



Nancy Alspaugh-Jackson



Crusader for Autism Treatment

When former television producer Nancy Alspaugh-Jackson took her adopted son, Wyatt, to the pediatrician for a checkup in 2004, she pointed out that the two-year-old had abruptly stopped talking and had begun to throw violent tantrums.

"My pediatrician knew virtually nothing about autism," Alspaugh-Jackson says. "He'd dismiss it by saying, 'Oh, boys, they're late talkers.'"

Shortly before her son's third birthday, however, a next-door neighbor noticed his behavior and said, "I think Wyatt is showing signs of autism." Alspaugh-Jackson called her pediatrician and reported what the neighbor had said, to which the doctor responded, "Since when did plastic surgeons' wives start diagnosing autism?"

After Alspaugh-Jackson raised the possibility of autism with her son's pediatrician a second time, he said Wyatt was due for his third-year checkup anyway, so she should bring him in. Afterwards, the doctor noted that Wyatt "was at least a year delayed," but still didn't diagnose autism.

"Then it was this wild goose chase for the diagnosis," the mother recalls, "which took another six months. At the end of the whole process, I remember

a particularly bad day when Wyatt threw a horrible tantrum for about an hour. He broke things. He scratched me. He bit me, and finally I was able to get ahold of him in my arms and rock him. I just prayed to God: 'If you can help me, if you help me figure this out, how to help my son, I'll do anything. I'll help other families.'"

Finally, Wyatt began receiving a form of therapy called Applied Behavioral Analysis, or ABA, which should be initiated within an autistic child's first two years. Wyatt was already four when his mother enrolled him. It started with an in-depth assessment. Once that is completed, behavioral-modification techniques are used to improve the child's skills in deficient areas. The lessons change as the child masters a given topic. For example, it may take one month for the child to understand labels, and another month to grasp concepts such as size or color. Wyatt's challenges were more related to interactions with other children: he got locked into repetitive behaviors that kept him from socializing. He wouldn't make eye contact, and his language skills atrophied.

Alspaugh-Jackson says, "It's almost as if you're taking somebody back and returning the brain. You're opening up those neuro-pathways. It makes every individual with autism better, and it recovers many. We're sold this myth that autism is incurable, and

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while we don't [say] that it can be cured, autism can be 'recovered' from."

Since psychiatrist Leo Kanner introduced the term "early infantile autism" in 1943, awareness of the condition has grown slowly. But over the past two decades in particular, the increase in the number of reported cases can be attributed to changes in diagnostic practices, referral patterns, availability of services, age at diagnosis, as well as public awareness.

For many years, autism was considered a psychological disorder, but experts now know that it's a neurological condition. They also know that the incidence of autism in a child is greater when the father is older than with the mother is older. One potential explanation is the known increase in mutation in older sperm.

Recent studies point to another possible explanation for autism: Compromised immune systems in those who develop the condition. So there may be a genetic piece to the puzzle, but it appears to be smaller than previously believed, which raises hope for the benefits of treatment.

In the past, many autistic children were considered hopeless, condemned to spend their lives in diapers, unable to brush their own teeth or dress themselves. Some autistic children have begun to make truly



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remarkable progress after just a few months of ABA treatment. For Nancy and Wyatt, the therapy has proved life changing.

In 1987, ABA's creator, Ole Ivar Lovaas, PhD, published a study indicating that, with his methods, autistic children could make a full recovery. Subsequent research has yet to reproduce his results. Lovass served as a mentor to Doreen Granpeesheh, PhD, when she was a graduate student at UCLA; she went on to become a supervisor at his facility, the UCLA Clinic for the Behavioral Treatment of Children, which remains committed to Lovaas's findings. Granpeesheh says she believes autistic children recover through ABA, because she has witnessed it time and time again.

"ABA depends on two things," Granpeesheh says. "One is good ABA. This means good therapy technique. What techniques do I use to shape a child who's nonverbal [until he or she can have the] completely normal conversation of a five-year-old? That's a lot of steps. If you know those techniques well, you can be a good behavioral analyst. The other side of effective ABA is knowing context. It's one thing to teach a child labels or colors; it's a little different level of complexity when you're teaching a child... about not being bullied, being assertive enough or having an appropriate conversation.



Joe Mantegna and Nancy Alspaugh-Jackson

“For example, if I teach a two-year-old child how to vocalize their needs and describe things in the environment, by the time that same child is five, I would have to teach them conversational skills. Conversational skills would be broken down into ‘who am I talking to?’ because there’s a difference between talking with a friend, an adult, or teachers. Is it formal or informal? What is my setting—school, home, casual, or in a supermarket? Is it one person or many? Am I listening to this person or am I just talking on about my own topic? Is my topic boring this person, based on their body language? There are 20 different aspects of conversation that would have to be taught.”

The higher levels of the ABA curriculum address social nuances that many of us could benefit from reviewing.

Many parents who take their children to the Tarzana, CA-based Center for Autism and Related Disorders (CARD) agree that ABA is life-changing. In fact, the US government recognizes ABA as the single most effective method of intervention for autism. Currently 31 states fund the treatment through health insurance.

The ABA program is both intensive and expensive: it requires children devote 40 hours a week to it, and costs about \$40,000 a year per child. To help families meet these demands, Granpeesheh formed a nonprofit

called ACT Today! which stands for Autism, Care, and Treatment Today. Many of the beneficiaries lack insurance coverage, so the board—many of whose members are parents and experts in the field—helps review applications and gives out grants directly to service providers.

Alspaugh-Jackson was so grateful for what CARD did for Wyatt that she wanted to give back in a big way. Now that Wyatt is on solid ground, Alspaugh-Jackson is honoring the promise she made to God to help others when she was so desperate for help herself. When she found out about ACT Today!, she immediately volunteered to help raise funds to support the organization. Drawing on her experience as a television producer, she organized events, set fundraising goals and managed logistics. She also leveraged her industry network, asking Leeza Gibbons of *Entertainment Tonight* and *Dancing With the Stars*’ Tom Bergeron to serve as hosts. She enlisted neighbors to donate items for auctioning. Before she knew it, she had orchestrated a successful backyard fundraiser in which tens of thousands of dollars were raised. Eventually, Alspaugh-Jackson was invited to join the board and today is executive director of the organization.

“In life, a lot of us have callings we never thought we would have,” Alspaugh-Jackson says. “I often say that I didn’t choose this path, it chose me.” She says she’s grateful to be able to contribute to such an important need, but is humbled by the scope of the problem. She recalls, for instance, a family in Uganda that ACT Today! assisted: “We helped bring a child here who was being tortured in his village; he was literally being beaten for having autism.” Alspaugh-Jackson worked through her church to obtain a visa for the boy so that he could come to the US for treatment. The child’s aunt told Alspaugh-Jackson that her nephew would’ve likely been killed had he not gotten out.

More and more, the community organizer recognizes how much there is that still needs to be done, but ACT Today!’s triumphs and the acknowledgements she gets from other parents keep her going. A smile spreads across her face as she explains: “I’ll get a letter from a therapist who works with a child and says, ‘This child has progressed more in the last six months with ABA therapy than in the last three years I’ve worked with him.’” ■ ABILITY

by John D. McMahon

act-today.org



Dr. Doreen Granpeesheh