APPROACHES: These interventions might include a behavioral focus on isolated skills or behaviors but downplay them in favor of an integrated approach, one based on a child’s current and ideal developmental stage. Developmental approaches emphasize social relationships and helping children learn to function in a “normal” environment. One such program is called “Floortime,” in which parents or other caregivers play with children in a natural way but also provide models and praise to help children play, interact, and communicate in appropriate ways.

Various aspects of both behavioral and developmental approaches can be combined with each other and/or with speech, occupational, physical, and social development therapies. In some cases, children may also need medication to facilitate the educational interventions and enhance their progress, or to target problems that don’t respond to behavioral approaches, says Dr. Mintz. These include anti-anxiety medications, alpha-adrenergic agonists, and beta-blockers to dampen exaggerated and impulsive responses to environmental stimuli; mood stabilizers such as antipsychotics; and stimulants (often used for symptoms of ADHD).

Why early? Because early in development, the brain has the **greatest capacity** to alter itself based on experience, says Rebecca Landa, Ph.D.

teach parents how to play and interact with their child to enhance appropriate skills; and develop the toddler's socialization and communication skills through a nursery school setting.

The study began a year ago, so there are no formal results yet. Nonetheless, says Dr. Landa, "We are seeing an amazing transformation in terms of the children's ability to engage socially, communicate, and play—and a huge transformation in the parents."

Such work on socialization in children with autism is vitally important, says Daniel B. LeGoff, Ph.D., a pediatric neuropsychologist and director of neuropsychology who, along with Mark Mintz, M.D., directs the Center for Neurological and Neurodevelopmental Health in New Jersey. The center is one of six Autism Centers of Excellence in the state. Dr. LeGoff created a LEGO® therapy to enhance interaction and communication in children with autism or other developmental disorders. Put simply, young kids learn to interact with one another while playing with the colorful plastic pieces.

"We're trying to teach children to be part of a peer group through naturalistic play," Dr. LeGoff says. He is also trying to teach children in a more "natural" environment than the reward-based small-group or one-on-one training that forms the core of most ABA programs. "You don't have to reward children to get them to play with LEGOs," says Dr. LeGoff. "It's a naturally reinforcing activity."

One study comparing children who received LEGO therapy with similar children who received non-LEGO social interaction therapy over three years found the LEGO group improved significantly more on scales rating social skills than the control group.

This "natural environment therapy," or, as Dr. LeGoff calls it, "new look in autism intervention," focuses on peers as models. It also emphasizes such naturally reinforcing activities as LEGOs and Dr. Landa's nursery school setting to encourage engagement. Some programs, including Dr. LeGoff's, also use "normal" peers to further the autistic child's integration. This approach is actually not new; peer models were used to mentor autistic children back in the 1970s. "They called it "the bossy girl" therapy," says Dr. LeGoff, because the peer was often a strong-willed girl happy to "work" for Skittles.

Carol Greenburg, the mother of a 7-year-old son with autism as well as a special education lay advocate who helps parents get the services their kids need, developed a similar program she calls "facilitated social inclusion." It involves training normally developing children to teach the autistic child how to play. It is one of several approaches she uses with her son, Arren, who was diagnosed at age 3-and-a-half. Her son, who used to barely respond to request to play from other children, now initiates play. Instead of the social isolation most autistic chil-

dren experience, Arren attends parties and play dates with both autistic and normally developing children.

Arren's parents, who live in Brooklyn, NY, began working with him in a home-based program until they found a private school, where he's been ever since. There, he receives one-on-one behavioral intervention along with home therapy. Today, the boy who used to only talk in memorized lines from his favorite TV show can ask for what he wants, follow directions, answer questions, and tell his mom where it hurts when he's sick. "We started seeing changes almost immediately" once therapy began, says Greenburg. He will continue at the school and with the therapy, says Greenburg, "as long as he needs and not a day longer."

THE COST

Carol Greenburg felt the services her local school district offered for her autistic son were inadequate. She and her husband paid the \$85,000-a-year tuition for their son's private school and sued the school board for reimbursement. While they did receive some reimbursement, many parents don't. And they can't turn to their health insurance for help; according to the advocacy group Autism Speaks, just 14 states require insurers to cover medically necessary, evidence-based autism therapies. In the other states, the group says, insurers specifically exclude behavioral therapies from policies. The group is pushing for a federal law that would supersede state laws and require insurance companies to cover such therapies.

"No health care reform is adequate without recognition of autism," says Greenburg. "It's a medical/neurological condition and the fact that it's not covered by insurance is a disgrace." NN

THE GENETICS OF AUTISM

While we don't know what causes autism, it is clear that the disorder has a strong genetic component. Researchers first suspected this when they looked at the high rates of autism in identical twins and siblings of children with the disease. Nearly 30 genetic regions linked to autism have been identified so far, and experts predict the number will be higher. Having these genes doesn't mean a child will have autism; but interactions between the genes and the environment that trigger changes the genes—or turn certain genes on and others off—likely contribute to the disease. Many of those interactions may occur in the womb.