

# Early Intervention in Deafness and Autism

## One Family's Experiences, Reflections, and Recommendations

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This article describes one family's experiences with the early intervention system in its treatment of their son, first diagnosed as deaf, later as autistic. Parents in both deafness and autism quickly find themselves mired in bitter disagreements, whether between sign language and speech advocates, or between believers in developmental versus behavioral approaches to autism. Experts in deafness, for all their squabbling, agree on early intervention's top priority: language. Specific methods and materials abound for teaching both sign and spoken language to deaf people. Autism intervention, dominated as it is by psychology/psychiatry gurus rather than educators, offers only the vaguest and the most schematic of intervention strategies. While often passed off as comprehensive curricula, these strategies fall far short of the specificity, practicability, and effectiveness of intervention materials for deaf children. Ultimately, parents realize that it is up to them to devise specific lessons for their children, and that it is up to all of us who work with autistic children directly—parents, teachers, and therapists—to compile, collectively, the truly comprehensive autism curriculum that we all so desperately need. **Key words:** *applied behavioral analysis, auditory-verbal, autism, cochlear implant, deafness, early intervention, floor time, sign language*

**T**HIS article will describe our personal experience with the early intervention (EI) system in its treatment of our son, first diagnosed as deaf, later as autistic. Neither the “deaf intervention” nor the “autism intervention” systems proved perfectly sensitive to our needs. Those areas in which the former differs from the latter, however, suggest ways in which autism intervention might be improved.

Experts in both deafness and autism are distracted by bitter disagreements between opposing camps, whether it's the sign language versus the speech advocates, or the developmental versus the behavioral psychologists. Not only does this prevent the experts from collaborating when they should, but it also affects parental choice. We, like many parents, saw some virtues in each camp, but when we tried to pick a la carte from their offerings we found once-friendly professionals now judging us as traitors or as bad parents.

In many ways, deafness is a more straightforward disability than autism. Experts, for all their squabbling, agree on both the key problem, inaccessibility to sound and speech, and the top priority of EI, teaching language. Specific, tried-and-true methods and materials abound for teaching both sign and spoken language to deaf people. Centers, clinics, and

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staff are abundant enough that we never waited long for their services. An empirically tested medical intervention for deafness has also emerged: the cochlear implant, which, for early implantees like our son, has proved to be a near-complete cure for deafness.

Autism, a much more recent diagnostic category, is far less straightforward. Experts still do not agree on the key problem, which leads to wildly different, mutually contradictory, intervention strategies. While those in different camps have outlined general approaches, none have provided materials as specific, and as clearly empirically effective, as those available for deaf intervention. As we quickly discovered, services are scarce and long waits are typical. Although every few months bring another claim of a miracle treatment, nothing approaching a scientifically proven cure has emerged.

Discouraging as it is that we haven't been able to cure our son's autism as we have his deafness, we accept that, as a far more complex disorder, it doesn't admit of easy solutions. What we found far less acceptable was the lack of specific intervention materials despite the many assurances that we kept hearing from professionals that these existed. One highly touted expert, book, or program after another turned out to offer little in the way of specific advice, specific treatment activities, or specific autism-focused curricula. Spoiled by all the specific teaching materials we'd found for deafness, we expected the same for autism.

Ultimately, we realized that the best way to intervene in our son's autism was to develop our own materials, and that the best source of existing ideas would come not from the high-level autism gurus, but from other parents of similar children and from the professionals—teachers and therapists—who work directly with them. With the autism gurus preferring philosophical debate to lesson planning, it's we "low-level" experts who should be compiling the comprehensive autism curriculum that we all so desperately need.

## **A BOY BETWEEN DEAFNESS AND AUTISM**

"He hears, but he doesn't know he hears."

We're sitting at a small table in a tiny therapy room at the Helen Beebe Clinic outside of Philadelphia—myself, Jane, the speech therapist, and Jason, my 2-year-old son. A moment in time: Jason peering under the table at the keys Jane has just jingled, me turning my head away from him to watch Jane's reaction, Jane uttering that strange sentence. I haven't realized it yet, but this moment marks a turning point.

It's been 5 months since Jason, born profoundly deaf, had his cochlear implant turned on; 3 months since he first turned toward the piano when I pounded out those chords; 1 month since he started making his soft, tentative vowel sounds. And now, for the very first time, we see him seeking and finding the source of a hidden noise. After more than 1½ years of silence, Jason is clearly, unequivocally factoring a new sense into his mental map of the world. Yet, Jane insists, "He hears, but he doesn't know he hears."

"But didn't you see him look under the table?"

How silly of me to ask: of course she did. But Jane is shaking her head at Jason, who is now looking off into the middle distance, his broad mouth ajar, his blue eyes glazed. Although she hasn't articulated it clearly, she has seen everything that I have, and more. Somehow witnessing Jason locate sound has squelched rather than rekindled the enthusiasm with which she first greeted him all those weeks ago. She now suspects something that will take me and my husband many months to discover.

At first we thought we could blame everything on Jason's deafness. Obsessively turning lights on and off, spinning things, staring at fans—this was how he had coped with silence, filling it with visual excitement; by the time sound arrived these habits were deeply ingrained. His social aloofness and frequent dazes were the lingering consequences of his first 9 months of life, before people realized

he was deaf and started using sign language—9 long months of isolation from so much human interaction. His still-limited vocabulary was both a relic of his delayed introduction to sign language, and an ongoing consequence of the clumsy signing of his rookie parents.

But now as Jason, through the miraculous technology of a cochlear implant, has gone from being deaf to being able to hear, and yet fails to tune in to people and absorb speech as Jane's other implanted clients do, she is the first to wonder. From this day forward she will sigh and shake her head, furrow her brow, lose steam, and address my son with an increasingly sad and subdued "Jason, Jason." More than the vague concerns that Jane's new attitude and oblique remarks start instilling in me, it's these signs in and of themselves, all these signs of this normally so optimistic and energetic woman giving up on my son, that will upset me the most.

### EI IN DEAFNESS

I hadn't expected our sessions at the Helen Beebe Clinic to be easy, but I thought our trials would be more pedagogical—a series of debates and dilemmas over auditory versus visual teaching methods. The late Helen Beebe, a pioneer in the auditory-verbal (A-V) approach to speech therapy, famously rejected sign language and lip-reading both as modes of communication and as therapeutic methods. Convinced that all deaf children have some residual hearing, which, amplified by hearing aids, suffices for mastering language through sound alone, she and her followers have argued that any signing or visual cueing will tempt the child away from the strict auditory regimen that is his only hope of functioning fully and independently in a world where communication is largely oral and visual cues are few and far between. Summing it up is the hallmark of an A-V training session: the black, face-sized screen that the therapist holds between her client's searching eyes and her own otherwise revealing lips.

Vociferously opposing A-V training are not only most people in the deaf community, but also the many educators and therapists who

consider sign language the only language fully accessible to profoundly deaf children. To them any speech-centered approach, particularly one that so completely rejects visual language, both undermines deaf culture and deprives the child of the only language he is capable of mastering. The teachers at the Pennsylvania School for the Deaf, whose signing-based EI program Jason had been attending since he was 9 months old, were no exception. When we let on that we'd be checking out the Helen Beebe Clinic, their faces filled with dismay. It was bad enough that we'd implanted Jason with a cochlear device; now it looked like we were doing what we assured them we would never do—abandon sign language and deaf culture.

"I'm really surprised that you're considering the Beebe Clinic."

"You're not giving up on sign language now, are you?"

"You're not planning to leave our program, are you?"

I couldn't fault our deaf friends for taking us to task, but it troubled me that some of our EI teachers, connected personally as well as professionally with the deaf community, stood in judgment, however diplomatically, as we navigated through this charged arena. I wanted to think of myself like any other parent, freely choosing among educational options—perhaps going whole hog for one approach, (eg, a "whole language" reading curriculum), or perhaps choosing a la carte (some "whole language"; some phonics)—without feeling pressure to explain myself to the professionals.

At first the dilemma between signing and speech seemed terribly forbidding. At stake was no less than Jason's intellectual, social, and professional future. Either approach by itself seemed doomed to fail him in key areas; combining them might yield the worst of both worlds. But then I remembered what my graduate work in linguistics had taught me about the popular notion that it's too confusing for very young children to learn several languages at once. This, in fact, has turned out to be

a myth. The multilingual child, while at first he or she learns more slowly and chaotically, soon catches up with his or her monolingual peers, with all the additional advantages of multilingualism.

For Jason, for any deaf child, I concluded, a heterogeneous strategy is best. Start him with sign language, the far easier and more accessible language, and add speech in a year or two when he's patient and disciplined enough to learn how to read lips, move his own mouth appropriately, make full use of his hearing aids, and, should hearing aids turn out not to yield enough useful sound, distinguish ambiguous lip movements through the manual cues of cued speech. Even after we'd learned how effective cochlear implants could be and decided to have Jason implanted, we stuck to bilingualism as the most robust, dependable strategy, though now Jason, if all went well, would learn his second language through sound alone.

It isn't just the individual professionals and their cultural and philosophical biases, but also the broader systems in which they work, that tend to discourage a bilingual approach to deafness. This, perhaps, is why deaf high school graduates, deficient in both the finer points of English grammar and the worldly knowledge that a more accessible language like sign would bring them, read on average at a third- or fourth-grade level. EI centers, like the grade schools their graduates attend, are typically either sign-based or speech based, and we parents have little choice within our designated school districts.

Our only recourse, then, is to supplement our publicly funded programs with private ones for which we must pay out of pocket. But private programs, able to turn down applicants, may hesitate to accept clients in EI programs whose philosophies they disagree with. When I looked into supplementing Jason's EI sessions at the Pennsylvania School for the Deaf with a speech-based EI class at a local private school, their admissions director told me: "If he's attending the Pennsylvania School for the Deaf and you're signing with him at home then that's a real problem. Our program is oral only." She'd have to think it over. How

narrow and patronizing, this second-guessing of me and of my child's best interests. What business was it of theirs what we did outside their building?

Were it not for a recent, dramatic shift in their philosophy, Jason's signing background would also have disqualified him from attending the Helen Beebe Clinic. Recognizing that many of the children newly implanted with cochlear implants attend signing-based EI programs, and that, despite this, their implants make them especially receptive to A-V training, the clinic had set up a separate "track" for implanted kids and, albeit grudgingly, allowed them to remain in their signing classes.

But among all these young implantees, Jason had by far the broadest, deepest background in sign language. While most deaf children aren't diagnosed until 1½ years, we'd found out he was deaf when he was 9 months old. Within months we'd hired a deaf, live-in nanny to immerse our family in sign language—something few parents can afford. Now, with the Helen Beebe Clinic's continued reservations about sign language in general and Jason's background in particular, I had to start second-guessing my decisions. Maybe deaf children, about whom there is so little data, are an exception to what I'd learned about multilingualism. Perhaps, even if they use implants, sign language still tempts them away from acquiring speech as readily as other young children learn their second languages. Could this be why Jason was falling behind? How I wished someone out there knew the answer.

Through Jason's first years up to this point, we'd enjoyed expert guidance. From the moment we set foot inside the Pennsylvania School for the Deaf, signing staff members greeted us with sign language classes, vocabulary lists, books, and videos. Teachers made home visits to show us how to integrate sign language into our home life, how to get Jason's attention, engage him in "sign play," read to him in sign language. A booklet of oral-auditory exercises from Jane at the Helen Beebe Clinic let me replicate what she did at home. For neither program did the philosophical debates and turf battles detract from

their main goal: educating and empowering the children and their parents.

And so, as it turns out, that moment in Jane's office marks another transition—from EI strategies based on education and detailed curricula, to strategies in which philosophical debate and vague theory hold sway over pedagogical specifics.

## THE SECOND DIAGNOSIS

Among all the EI specialists we worked with, it was Jane who knew her clients most intimately. In a private institution unaccountable to the state, free of the oversized classes and time-consuming paperwork that plagued the teachers at the Pennsylvania School for the Deaf, she spent nearly every working hour in intensive, one-on-one sessions with deaf children. Only she could begin to disentangle the overlapping symptoms of deafness and autism—social aloofness, delayed language, a predilection for visual stimulation. Only she could see just how Jason differed from his peers.

But what exactly she sees I never find out. Like so many parents in so many similar situations, I can only wish that everyone who suspects additional problems would be as direct with me as others were about deafness. Honesty couldn't possibly distress me more than Jane's mournful "Jason, Jason."

Or her sudden announcement, now, that the Helen Beebe Clinic requires its patients to undergo occupational therapy evaluations. Why did no one mention this earlier? Suspicious, I make the appointment anyway: accustomed to the informative content of Jason's speech and hearing evaluations, I hope to learn something new. But the nonsigning occupational therapist focuses more on me than on Jason, with a questionnaire about what he can and can't do, and her report, when I finally receive it, is little more than a summary of what I told her. Its most salient red flag: "Of concern is Jason's eye contact."

This inconclusiveness seems to be everywhere. There's our doctor's response to my reports from the Helen Beebe Clinic: "They're probably worried about something

called pervasive developmental disorder [PDD], which isn't as bad as it sounds and may simply mean social aloofness or eccentricity."

There are those parting remarks from Jane on her last day at the Helen Beebe Clinic: "He's tuning in more and more, and I'm not nearly as concerned as I was. But in case you need it, here's the phone number for that psychiatrist specializing in deaf children."

Most maddeningly, there is Jason himself—at times so alert and engaged, always clever, and understanding more and more spoken words; other times so dazed, unaware, and uncomprehending, especially of people.

Something finally tips the balance. I make my first call to the psychiatrist Jane recommended. Weeks pass before our insurance is cleared and the appointment set up. Months pass before the appointment day. Finally, the actual appointment, and again I expect to learn something.

"He does have a problem," the psychiatrist remarks, as she observes our 2<sup>1</sup>/<sub>2</sub>-year-old son crawling across her feet.

"What is it? Is he autistic? Does he have PDD?" I ask.

"I don't like labels" she replies.

We attend each successive appointment hoping to learn more. But the psychiatrist shines her psychotherapeutic stethoscope on us rather than on Jason. As it turns out, it is we, not she, who must serve as Jason's therapists. It's up to us to engage him and draw him out into our world. Her job, apparently, is to sit back and critique us. Unfortunately, since she hardly interacts with Jason herself, many of her criticisms are way off-base. Unaware of how little he understands, she insists we explain things to him that we simply cannot communicate.

Jason, meanwhile, has become so wild and unfocused that all of us who live and work with him grow desperate for supportive services—wraparound aids—to help manage his behavior at home and keep him on task at school. But services require diagnosis.

In fact we know the diagnosis. Since our psychiatrist wouldn't tell us, we've sought it out ourselves. We've read and read. We've

learned all about the hodgepodge of symptoms that constitute autism. We know that Jason shows enough of them to qualify as at least mildly autistic. But only a professional can make the official diagnosis it takes to get services.

When our psychiatrist finally agrees to put Jason's needs ahead of her distaste for labels, I hope she will include a prognosis and recommendations for treatment. All autistic children are different, and nothing we've read addressed Jason's specific case. Surely, after all these months, our psychiatrist, despite her limited interaction with him, knows him well enough to make some predictions. My hopes rise as I see just how long and comprehensive is the questionnaire that she is now putting us through. But her report, like that of the occupational therapist, turns out to be little more than a digest of our responses and descriptions—attached to the label PDD.

## **EI IN AUTISM**

Like other parents of multiply handicapped children dependent on sign language, we have little choice besides Jason's signing-based EI program. But his combination of deafness and PDD prove a blessing in disguise. For the Pennsylvania School for the Deaf surrounds him with socially typical classmates sharing both his normal intelligence and his one academic deficiency—language. Pure autism would have relegated him to the Philadelphia Public School System, to classrooms of children with similar or more severe mental and emotional challenges, few of them intellectual peers or social role models.

However, for all the creative initiative of his great teacher and equally wonderful wraparound aid, nothing in the formal classroom curriculum purports to address Jason's severe deficits in social reasoning and relatedness. Nothing, that is, until their conversion to Stanley Greenspan's Floor Time—an approach intended for all children, but in particular for kids with autism and PDD.

What looks serendipitous, however, is misfortune in disguise. For Floor Time amounts to little more than child-centered interactive

play, with no detailed curriculum or explicit teaching. Gone is the classroom structure that had seemed so beneficial; now the children and teachers are mostly building things, working with clay and sand, dressing up, getting out pots and pans in the toy kitchen—all things that Jason loved to do. But what does he get out of this?

In sign language as well as in speech, Jason continues to be dogged by limited comprehension—indeed he is turning out more classically autistic than his PDD diagnosis suggested. Most of the specific Floor Time activities Greenspan describes have parents and teachers evoking imaginary scenes and engaging children and their toys in role-play; nowhere does he show how to raise the truly autistic child to the requisite level of linguistic and emotional comprehension.

Instead he presupposes that any child can pick up language, however slowly, simply by hearing others use it in conjunction with the child's activities and emotions. But as the psycholinguist, Paul Bloom, explains, this requires the child to monitor what the speaker is looking at and deduce his communicative intent. In these skills, as studies confirm, autistic children fall far short. Many never acquire the receptive vocabularies upon which most of Greenspan's specific suggestions depend. At school Jason remains linguistically and socially adrift; at home we start teaching him explicitly all the words, concepts, and phrases for which we can formalize lessons.

The most detailed curriculum for autism, in vigorous competition with Floor Time, is Applied Behavioral Analysis (ABA)—an intensive, one-on-one therapy that few EI programs can afford. But even ABA fails to deliver. Most of its lessons recapitulate in misleading detail the general protocol (the physical positions of child and therapist, the modeled behavior, the prompted imitation, the fading of the prompt), but fail to show topic-specific ways of actually eliciting the behavior or of decoupling it from the prompt. Accomplishing this is straightforward enough, perhaps, with physical imitation, object identification, and shape sorting, but not with pronouns, wh-questions, and most other linguistic topics.

ABA, thus, falls short exactly where Floor Time does: in receptive language.

In this key area, the few purported autism curricula, even Greenspan's latest "Affect-Based Language Curriculum," amount to little more than sketchy, schematic protocols. Nothing comes close to matching the specifics of all those deaf EI materials—the sign language lessons and textbooks; the detailed speech curriculum of the Helen Beebe Clinic.

Worse, neither the structure of the EI programs nor the existing therapeutic protocols reflect the many subtypes and learning styles within autism, instead lumping kids together and making sweeping generalizations. A good teacher will appreciate individual differences and figure out how best to address them, just as she will wrack her brain and plan specific lessons with little outside guidance, but adequately meeting such heterogeneous needs is nearly, if not wholly, impossible.

Ideally, some well-connected expert would solicit, compile, and disseminate the best of the teachers' and parents' activities and les-

son plans. But, unlike EI in deafness, this is an arena dominated by psychiatry/psychology gurus rather than therapists. The competition between the ABA and Floor Time camps, instead of being a small distraction, infuses their therapeutic materials, keeping them vague, narrow, and guru-promoting instead of detailed, workable, and child-focused. Like their counterparts in deaf intervention, the various professional devotees are quick to judge parents for pursuing what they're sure is the wrong approach; unlike the deaf experts, they fail to offer specific, practicable alternatives.

And so creating for autism intervention what already exists for deafness is up to those of us who work hour after hour, directly and intensively, with young autistic children. Only we parents, teachers, and therapists can address fully the tremendous diversity of their misunderstood and undertreated conditions. Only we, collectively, can create and compile for these children something truly worthy both of their specific needs and of that overused label of "comprehensive curriculum."

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