



Working With Young Children

It may seem a little paradoxical but our understanding about how autism first presents itself has, until relatively recently, been pretty limited. One of the big problems was that almost all the data came from parent reports of their children at age 3, or 5 (or later) when the children first were diagnosed. Essentially, parents were asked to look back and recall information accurately, which is not so easy to do. Another approach was to look at videotapes of children at first birthday parties, at Chanukah, or Christmas, and observe their behavior looking backward in time. Both of these approaches gave us some information, but it was frustrating for researchers not to be able to see and work directly with very young infants with autism. This situation is now changing dramatically. This has implications for services since it seems for many children that early diagnosis and treatment can make the biggest difference. It also has important implications for research because we can try to sort out important aspects of *how* development happens in autism. Perhaps that knowledge will let us develop better treatments. Being able to know the first warning signs of autism, perhaps even very subtle ones, would also help us do a better job of screening.

In this chapter, we review what is known about autism as it appears in infants and young children and some of the intervention methods used. Keep in mind that, in contrast to some other areas in autism research, this is an area where knowledge is evolving very rapidly. Also keep in mind that what we do know is mostly about autism. Children with Asperger's come to diagnosis much later while those with "autistic-like" features (pervasive developmental disorder not otherwise specified [PDD-NOS]) are variable in terms of when they come to professional attention. At least some of what we know about autism probably applies, however. We talk about early development in these conditions later in this chapter.

In his original report, Leo Kanner suggested that autism was congenital, something the child was born with. Studies that ask parents about when they were first concerned about their child's development tell us that for children

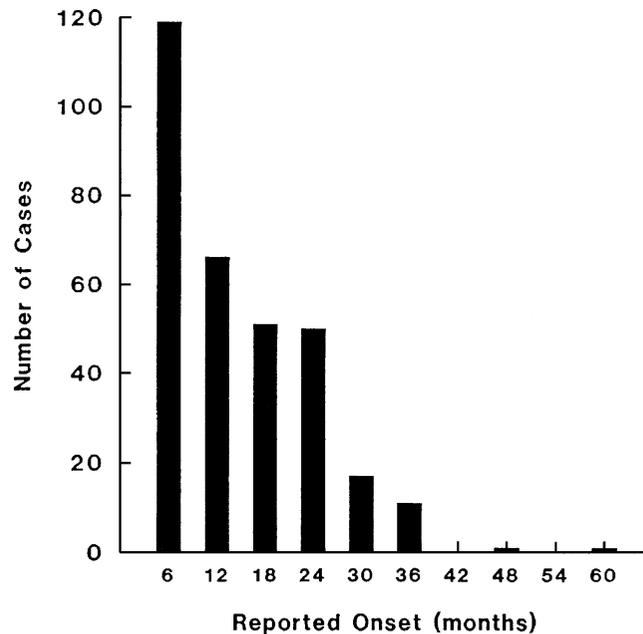


FIGURE 7.1 Age of onset. Cases with clinical diagnosis of autism from DSM-IV Field Trial.

Reprinted, with permission, from Volkmar, F., & Klin, A. (2005). Issues in the classification of autism and related conditions. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., p. 20). Hoboken, NJ: Wiley.

with autism, most parents are concerned in the first year of life, about 90% are worried by 24 months, and essentially all parents are by the time the child is 36 months of age. Figure 7.1 shows data on reported age of onset from the work done as part of the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (DSM-IV) definition of autism. Keep in mind that this is when parents were worried, *not* when very subtle signs of difficulty might have been seen by specialists. Those difficulties probably might be detectable even sooner. Given the data we do have, what are the kinds of things that worry parents (and professionals) early in life?

Observing babies is complicated because they change so quickly and also because, even within a single day, behavior can vary tremendously. Furthermore, they usually sleep a lot and, accordingly, being able to catch the baby at just the right moment is critical for people who want to observe them. Also, some behaviors that are perfectly fine at one age may be a warning sign at a later age. For example, some of the simple play that babies do in exploring things with their

mouth becomes worrisome if it isn't replaced by more advanced play skills as the child gets older. In infants, there can normally be what appear to be major "disconnects," for example, between what the baby seems to want and how good he or she is at getting it, such as being able to reach for something *and* signal the parent with eye contact that he or she is interested in it. Such abilities develop in the first year of life. Given variability in the child's state (awake/asleep) and behavior and motivation, it may be hard for parents to get the child to demonstrate things that show either normal development or worrisome behavior. This creates some problems for assessment (people who work with babies learn to be patient!). There are also many reasons babies can be slow to do things. Some develop alternative methods for doing something.

Another issue, which we discuss in much greater detail in Chapter 13, is the problem of regression. That is, some babies seem to develop normally and then lose skills. Often, this can be seen with word use. Twenty percent or more of parents of children with autism report the rapid or gradual loss of words. The child then seems less interested in social interaction. Research on this group of cases is complicated for a number of reasons. Given that, until recently, we almost always are looking backward, as it were, our sources of information are limited. Research using video tapes suggests that in some cases the children do indeed look good at around the first birthday but then regress. That being said, other work suggests that sometimes what parents see as a regression is actually more of a failure to progress; that is, the child has developed reasonably normally but development then slows down. In other cases, even though parents report a regression, careful discussion with them reveals that there was reason to be worried even earlier! Given these complications, as you can imagine, it is hard to know how best to think about regression in these cases. It is clear (see Chapter 13) that a very late onset with perfectly normal development to age 3 or 4 and then a profound regression is not a good sign—those children tend not to do well. Research is under way to try to understand the meaning of regression in autism.

SIGNS OF AUTISM BEFORE 1 YEAR OF AGE

In most cases children don't seem to regress, but parents become concerned as the child fails to develop words or to respond to sounds or seems socially "disconnected." In his first report on autism, Leo Kanner emphasized this social disconnectedness in his use of the word *autism*. He was careful to say that, unlike typically developing children, the infant with autism didn't engage in early social routines and seemed to lack social interest. Other behaviors that he also described in older children, for example, echolalia or motor mannerisms/stereotypies, require more developmental skills than young babies can muster.

There is good reason to stick with what Kanner said about focusing on social abilities because we realize those are things present in the typical child from birth. Interestingly, Kanner also thought that infants with autism had trouble in adjusting their bodies when they were picked up or in assuming what are called “anticipatory postures” when the parent is getting set to pick them up (adjusting themselves to be held). A general lack of social engagement and limited interest in eye contact is often reported, as are problems in imitation. Problems in imitation can include copying motor things (pat-a-cake) or vocal ones (babbling to imitate). Sometimes babies who go on to have clear autism are described as easily startled or “on a high wire act” all the time. When picking up the baby, by 6 months or so he or she may seem to be floppy (what is called low tone) or too stiff (high tone).

Parents, of course, notice many different things. But most of the studies that try to group these find that early parental concerns often cluster around the social difficulties and some of the problems in what we call arousal and regulation. In a study from our Center, we talked to parents of preschoolers with autism about behaviors that emerge very early in life in typically developing children.¹ We found five of these behaviors that children with autism didn’t do; this was true even when we compared the children to another group of children without autism but who were developmentally delayed. These five behaviors were:

- Showing anticipation of being picked up
- Showing affection toward familiar people
- Showing interest in children or peers other than siblings
- Reaching for a familiar person
- Playing simple interaction games with others

Other studies have also found early differences in what is termed *temperament* (a shorthand term for baby personality style). These studies have found that parents of children with autism who noted troubles early often reported the child to be either very difficult or very passive. Typically developing babies are interested in faces from very early in life, and by 8 or 9 months old they have become so good at looking at faces that they readily recognize familiar people and usually become afraid of strangers. Children with autism may not show this.

Using home movies and videos has also shown some differences in the first year of life in children with autism. It is often found that children who go on to

¹Klin & Volkmar (1992). The development of individuals with autism: Implications for the theory of mind hypothesis. *Journal of Child Psychology and Psychiatry*, 15, 317-331.

TABLE 7.1 SYMPTOMS OF AUTISM IN THE FIRST YEAR OF LIFE**Social Symptoms**

- Limited ability to anticipate being picked up
- Low frequency of looking at people
- Limited interest in interactional games
- Limited affection toward familiar people
- Content to be left alone

Communication Symptoms

- Poor response to name (doesn't respond when called)
- Does not frequently look at objects held by others
- Restricted interests and stereotyped behaviors
- Mouths objects excessively
- Does not like to be touched

SOURCE: Reprinted, with permission, from Chawarska, K., & Volkmar, F. (2005). Autism in infancy and early childhood. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., p. 230). Hoboken, NJ: Wiley.

have a diagnosis of autism seem less likely to look at other people or to smile or vocalize to others. They may be less likely to seek out others. As babies get a little older, they start to respond to their own name, but children with autism, by about 8 to 10 months, often don't seem to do this. Infants with autism may put things in their mouths more than other infants—even ones with delays. They may seem not to like to be touched. Some of the unusual sensory behaviors seem to develop a bit later than others and sometimes don't become really striking for another year or more.

Overall, it seems that many infants with autism do display differences in the first months of life. Sometimes parents will notice differences from very early on. More frequently, parents start to notice problems at 6 to 8 months of age, as the child seems not very interested in interaction with them. The infant with autism may still have an interest in the nonsocial world. Failure to respond to name is one of the striking manifestations by the end of the first year of life (and an item frequently included in screening instruments for autism). Symptoms suggestive of autism in the first year of life are summarized in Table 7.1.

SIGNS OF AUTISM BETWEEN 12 AND 36 MONTHS

By about a year of age even more sophisticated social skills start to emerge, for example what are called *joint attention skills* are usually starting to develop and these skills help the infant engage with their parents and learn to focus on what is important. Although we know a lot about this issue based on parent reports and looking back at home videos, only now are we starting to get good information collected *at the time*. This is coming from a series of what are called

prospective (forward-looking) studies following large numbers of children at risk for autism, starting at birth to see how the first symptoms of autism develop.

Even when they are worried early on, it is presently most typical for parents to start to seek help after the child turns one. Many parents are told to “wait and see” or that “he’ll grow out of it” or that “Einstein didn’t talk until he was 5.” In a study some time ago, it was typical for several years to elapse between the time parents were first worried and the child’s diagnosis. Fortunately, awareness of autism has grown both on the part of parents and on the part of health care providers. All that being said, it still can be hard to diagnose autism in very young infants, and parents often start pursuing assessments after the first birthday. What kinds of things trigger this? Common reasons for parents to seek assessment include:

- Speech delay
- Lack of response to speech (worries the child may be deaf)
- Regression or loss of skills or failure to make usual gains in skills
- Unusual behaviors (preoccupations, early repetitive movements)
- Limited interest in playing and interacting with others

The unusual interests and behaviors usually appear sometime after 12 months and before age 3 years. These can include staring at fans or spinning things or developing repetitive movements (often of the hands or fingers). After 1 year of age, the kinds of things parents start to notice correspond with the kinds of things we look at in older children in making a diagnosis of autism: problems in social interaction and communication and play, and unusual responses to the environment. Of the behaviors required for a diagnosis, this last category seems to be the one that comes later, sometimes raising problems in diagnosis if a baby has trouble in the other two areas but not yet the third one.

After 12 months, problems in communication often become more notable. These include delays in both development of language and nonverbal means of communication, that is, gestures and eye contact. Young children with autism typically do not use pointing gestures, do not show things to other people, and rarely give objects to others to share or to get help. Young children often engage in what experts call **joint attention**, which refers to the two way back-and-forth between people around a third thing, often an object. So if, say, something interesting (or scary) happens, or maybe just something a little new, the typically developing baby will more or less immediately “check in” with the parents, looking at them to get their take on the situation. Or the child will look at the parent and then look at the thing they are concerned about and then back to parent, drawing the parent’s attention to it. Toddlers with autism may use their finger to point to something they want but not usually with eye contact with

their parent. The child may not follow if the parent points to something and may have little interest in imitating parents or siblings. The child's preference for being left alone may also be dramatic. The child's emotional response to things may be unusual—not happy with things other children would be happy about, but panicked around other things. The child may seem less sensitive to pain or may start having marked taste sensitivities and unusual food preferences (often refusing to eat new foods).

By this age, research studies often are able to compare toddlers with autism to toddlers with other kinds of problems, such as toddlers whose language is delayed. Compared to such children, those with autism have trouble with pointing to show and in using gestures. Children with other language problems are able to do these things. As children get a little older those with autism may not be using imagination in play. Signs of autism between 12 and 36 months are summarized in Table 7.2.

In one of the first follow-up studies of 2-year-olds referred for possible autism, Cathy Lord (1995) followed a group of 30 children and found several items at age 2 that predicted which ones were likely to have autism. These included a lack of a number of social behaviors (shared enjoyment, interest in other children, social reciprocity, greeting behavior) and use of the other

TABLE 7.2 SYMPTOMS OF AUTISM: AGES 1 TO 3 YEARS

Social Symptoms

- Abnormal eye contact
 - Limited social referencing
 - Limited interest in other children
 - Limited social smile
 - Low frequency of looking at people
 - Limited range of facial expression
 - Limited sharing of affect/enjoyment
 - Little interest in interactive games
 - Limited functional play
 - No pretend play
 - Limited motor imitation

Communication Symptoms

- Low frequency of verbal or nonverbal communication
- Failure to share interest (e.g., through pointing, sharing, giving, showing)
- Poor response to name
- Failure to respond to communicative gestures (pointing, giving, showing)
- Use of other's body as a tool (pulls hand to desired object without making eye contact, as if *hand* rather than person obtains object)
- Restricted interests and stereotyped behaviors
- Hand or finger mannerisms
- Inappropriate use of objects
- Repetitive interest/play
- Unusual sensory behaviors
- Hyper/hyposensitivity to sounds, texture, tastes, visual stimuli

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person's body as a tool. When you see toddlers with autism try to get something, such as something out of reach, or if they want something to happen (like ringing a bell), they may take your hand to the object but without looking at you—it is as if the *hand* rather than the person is supposed to get the object. Other problems included attending to voice, pointing, and understanding of gestures. Some of the repetitive and restricted behaviors also were noted, including unusual hand and finger movement and odd sensory behaviors. Abnormality in two of the behaviors (showing and attending to voice) could be used to correctly classify over 80% of cases. One of the things that was very helpful about this study was the clarification that some children, at age 2, did not show the unusual finger/hand movements or sensitivities characteristic of autism, but did start to do so by age 3. In other words, it seemed that some children only gradually developed all the symptoms needed technically for a diagnosis of autism, but did so by 3 years of age. Much less commonly, a child who looked like he had autism *before* age 3 did not look like he did by age 3.

Some children who go on to have PDD-NOS (or what it sometimes called autism spectrum disorder [ASD]) may look like they have autism early on, but then develop more skills and lose some of the unusual behaviors. For children who continue to have strictly defined autism, the social and communication behaviors remain very consistent. By around age 3, the child may seem more easily distracted and may have unusual reactions to sounds.

Given their problems in social interaction, it is important to know that young children with autism do form attachments to their parents. At first, this might seem counterintuitive, given what parents often report as their experience of the child. But experimental work does demonstrate that children with autism do form such attachments. Interestingly, the process of attachment formation can sometimes also be a bit indiscriminate. For example, the child may develop attachments to unusual objects. Attachments to objects are frequently seen in typically developing children (the technical term for this is a *transitional* object, since it helps the child deal with transitions like being left in day care or going to sleep at night). When these are seen in typically developing children, the objects are usually soft (teddy bear, blanket) and the actual object is very important (one of us once pawed through a dumpster at a McDonald's on interstate 95 looking for our older daughter's puffy, which she was very attached to and had, as is typical, inadvertently thrown out in the trash!) In autism, these objects differ in two respects: They are unusual in that they are typically *hard* and not soft and may be unusual in other respects (e.g., *Reader's Digest* magazine, Wheaties boxes, bundles of sticks, rocks, metal airplanes, firetrucks), *and* the specific object is not so important as the class of object (any magazine of the same type will do). It may be that the attachments we see in autism are "strategic" rather than "affiliative," that is, that they have to do less with purely social connections.

To briefly summarize, in the first year of life, the earliest signs of autism are decreased interest in looking at people and in responding to being called by their name. Problems in the sensory area may be noted, but this is much less consistent; similarly, it is less likely that infants under 1 year of age have some of the kinds of mannerisms and repetitive behaviors and interests that seem to develop a bit later with autism. After the first birthday, though, the features of autism usually become more apparent. Many different aspects of the child's development are affected. Occasionally, infants seem to develop normally and then either have development slow down or they actually lose skills. For the typically developing child, by 2 years of age, there usually will be tremendous social interest and many words, along with the beginnings of more imaginative play, while toddlers with autism seem to have little interest in others—including other children—and may prefer to be left on their own. The child's emotional range, as reflected in their smiling and taking pleasure in things, may seem restricted. After the first birthday, problems in communication start to become more noteworthy. Words are often delayed, and some of the usual gestures and nonverbal behaviors may not develop. Pointing without prompting to show things and difficulties understanding the gestures of others may be seen, and the problem with ignoring their own name usually continues. With toddlers who have some words, echolalia (repeating) may start. The unusual motor behaviors seem to emerge for many children between ages 2 and 3. These often include hand and finger mannerisms. They may also include unusual sensory preoccupations or fears, such as staring at the blades of a fan for long periods or developing panic about the sound of a vacuum cleaner.

ASPERGER'S AND PDD-NOS

Much less is known about the early development of children with Asperger's and PDD-NOS, although some infants with early delays of the type seen in autism clearly develop into the latter category. In Asperger's, most of what we know comes from reports of parents and, in general, is fairly consistent with what Asperger said in the first place. If, like Asperger, you think of the condition as one where social difficulties occur in the face of what seem to be good language (but not necessarily communication) skills, you might suspect that these are children whose parents would be worried much later—and this indeed usually is the case. The typical time for parents of a child with Asperger's to become concerned is at entry to preschool when social difficulties become much more noticeable. Asperger reported things like the child's talking before walking, and it is not uncommon for parents to report this or to say (as Asperger did) that "words are his lifeline." Motor delays are usual, but parents are typically not very concerned because they see the child as very bright and verbal. In contrast to

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autism, the unusual motor manifestations are less likely to develop early on, and the child is more likely to start exhibiting unusual interests and preoccupations that start to interfere in other ways with the life of the child and family. These may include things like train or bus schedules, the weather or the Weather Channel, dinosaurs, or astronomy. Sometimes the child is interested in something that originally frightened him. For instance, he may develop an interest in snakes because he is afraid of them. Usually, however, parents are not so worried until the child goes into preschool and they receive a call from a concerned teacher that the child isn't fitting in. Often, the child is interested in being social, but his attempts to make friends put off other children—hugging children he barely knows or engaging them in long discussions about his topic of interest. Sometimes the child will have trouble tolerating changes in the schedule—if circle time is supposed to happen at 10:15, it had better not happen at 10:16. We talk more about Asperger's in the next two chapters.

Are parents always the ones who are first concerned? The answer is no. Often, parents particularly first-time parents aren't the experts in child development they will become after they have had a child. Parents may not be worried if the child has developed some language. While parents are often the first ones to be worried, sometimes it is grandparents (who have had a lot of experience) or other family members. Sometimes it is the pediatrician or health care provider (and, as we talk about in the next section, screening for autism is increasingly common). We have now had the experience of having day care providers worried about autism in a child who seems not to be developing normally. All this reflects the greater awareness of autism and the greater access to information about it.

**SCREENING FOR AUTISM—FIRST STEPS
IN GETTING A DIAGNOSIS AND SERVICE**

As we discussed in Chapter 3, a number of different screeners for autism have been developed. Some of these are specific to autism. Others assess development more generally. Some are based on parent report, some on observation by a professional, and others use both sources of information. Essentially all of these try to tap into some of the characteristics in autism. At this point, what are critically needed are more objective, physiologically based, screenings, based, for example, on how the child takes in social information. Efforts are under way to develop such techniques. An example of one potential method is shown in Figure 7.2 (baby eye tracking).

Usually, the first person parent's talk to when they have concerns about their child's development is the child's pediatrician or other health care provider. If the pediatrician has not followed the child since birth, he or she needs to meet with



FIGURE 7.2 Eye gaze pattern in a 2-year-old with autism. This image, generated using infrared eye tracking shows the unusual gaze of a toddler with autism. Rather than looking at any of the characters in the scene, the child focuses on what, to most toddlers (and adults), would be irrelevant details.

Reprinted, with permission from Klin, A., Jones, W., Schultz, R., & Volkmar, F. (2003). The enactive mind—from actions to cognition: Lessons from autism. *Philosophical Transactions of the Royal Society*, p. 350.

the parents and take a thorough history, starting with a family history, the details of any problems during the pregnancy and delivery, and careful developmental history of the child up to the current time. The pediatrician will want to focus on speech and language development, fine and gross motor skills, social skills, and whether any restrictive interests, stereotypies, or repetitive behaviors exist.

After taking a careful history, a thorough physical exam (including looking at the child's growth charts) needs to be done to see if there are any signs of underlying disorders that can be found with developmental delays. An underlying disorder is rare, but the ones to consider with autism are fragile X, and tuberous sclerosis (see Chapter 10). The child also needs to have a good hearing test done, since children with hearing loss can have speech delays or some autistic features. That may be done in the pediatrician's office, or you may be referred to a specialist for this testing. If there is any suggestion that the child has a seizure disorder, he or she will need an electroencephalogram (EEG) or appointment with a neurologist. Depending on what is found during the history or physical exam, the pediatrician may order some blood work or other diagnostic testing.

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Once your health care provider is concerned about a developmental delay, he or she will probably have you fill out one of several screening questionnaires that we referred to earlier. The age of your child will help direct your health care provider to a specific screening test. The American Academy of Pediatrics (www.aap.org/healthtopics/autism.cfm) has recently come out with a Resource Toolkit for Clinicians to help pediatricians evaluate children for ASDs.² For children under 18 months old, they recommend a screener called Communication and Symbolic Behavior Scale Developmental Profile (CSBS-DP). For children 18 to 24 months old, they have recommended a screener known as the Modified Checklist for Autism in Toddlers (M-CHAT). Parents answer a series of questions, and the pediatrician then scores the test. If, after putting all of the information together, you and your doctor are concerned about an ASD, your child will probably be referred to a state-run early intervention program that provides evaluation and treatment of children from birth to 3 years old. These have been funded through money provided by the Individuals with Disabilities Education Act (IDEA). You and your doctor may also want an evaluation by a team of specialists in ASDs, but that may take longer to arrange.

Keep in mind that the idea of screening is to quickly see if there is reason for concern. Children can “fail” screens for many reasons other than having autism. For example, language problems or cognitive delays may be picked up on a screening test. For somewhat older children, problems with attention may also turn up in the screening.

Some aspects of development are more affected by autism than others. As a result, sometimes you see areas where the child with autism is relatively (or sometimes absolutely) advanced. This can result in what are called *splinter skills* or “savant” abilities. In autism, these usually are skills that are nonverbal (puzzles), whereas in Asperger’s, verbal abilities often are an area of strength. In any case, the sometimes very divergent abilities within a single child can make for real challenges in intervention. It is important that teachers and parents are realistic about where the child is functioning and aim neither too high nor too low.

Diagnostic Assessments

For younger children, assessment issues can be complicated. Many of the behavioral problems associated with autism, along with lack of social interest and communication problems, can interfere with assessment (see Chapter 3; also see the reading list for additional reading—particularly chapters by Bishop, Lustyier,

²Other good web sites with information on early diagnosis of autism include First Signs (www.firstsigns.org) and the CDC’s autism website (www.cdc.gov).

Richler, and Lord; Chawarska and Bearss; Paul; and Baranek and colleagues, 2008—all in a recent book on autism in infants edited by one of us and our colleagues Chawarska, Klin, and Volkmar, 2008). Young children with autism may have trouble with new materials and transitions and become frustrated easily. Accordingly, patience and often multiple sessions may be needed to get a good sense of the child's profile of strengths and weaknesses. For older children, it is common for a psychologist to give various tests, including tests of intelligence. For preschool children, developmental tests are often used. These are like traditional IQ tests in many ways, but by avoiding the use of the term *IQ*, there is more emphasis on emerging skills and less stress on long-term prediction. Several different tests can be used. We summarize a few of them here:

- *Bayley Scales*. These scales are based on one of the oldest of the developmental tests, which have been revised and updated recently as the Bayley-III (Bayley, 2006). The Bayley Scales have traditionally been the most generally used tests in infants and toddlers for both research and clinical work. This test is used for infants from 1-to 42-months and includes several different scales focused on cognitive, language, motor, social-emotional, and adaptive behavior development (only the first three of these are given to the child; the other two are done with parents). Testing time varies, depending on age of the child.
- *Battelle Developmental Inventory*. This is a test developed for children from birth to 7 years of age. It assesses development in several areas, including personal-social, motor, communication, adaptive, and cognitive. Compared to other tests, it takes a long time to administer—up to 2 hours. There are some potential drawbacks to this test based on the way it was developed (normed), and there can be some issues in understanding the scores.
- *Mullen Scales*. The Mullen Scales of Early Learning can be used in children up to 58 months of age. This test yields what are called T scores (the average is 50, and the standard deviation is 10) as well as age-equivalent and percentile scores. One great advantage of this test is its use of multiple scales assessed separately: gross and fine motor skills, visual reception (somewhat like nonverbal learning), and **receptive and expressive language**. The ability to disentangle language skills from nonverbal learning is a plus, since it appears that nonverbal abilities may be a better predictor of an ultimate ability to develop language. The test takes from 15 minutes to an hour to administer, depending on the age of the child. This test is now fairly frequently used in developmental assessment of children with autism.

All the tests we've just mentioned assess an infant's or toddler's skills against some standard. Another approach focuses on expected competencies. This

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approach, called criterion-referenced testing (as opposed to norm referenced testing) is more focused on sampling skills, which can be important for intervention. Tests of this type include the Brigance Diagnostic Inventory of Early Development Revised and the Hawaii Early Learning Profile (HELP). A similar test, the Rossetti Infant Toddler Language Scale, focuses only on communication and parent–child interaction. While these tests can help clarify some of the things the child can and can't do, they typically do not replace norm-referenced tests in a diagnostic evaluation.

Delays in development of speech and communication are common in children with autism, and, as compared to typically developing children, they tend to develop language later than other children and their language is unusual in many ways. For example, the range of babble the baby with autism produces may be more limited (few sounds and unusual sounds) and problems in non-verbal communication are common. Similarly, at around 9 months of age, typically developing infants start to coordinate eye contact and gestures when they request things (looking at the parent while reaching for an object) and a shared focus of interest becomes important. As compared to infants with other problems, those with autism are not as likely to use conventional gestures like pointing and showing. They may use the hand of the parent as a tool to get objects (without making eye contact). In this situation, it is almost as though only the hand, but not the person attached to it, exists. For children with autism, behaviors that signal a *joint* attentional activity tend to be reduced in frequency, as are other communicative behaviors, like responding to their own name.

The communication portion of the diagnostic assessment usually is done by a speech pathologist, although some of the assessments can be done by a psychologist or other trained professional. It focuses on several different aspects of communication development, including vocabulary word knowledge, both receptively and expressively as well as more general communication skills. Usually one, or often several, of the standard speech-language tests are used to establish levels of functioning. If delays are found, areas known to be specifically at risk in autism are targeted. Following are some of the tests that are used:

- *Peabody Picture Vocabulary Test*. This test looks at understanding of words (single word vocabulary) in children from age 2 years 6 months through adulthood. This is a well-established, frequently used test. The child is given a word and asked to select it from a panel of pictures.
- *Expressive One-Word Picture Vocabulary Test*. This test is used with children age 2 to 18 years. As you might expect, it assesses the ability to name (as opposed to understand) objects, actions, and concepts. The child is shown a picture and asked to provide a name. The test is well done and is also frequently used.

- *Rossetti Infant-Toddler Language Scale*. This test assesses communication (not just vocabulary) in children from birth to age 3. It is a criterion-referenced test that looks at both verbal and preverbal communication skills. Information comes from both direct observation and parental report.
- *Reynell Developmental Language Scale*. This test assesses both receptive and expressive language, but more broadly than only vocabulary; that is, it looks more at communication. It takes about 30 minutes to be administered and uses materials that interest most children. It is well standardized, and information can be readily translated to an intervention plan.
- *Communication and Symbolic Behavior Scales*. This norm-referenced, standardized instrument uses a play-based format to look at children's language as well as symbolic development. It can be used in infants and toddlers whose language abilities are between the 6- and 24-month levels of the typical population (up to age 6 years for children with delays). It takes an hour or so to complete.

In addition to formal testing, the speech pathologist will be looking at the entire range of behaviors involved in communication, including the range and types of sounds produced, unusual language features (such as echoed language, pronoun reversal), unusual or idiosyncratic language (word/phrase use that is unique to the individual), and other language abnormalities frequently seen in autism. For children who have some spoken language, a focus on their social use of language (what speech pathologists call **pragmatics**) will also be included.

As part of the assessment, the speech pathologist may engage in a number of behaviors that parents might see as odd or even a bit disrespectful. For example, she might seem to tempt the child with a toy, but then keep it to herself or offer the child something that is hard to reach or in a container. She may pretend not to understand something the child says or seems to want. All of these are ploys to see what the child will do to ask for help, to protest, request, and so forth. Often, the speech pathologist will try to get a language sample (if the child is verbal). Even if the child isn't yet using words the speech pathologist will be interested in the range of sounds the child makes and the kinds of communications he uses and their function (e.g., does the child only communicate to get something?). It is very typical for assessment of younger children to include both informal, naturalistic observation (often play based) as well as more formal assessment instruments.

Sensory and motor assessments are available as well. These are described in greater detail in Chapter 3. These can include parent report measures (e.g., the Vineland Adaptive Behavior Scales for motor skills or the Sensory Experiences Question for sensory responses) or be direct assessment (the Mullen Scales for gross and fine motor skills).

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In addition to the results of formal testing, the observations of the occupational therapist, psychologist, or speech pathologist can also add to intervention planning. For example, while the professional may have to give certain items in certain ways to correspond to the way the test has to be done, there are many opportunities to see how the child approaches tasks, what kinds of things the examiner can do to get the child interested, and ways you can get the child engaged. These kinds of observations can often readily then be used to help develop the intervention program.

Depending on the child's age and levels of function some of the more traditional diagnostic assessment instruments can be used such as the Autism Diagnostic Interview-Revised (ADI-R). Particularly for young children, there is considerable potential for developmental change. Evaluators have to make judgments about how representative results are and be aware that tests may have specific requirements; for instance, the child's mental age or developmental level may have to be at a certain level to use the test appropriately.

Access to Services for Very Young Children

As we discussed in Chapter 4, the law in the United States mandates school responsibility for providing a free and appropriate public education (FAPE) for every child, starting when the child is 3. Before that time a different federal law, sometimes called Part C, applies and is designed to "enhance the development of infants and toddlers with disability and minimize their potential for developmental delay."³ This eligibility applies to all infants and toddlers with disabilities and delays in physical, cognitive, social, emotional, communicative, or adaptive development and, at the discretion of the state, to give services to children at risk who might experience delay if they were not given early intervention services. Unlike the law for children of school age, states have a choice to participate in offering early childhood services. Parents can be asked for part of the cost, but families who can't pay still should be able to get services.

As part of this program, early intervention services, known as EI (early intervention) or as Birth-to-Three or other such names, are supposed to develop a program of coordination across responsible state agencies. As a practical matter, the lead state agency is often either the department of education or the department of developmental disabilities (these have different names in the different states). Once a child is referred to the agency, it should provide an evaluation and develop what is termed an individualized family service plan (IFSP) that is similar to the individualized educational plan (IEP) developed for school-aged

³The actual law is found in 20 USC §§1431 and subsequent sections.

children. It differs in that the plan is focused on early intervention and must emphasize services for the family. Parents have to be involved in the process and have to consent to delivering services. Given the focus of the IFSP on the family, there usually will be discussion about helping parents foster the child's development and helping other family members (e.g., the siblings) cope. Typically, there is a regular review of the IFSP at 6-month intervals. Many of the same considerations that apply in being involved in an IEP (see Chapter 4) apply here. There are some special issues for families of younger children, and supporting the family and child is particularly important (see Bailey, 2008).

As a practical matter, early intervention services are quite variable around the country and sometimes even within the same county or town. As we described in Chapter 5, there are a number of different programs that may be applicable to your child. Sometimes these are center-based (the child goes for some hours each day or some days during the week to an early intervention center). Sometimes the service providers come into the home. In some cases, the child works with trained professionals; in others, parents are trained in simple procedures aimed at helping the child develop new skills, and often different approaches to early intervention are combined. Often, an early intervention program will include educational therapy, speech-communication, and occupational or physical therapy. There may be work on family issues and training. Even when the forms of early intervention differ, the goals are generally the same minimizing any disruption that autism or another condition has on the child's development and enhancing the child's cognitive, communicative, and adaptive skills.

Early intervention programs commonly draw on the range of special education services and interventions provided to slightly older children. The law specifically encourages providing services in the "natural environment"—the home. Providers of care may come into the home on a regular basis. A special education teacher might visit and work with the child but also give suggestions to parent(s). The speech pathologist or occupational therapist might come into the home and work with the child and family, or they might work in a center-based program. Toddlers with autism are very good candidates for early intervention. They can be taught using various methods, and it is while they are young that they are most likely to learn new skills. As children turn 3, the school district is obligated to provide services, and in many cases this works well because a more intensive program can be provided and it is easier to coordinate all the services in one setting. Occasionally, parents will continue home-based programs until the child is a bit older. This is particularly true if the child seems to be making good progress and the parents can support (and sometimes afford) the level of services provided. One of the problems with home-based programs is the lack of access to typical peers, who

can be powerful teachers of social skills. A number of excellent books on teaching social and play skills appear in the reading list.

Usually, parents will have let the school district know that they have a child who is 3 or nearly 3 and in need of special preschool services. Almost intrinsically, there will be some logistical problems, since schools are less focused on the family and more likely to use a center-based approach. The early intervention providers should work to coordinate a smooth transfer. Parents must be part of this process and give consent. As we describe in Chapter 4, the school may wish to do its own assessment and will involve the parents in developing the IEP, which then takes the place of the early IFSP.

Program Content

As we discuss in Chapter 5, a large body of work has now shown the importance of early diagnosis and intervention for improving long-term outcome. The report from the National Research Council that we discussed in detail in Chapter 5 emphasizes that the evidence for many programs' effectiveness is strong. These programs have similarities and differences, as we've discussed. In some programs, the teacher very much sets the agenda; in others, the child is allowed some role in this process. Some programs emphasize more traditional developmental principles, trying to build on the child's behavior in a systematic way consistent with what happens in typical development. As we mentioned in Chapters 5 and 6, regardless of their differences, these programs also have a number of things in common. This includes providing a reasonably intensive treatment, a focus on data-based instruction and record keeping, and an explicit focus on intensive teaching and helping the child become more independent.

The applied behavior analysis (ABA) model is probably the most well-known and most common treatment approach and has a solid research basis (Harris and Weiss, 2007). Other programs may focus more on natural settings and target what are thought of as highly critical and important behaviors (that is, pivotal response training programs; Koegel et al., 2008). Other programs are more developmentally based, giving the child a role in helping set the agenda for what is learned; the Greenspan approach (Greenspan, 2009) and SCERTS models (Prizant et al., 2004; Wetherby and Woods, 2008) are examples of these approaches. In other cases, programs are what might be called eclectic picking and choosing based on a range of techniques; the book *Educating Children With Autism* (National Research Council, 2001) has good summaries of all these programs. Increasingly, states are adopting explicit guidelines for early intervention in autism. In a handful of states (e.g., North Carolina and Delaware), statewide service programs have been established. Given how diverse children with autism are, it may not be surprising that there are so many choices!

Unfortunately, as we talked about in Chapter 5, there can be some issues. It is typical for the school to want the child to be in their autism program, sometimes this is like trying to fit a square peg into a round hole! Put another way we don't always do as good a job as we might in terms of matching children up to the programs that are best suited for them. Fortunately, many—probably most—programs work well for most children. But when there is an exception, parents and teachers need to be more creative in thinking about solutions. Sadly, there also is a lot of variability—in some states, this variability is marked from one town to another or one county to another, or sometimes even from one school to a different school in the same town.

To a great extent, what is worked on in early intervention and preschool school-based programs will have to depend on the child and his or her special needs and issues. There are, however, some general things that often run through good programs. These include a very explicit focus on teaching communication and social interaction skills. There also will be a focus on dealing with problems in behavior, particularly if these interfere with learning. Given difficulties in social interaction and play, there is also often a very explicit focus on teaching play skills (one of the areas where typical peers can be very helpful). Given the tendency children with autism have to be very rigid in what they learn, there usually is a strong focus on adaptive skills (taking skills into the real world) and on generalization.

Early intervention programs typically will focus on a number of areas that cause trouble for young children with autism. Given difficulties with social engagement, it is probably not surprising that problems arise with organization and attention. Organizational difficulties (technically referred to as executive functions) have to do with what you might think about when planning your work agenda. Usually, these start to emerge as the child reaches school age, but some organizational difficulties can be seen early on. These can be addressed in various ways, including pictures, schedules, and other supports (see Chapters 5 and 6). Being able to focus one's attention is also important. One of the difficulties in young children is not that they don't attend but what they attend to. Accordingly, programs will work on helping the child learn to use joint attention (social cues). Attention may be fostered in a number of ways, including keeping the environment simple so that the child is forced to focus on what is relevant. Given the importance of communication for subsequent development, a focus on fostering communication is almost always part of the early intervention program. There should be a focus on all relevant aspects of communication, including both understanding (receptive language) and speaking (expressive language). Because communication is also intrinsically social, there is usually a focus on social aspects of language and communication. The kinds of activities that are worked on include imitation

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of other people's movements or sounds they make, building up vocabulary, using words for objects/actions or both, developing sentences, and then adding the "bells and whistles" of language, starting with things like yes and no and moving to more sophisticated concepts. For children who have trouble with verbal communication, a variety of alternative methods are available, including picture exchange, computerized systems, or sign language. As we discussed in Chapter 5, parents sometimes assume that if the therapist wants to use these methods, it means they've given up on the child's talking. In fact, anything that can be done to help the child learn to communicate can help the child eventually learn to speak.

Self-help skills (see Chapter 6) are usually an area of real trouble for children with autism. Any variations from the usual or routine can cause trouble. This likely reflects the fact that they may have a rigid and context-dependent learning style and, lacking the social "glue" that most of us have for pulling the world together, children with autism are constantly relearning solutions to old and recurrent problems. As a practical matter, personal independence and self-sufficiency in adulthood starts with teaching adaptive skills in preschool. These include dressing and undressing, personal care, how to behave in the community, using the toilet, and so forth.

TOILET TRAINING

Requirements for Toilet Training

- Understanding what is wanted
- Motivation to do what is wanted
- Motor coordination

Obstacles to Toilet Training in ASDs

- Cognitive problems (may not understand what is wanted)
- Social problems (problems with imitation, problems with body awareness)
- Motor and sensory issues (may interfere)

Approaches to Toilet Training

- Develop a routine—be aware of optimal times
- Develop system for communicating need (words/pictures/object swap)
- Plan clothing ahead of time (to expedite the attempts)
- Use visual schedules/supports
- Identify problem areas (sound of the toilet)
- Think about motor issues (step stool may help child)

- Praise/reinforcement for success
- Keep language simple (also use visuals)
- Practice in less familiar environments (encourage generalization)

For a detailed discussion of issues and procedures, see Wheeler, M. (2007). *Toilet training for individuals with autism and other developmental issues*. Arlington TX: Future Horizons.

Some young children with autism have fairly good motor skills early on; others have delays. As time goes on, motor skills often become much more social (think about how socially related you have to be to play football or baseball or soccer). To foster development of these skills, early intervention often focuses on activities that involve big muscle movements (gross motor skills) like riding a trike or kicking a ball, as well as more fine motor abilities (fine motor skills) like building with blocks, tracing a diamond, or cutting paper with scissors. Both kinds of skills are important. Often, in relation to work on motor problems, there is work on sensory skills. This might focus on helping the child tolerate a greater range of sensations or materials (see Chapter 16 and also Baranek, et al., 2008). Often, the physical—and particularly the occupational—therapist will be involved in sensory and motor interventions.

Teaching Play Skills

You might think that play is something you wouldn't need to teach, but for children with autism, you'd be wrong. For the typical child, early play involves a lot of exploration of the feeling, color, and smell of objects or the sounds they make. For the child with normal social abilities, this changes dramatically in the second year of life, when play focuses more on the function of things (cars are to roll, cups to drink from). This is then followed by much more complicated imaginative play. Play sets the stages for a number of different developments critical for the growing child. It helps the child learn flexibility: The cup can be a cup, or a bathtub, or a rocket—whatever you want it to be. Play also becomes very social, with children learning to move very quickly in play with roles of people and materials changing rapidly. Among its many other functions, play also helps children develop more sophisticated ways of thinking; it is the beginning of being able to imagine how things could be and to be able to take the world apart and put it right back together, sometimes in very creative ways. Because play is also very symbolic, it is intimately related to language development. For the typically developing child then, play opens up whole new worlds

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and the child learns to seek new experiences from which he or she can learn. In children with autism, there are many challenges for play. They don't much like social interaction. They also don't particularly like new things and the challenges that new things bring.

Accordingly, children with autism start to exhibit problems in play, often around a year or so of age. In contrast to the developing imaginative play of the typical child, the child with autism may fixate on one aspect of the material—sometimes one that isn't very productive, such as its taste or smell. By age 2 the unusual patterns of play are often very striking, and by age 3 they tend to be very dramatic. Imaginative play does not “kick in” as usual. Instead, children tend to be fixated on a narrow range of materials, often wanting to play with simple cause-and-effect toys (push a button and something happens)—the sort of play behavior more typical of much younger children. Fortunately, it is possible to explicitly teach skills needed for play. The use of typical peers can be very helpful in this regard (see Chapters 5 and 6).

Harris and Handleman (2000) have created a particularly helpful summary of 10 early intervention programs. We reviewed many of these in Chapter 5. Research on early intervention and early diagnosis is now proceeding at a much more rapid pace. Work on specific problems (e.g., joint attention) is now highly focused, with rigorous control groups and good scientific methods. Although some differences in emphasis exist, the preschool intervention programs share many similarities. These include a focus on social skills (particularly imitation, joint attention, affective engagement), expressive and receptive language, motor and self-help skills, and play, as well as the more usual pre-academic and preschool skills (Weiss, 2001; Baker, 2003). An explicit focus on learning readiness skills is also typical. Also, as we noted in Chapter 5, there are some variations between programs. Some programs may emphasize use of routines, schedules, and visual support, while others may emphasize peer interaction or incidental teaching. Still others focus on more naturalistic methods while others focus on discrete trial learning, particularly at the beginning of treatment (see Wetherby and Woods, 2008 and Koegel et al., 2008).

Unfortunately, we still don't know why some children respond better to intervention than others. Sometimes it seems (with the wisdom of hindsight) predictable, for example, the child who was very, very uninterested in other people versus the child who was interested but very odd. It does appear that children who have greater cognitive delay when treatment starts may be less likely to improve, although, of course, they are also starting from a position where even more catch-up is required. Parents understandably want an opinion about the child's long-term prognosis, but this is inevitably impossible to give. The good news is that there is much potential for change. The bad news is that we don't always know who will change and in what direction. Another major problem

for prediction is that in the preschool years, the tests we use to look at cognitive development and language tell us about the child relative to other children the same age but not about the future. The reason for this is that only as the children (of all types) become older do traditional tests of intelligence or cognitive ability start to tap the kinds of skills closely related to school success.

CASE REPORTS

The following reports are based on actual cases, although names and other identifying materials have been changed. These three cases illustrate the range of needs exhibited by young children on the autism spectrum and some of the challenges in programming for them. They share some similarities but also, of course, some differences.

Case 1: Bob

Robert, called Bob by his parents, was a 24-month-old boy brought to us by his parents for an opinion on diagnosis and treatment. He was the second of two children born to an immigrant family in which both parents had college degrees. The pregnancy with Bob was uncomplicated; he was delivered by cesarean section because he was breech but was in good condition at birth. Early developmental milestones were within normal limits. He was walking by 12 months and said first words around that time as well. However, his language did not seem to “take off” as expected. His parents assumed that this was because they spoke their native language in the home, while Bob was exposed to English only at day care. At his 18-month check-up, his pediatrician noticed that in addition to expressive language delays Bob also seemed less related to his parents than expected. He had a placid and easy disposition and was undemanding. The pediatrician expressed some concern and asked to see Bob again at 20 months; at that time, he did a screening test for autism given the delayed language and what seemed to him lack of engagement. At 20 months on the Modified Checklist for Autism in Toddlers (M-CHAT; see Chapter 3) Bob failed three of five critical items and was referred to the local state Birth-to-Three agency. That agency did a screen of his development at 21 months. At this screen there was considerable concern. Bob was exhibiting significant delays in expressive and receptive language (on the screening instrument, expressive skills were at the less than 1-year level, and receptive skills at about the 15-month level). Fortunately, his personal social and gross and fine motor and problem-solving skills appeared (on this parent report screen) to be within age-expected limits. Bob was enrolled in two sessions of speech-communication therapy a week. His parents sought an evaluation with us.

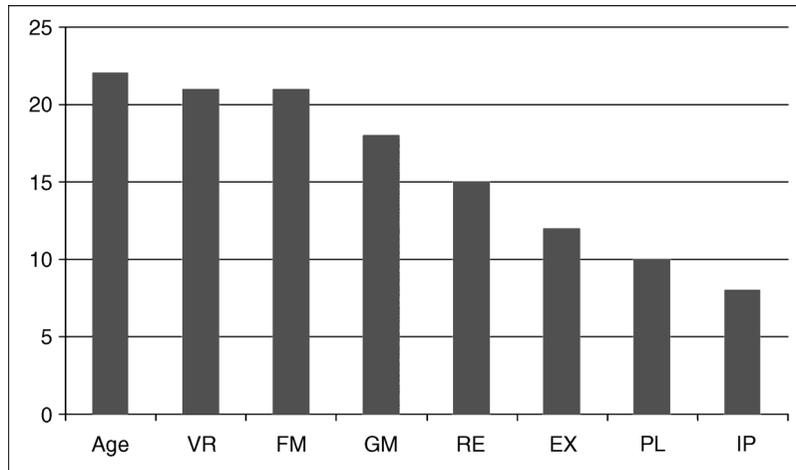


FIGURE 7.3 Assessment results for Bob at age 22-months (results expressed in age equivalents). Results from the Mullen Scales of Early Learning. VR = visual reception (nonverbal problem-solving), FM = fine motor, GM = gross motor, RE = receptive language, EX = expressive language; results from the Vineland Adaptive Behavior Scales for PL = play, and IP = interpersonal.

As part of his assessment with us, Bob was seen for developmental testing, speech-communication assessment, and psychiatric assessment. He was also referred for some additional medical testing. A behavioral hearing test had been done, but the results were equivocal, so a more definitive test was requested and completed and showed that Bob had normal hearing. The results of Bob's developmental assessment using the Mullen Scales of Early Learning are presented in Figure 7.3.

Bob showed average skills in the areas of visual reception (nonverbal problem solving) and fine motor skills, both at the 21-month level. His score in the gross motor area was below average (18-months age equivalent). Both receptive and expressive language were significantly delayed, at 15- and 12-month age levels, respectively. During the testing, the psychologist noted that it was often difficult to get Bob's cooperation—he was often out of his seat, exploring various parts of the room, and was easily frustrated. He had few “learning to learn” skills. His eye contact was poor, and he responded to his name less than half the time. He would respond to requests for joint attention—that is, if something interesting happened, he could be prompted to notice but never initiated such interactions, nor was he interested in showing things to his parents or the examiner. He did make more overtures to his mother than to the examiner, but sometimes used

her hand (without making eye contact) to obtain desired objects. Although not yet very dramatic, we did note that Bob was starting to engage in some repetitive activities. There was one occasion when we saw what might have been the beginning of hand flapping. His parents told us that for some time he had been interested in watching spinning things, and that certain sounds, like the garbage disposal or vacuum cleaner, were very upsetting.

On the Vineland Adaptive Behavior Scales, based on his mother's responses to the semi-structured interview, Bob's gross and fine motor skills were areas of relative strength for him, being closest to age level. Daily living skills were somewhat delayed, but play and socialization skills were quite delayed at the 10- and 7-month level, respectively. The levels of receptive and expressive language ability were slightly higher than observed by us on the Mullen, probably reflecting his slightly greater difficulty in a new situation in showing us all that he was capable of in a more familiar context.

During the speech-language communication assessment, various materials were used to elicit intentional communications. Bob was heard to possibly use the word *hi* on one occasion, and several times said "no," but otherwise no words were heard. His mother indicated that she had not heard the word "hi" before, although the family had been working with him on greeting and leave taking, and he was now occasionally saying "bye." The Reynell Developmental Language Scales were used to assess his speech, language, and communication skills, along with a play session during which he was presented with a series of situations to tempt him to communicate. Bob was interested in some games but wouldn't engage in play with a familiar toy in the new setting; as reflected in this and other examples, it appeared that he had some difficulty in generalizing skills learned at home to new contexts. Bob did enjoy playing one simple game with a cause-effect toy. In addition to his occasionally using the word *no*, Bob more frequently would attempt to avoid tasks, for example, by leaving the table, lying on the floor, failing to look, or pushing with his hand to move something away from him. His parents reported that this was typical in his work with the speech pathologist. His parents reported that he had used some words in the past but that these had seemed to drop out of his vocabulary; for example, he used to say *car* and *open*, but could not demonstrate these for us during the assessment. He did have some interest in pictures and was able to produce a few words. He also produced runs of syllables during play including "ahsee," "hoola," "to-to-to," but these seemed devoid of meaning, intent, or awareness. His **prosody** (the melodic aspect of speech and language) was unusual. On the Reynell, his expressive and receptive language skills were severely delayed.

During the assessment, Bob generally related to his parents and the examiner when he needed something. He generally could not be engaged in tasks that involved either motor or vocal imitation. Occasionally, he would lean against

the person who was working with him but had little apparent awareness that he was in physical contact. He was probably most engaged when his mother sang a familiar song to him; he notably brightened and seemed to sway with the music but did not ask for more when the song was over.

In reviewing the history with the family, it became clear to us that although the parents had reported his language to have developed on time, this actually was rather questionable. Both parents were concerned about his language delay and probably had over-interpreted the sounds he did make.

Medically, apart from these developmental problems, his physical examination did not reveal any likely medical cause for his difficulties. Fragile X testing and chromosome analysis were normal, as were some screening laboratory and genetic studies.

Recommendations and Follow-up We shared with the family that our impression was that Bob very likely had autism, although we emphasized that this would be clarified over time. At this point, our major concern was helping him be enrolled in a much more intensive program. We pointed out that he had some important strengths. Notably, his nonverbal problem-solving skills were close to age-expected levels, he had a few words, and he enjoyed a few social activities that might be used to motivate him. At the same time, we expressed significant concern about his delayed social skills, his problems tolerating adult intrusions, and some of the problematic behaviors, all of which interfered with his learning. We also were concerned about fostering his language and the broader notion of communication. We had a number of recommendations to discuss with them. These very specific recommendations were grouped into a number of areas.

Bob needed considerable work on his behavior and on his learning to learn skills—that is, he needed to be able to sit and work without quickly going off task. He had some behaviors that also interfered with learning, and these needed to be targeted as one part of his overall intervention program. We strongly suggested an ABA program, given what seemed to be his major behavioral needs.

Goals for communication included developing consistency in responding to people (e.g., around greetings). We emphasized that adults' bids for communication should be highly contextualized and relevant to his ongoing routine. Second, we recommended that his program attempt to increase the frequency and the consistency with which he communicated, through use of either words or picture exchange to request a range of things: objects, food, actions, refusal, cessation of activity, recurrence, protest, greeting, and leave taking. We also recommended that an important goal would be to increase the frequency with which he initiated his own requests for things he enjoyed, such as music and games. We also helped his parents develop a vocabulary checklist so they could

consistently use words relevant to his daily experience. We also talked with the parents about potential uses of visual schedules and visual materials to help Bob be (and feel) more organized.

Goals for occupational and physical therapy had to do with use of materials to foster his problem-solving abilities, turn taking, body awareness, and tolerance of physical touch. We also flagged for the staff his potential to get lost in off-task exploration of toys (e.g., absorption in their contours, texture) or visual stimulation.

In going over the results of the Vineland with the parents, we outlined a set of goals that would be reasonable next steps to work on in terms of self-care and other skills. Following our assessment, Bob was enrolled in a new center-based program with a strong ABA emphasis. The amount of time Bob spent in a program was dramatically increased to 4 hours a day, 5 days a week, and his parents were able to attend school on occasion to work on generalization of skills and ask questions. His new program included some individual therapies (speech-language and occupational therapy), and a staff member visited the home once a week. This included discrete trial training to work on basic learning to learn and other skills. As part of his beginning work at the center-based program, a list of reinforcers was produced and his team worked with us to develop a set of immediate, medium, and long-term goals for Bob. These included developing a consistent work routine to enable him to spend increasing time in one-on-one work with an adult. There was also an emphasis on functional use of behaviors and generalization of skills. Objectives were broken down into explicit steps, with a plan for building basic social and communication skills. His intervention plan included a focus on developing more social skills, such as tolerating work with adults and following the adults' lead, expanding joint attention, and so forth.

Although progress was initially slow, within 6-months Bob had started to show major gains in his organization, learning, and language. He is now, as an 8-year-old, enrolled in a regular public school class (second grade) with pull-out support for speech-communication work.

Case 2: Adam

Adam, age 4 years, was seen at the request of his parents for a consultation. He had started preschool (shortly after his third birthday) and had experienced significant problems with peers. Adam, a first child, was born after an uncomplicated pregnancy, labor, and delivery. His early development had not caused his parents' concern. He had spoken words before a year (at 10 months) and had walked at around 14 months. From early in life, words had seemed his "lifeline," according to his parents. He seemed to use language for many

different purposes and at a very sophisticated level. His parents thought that, if anything, his development was advanced over his peers (and in many respects it was).

Adam had an early interest in letters and numbers. His first interest had been in car hood ornaments. He learned to sound out words early. When he entered preschool at about age 3½ years, he had major difficulties with peers. He was very interested in interacting with other children, but approached them in very one-sided (and off-putting) ways, for example, coming up behind and hugging peers in his class. He was distressed when they did not respond positively. His medical history did not reveal any unusual problems. His paternal grandfather was noted to have been somewhat isolated and a bit of an eccentric; he had worked as a map-maker for many years but had a wife and several children.

At the time of our assessment, Adam was given the Wechsler Preschool and Primary Scale of Intelligence, 3rd edition (WPPSI-III). On the WPPSI-III (see Chapter 3), his areas of greatest ability were in the verbal areas with scores in the superior and above-average range, as compared to his performance (nonverbal) abilities (in the average range). For example, his scaled score in the information subtest was 16, while his block design subtest score was 12. His full scale IQ was 120, with a verbal IQ of 127 and a performance score of 108 (98th vs. 70th percentile, respectively). His reading (both understanding and comprehension) was at about the first grade level. During the communication assessment, he had very good expressive and receptive vocabulary (at, or even somewhat above, his verbal IQ), but his social language use was quite impaired, and he had major difficulties carrying on a conversation and producing coherent narratives.

On the Vineland, his written communication skills were high but his “real world” receptive and expressive skills were lower than would be expected given his scores on the individually administered language communication assessments. His daily living skills were moderately low, and his socialization skills significantly impaired. His age-equivalent score in the interpersonal relationship area of the Vineland was at the 2-year level. He had some problems with **visual-motor** coordination, as shown by a test (the Beery Developmental Test of Visual-Motor Integration) of his ability to copy designs. His parents reported problems with attention, as well as significant social difficulties with peers. The school program was working hard to foster Adam’s academic abilities, seeing his reading, in particular, as an area of strength. At the same time, there was much less of a focus on teaching social skills.

At the time of our assessment, Adam had a number of important strengths, including some in the area of social motivation. He was very interested in interpersonal interaction and genuinely puzzled by why his peers seemed oblivious to him. In interacting with adults, his social motivation was very apparent, as were

his many areas of social vulnerability. Indeed, in many respects, and consistent with his scores on the Vineland, Adam acted like a child half his age. He had difficulties delaying gratification, had problems in using eye contact to help regulate social interaction, and was basically lost at sea when it came to fast-paced play activities. Although his preoccupation with letters and numbers seemed to represent an area of strength, this served, in many respects, to further isolate him from other children. In play, for example, he would assign each participant a letter or number, and then refer to them as such—a rather unusual procedure for dealing with typical peers. He had some unusual sensory interests and sensitivities, although these were not particularly striking and didn't seem to interfere at school.

Recommendations and Follow-up In discussing the results of our assessment with Adam's parents, we emphasized his young age and the need to follow him over time. We did, however, flag for them the possibility that he was exhibiting Asperger's disorder, with good verbal abilities and more impaired nonverbal and visual-motor and severely impaired social skills. Although Adam's parents and school had been understandably impressed by his areas of strength, we indicated that his areas of vulnerability were not being adequately addressed. Accordingly, we recommended a program that emphasized acquisition of social skills (with exposure to typical peers in a structured, supported context), explicit teaching of social and other skills, and an emphasis on areas of weakness, as well as areas of strength. We made a number of recommendations for both school and home. These included supported exposure to typically developing peers and individualized interventions, with a specific focus on social goals in natural contexts using discrete trial and pivotal response training. An explicit parent component to his program was recommended to encourage generalization of skills over various settings. Explicit social skills teaching was recommended, along with a focus on teaching play skills. Speech-communication therapy focusing on social use of language (pragmatics) was also recommended. Occupational and physical therapy interventions were recommended for dealing with gross and fine motor skill areas. We underscored with his parents the need to help Adam manage his strong interest in letters and numbers and place it within a broader context. We also suggested to them that, over time, his areas of interest may change and that it would always be important to help him get the "big picture" even while trying to use his natural motivations and interests.

At the time of follow-up, at age 6½, Adam continued to exhibit a somewhat eccentric and one-sided social style. He had, however, made major gains with peers and was fully mainstreamed. He did receive some special services to support gross and fine motor as well as social communication skills, but he had made a good adjustment to school. At the time of our last visit, he had a

relatively strong interest in one fairly circumscribed area (dinosaurs) but was able to use this in connecting with typical peers.

Case 3: Helen

This case differs from the two previous ones in several ways. Probably most importantly, Helen was seen at the ages of 15, 34, and 50 months, and we have presented her case as an example of a very young child with autism (this is published in more detail in Klin et al., 2004; and summarized in Klin et al., 2008).

We have known Helen since she was 2 weeks of age (when her older brother was just diagnosed as having an ASD). This is a reminder of the potential for families to have multiple affected children (see Chapter 2) given the strong genetic base of autism. Helen's case also serves as a reminder that, for some children, noteworthy developmental regression can occur and that sometimes improvement is very slow even when good services are provided.

Early History Helen was born after a pregnancy complicated by her mother's thyroid disease, which was treated during the pregnancy. She was observed for a short period of time after delivery in the newborn special care unit because of low blood sugar, but then did well. She was smiling by 3 weeks of age, sitting at 4 months, crawling at 6 months, and walking by 12 months. At that point in time, her parents (and her pediatrician [LW]) noted that she was saying a number of words, including *hi*, *baby*, *mommy*, and *daddy*. Unfortunately, at around 14 months, she seemed to become less socially engaged and stopped not only talking but making many sounds at all. Within a few weeks, when she was seen for a comprehensive assessment, she had developed a dislike of loud noises and bright lights.

Family and Medical History Helen's brother had exhibited features of autism shortly after birth. Apart from his history of difficulty, there was no history of developmental or psychiatric problems in members of the family. Except for several (four) ear infections, Helen had been in good general health, and her development had been closely followed by her pediatrician, given her brother's history. Originally, her parents wondered if her loss of words had to do with an ear infection.

On genetic and medical evaluation at 15 months, Helen had a large head size (>95% of the population of children her age). At 6 months, her head circumference was at the 50th percentile (her brother and parents also had large heads). Otherwise, genetic screening and neurological consultation (including neuroimaging studies) did not reveal any abnormalities (see Chapter 2).

Assessment at 15 Months At this age, Helen was scoring at age-expected levels in terms of her nonverbal problem-solving abilities (her ability to use objects,

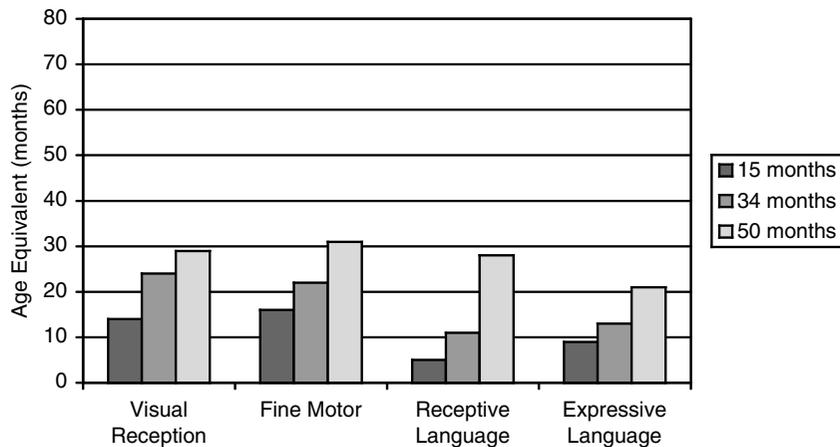


FIGURE 7.4 Age-equivalent scores on the Mullen Scales of Early Learning achieved by Helen.

Reprinted, with permission, from Klin, A., Caulnier, C., Chawarska, K., & Volkmar, F. (2008). Case studies of infants first evaluated in the second year of life. In K. Chawarska, A. Klin, & F. Volkmar (Eds.), *Autism spectrum disorders in infants and toddlers* (p. 145). New York: Guilford Press.

discriminate shapes) as well as in both her gross and fine motor development (running, scribbling, throwing a ball). Unfortunately, her language at the time of the assessment was very delayed, with receptive skills 6-months delayed and expressive skills 8-months delayed (her scores on developmental testing over time are presented in Figure 7.4).

During the speech-communication assessment, Helen would pull a person's hand to get desired objects without making eye contact. She exhibited no gestures to communicate and was happy to be left on her own. She inconsistently would seek out her parents if she was upset and did respond to some verbal directions if these were kept simple and exaggerated visual cues were also provided. She was not heard to use any words at that time and made a limited range of sounds that were not directed at other people.

On the Vineland Adaptive Behavior Scales, she had severe delays in socialization and expressive language skills. Her motor skills were somewhat stronger, as were her receptive language skills (i.e., within familiar contexts at home she was scoring somewhat higher than she did during her session with the speech pathologist). Her scores on the Vineland over time are provided in Figure 7.5.

Observations of her behavior at 15-months revealed a child who presented as very isolated and self contained. She tended to fixate on some kinds of toys and had troubles with transitions. She also had some unusual interests, for example, in

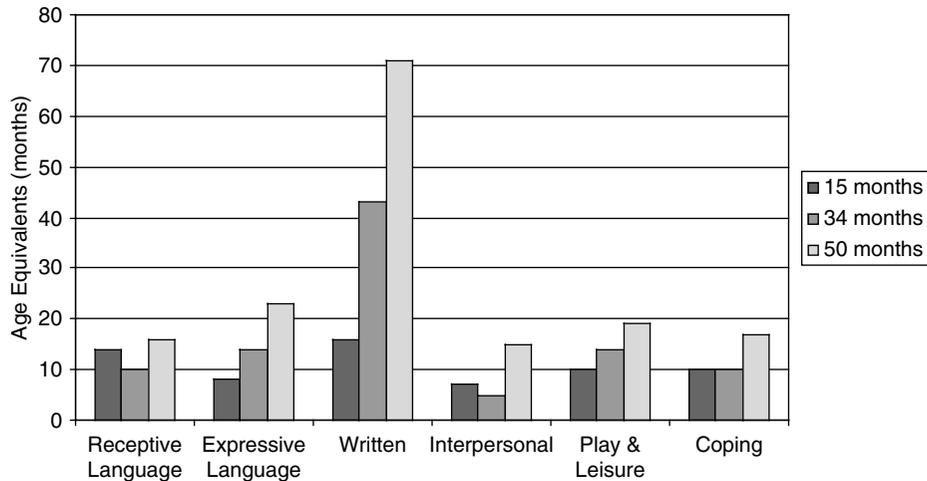


FIGURE 7.5 Age-equivalent scores on the Vineland achieved by Helen.

Reprinted, with permission, from Klin, A., Caulnier, C., Chawarska, K., & Volkmar, F. (2008). Case studies of infants first evaluated in the second year of life. In K. Chawarska, A. Klin, & F. Volkmar (Eds.), *Autism spectrum disorders in infants and toddlers* (p. 147). New York: Guilford Press.

certain textures. At the same time, her social engagement was very concerning. She had only occasional eye contact with others and often seemed to ignore other people. When she did smile or seem happy, this seemed to be in response to her own experience and not some shared enjoyment with another person. She often ignored adults, and it was impossible to engage her in simple games like peek-a-boo. Her interest in more representational toys was quite limited. Frustration led Helen to make a number of high-pitched, unpleasant sounds. Unlike many young children with autism, she exhibited stereotyped mannerisms (hand flapping and finger posturing) even at 15-months of age. She had some trouble with change and novelty. We shared with her parents our concern that even despite her young age, she was exhibiting a profile very, very suggestive of autism.

Within a month, she began to receive 3 hours of speech-language therapy and 1 hour of occupational therapy each week through the state early intervention program. In addition, 8 hours a week of applied behavior analysis (ABA) were provided, along with a 1 hour play group each week. Over the next months, these services were all increased in intensity until she transitioned into the school system at age 3.

Assessment at 34 Months We saw Helen again at 34 months. During the interval between these two visits, she had made slow but steady progress. Her fine

motor and problem-solving skills were at the 20- and 22-month levels. Language continued to be her area of greatest vulnerability (along with social skills). At 34 months, her language skills were about 2 years delayed (i.e., at around a 10 month level). During the speech-communication assessment at 34 months, she had not made many gains. She was mostly interested in observing herself in a mirror and had little evidence of differential responses to adults (e.g., parents vs. stranger), although she would, at times, turn to her parents for help or support. All communication functions (verbal and nonverbal) were significantly delayed. She did some singing (including one nursery rhyme) but made little eye contact and was very unengaged with the adults. Interestingly, by this time Helen had become fascinated with letters and numbers.

Diagnostically, Helen was very much the same child at 34 months. She had few consistent words, and her language was unusual for its self-stimulatory quality and limited range of intonation. She did seem to like to label things (a frequent activity in her intervention program) but did not use words to communicate in a consistent way. She did enjoy rough and tumble play with her parents, but even then often seemed more engaged with herself than her parents. She was exhibiting higher levels of motor stereotyped behaviors and unusual sensory behaviors at this age.

Helen was enrolled in a public school program at age 3. By the time she was just past her fourth birthday (at 50 months), she was receiving ABA services 4 hours a day 5 days a week in the morning, with an afternoon preschool program that included typically developing peers and opportunities for pull out work with the occupational therapist and speech language pathologist, as well as about 10 hours a week of individual special-ed work.

Evaluation at 50 Months When she was seen at 50-months of age for her third assessment, she had made progress in her communication skills, although her growth in terms of problem-solving/nonverbal reasoning and fine motor development had slowed. Her levels of delay ranged from 19 to 29 months. During the speech-communication assessment at 50 months, Helen knew a number of words but primarily only labeled things (i.e., she didn't use the words to communicate in other ways). She could follow very simple, two step directions but more complex language was beyond her. It was easiest for her to respond when language was kept very simple, with short phrases rather than long sentences. Sometimes her use of language was very idiosyncratic (she would use a word in a very odd way that most people wouldn't understand). Although she had made progress in her vocabulary, her overall language/communication skills remained severely impaired.

Helen continued to exhibit delays in adaptive skills, although her profile of delay was scattered with social and receptive/expressive skills most severely

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delayed and motor skills closer to age level. By this time, however, her reading abilities were quite strong. She was reading to “decode” at about the 6-year level, but her understanding of what she read was minimal; for example, one could give her a written instruction like “sit down,” and she could sound it out but not follow the direction.

By 50 months, Helen had made some important gains in terms of her ability to focus, tolerate adult intrusion, and engage with adults (if only for short periods of time). She was also less likely to engage in stereotyped mannerisms or even self-injurious behavior when she was frustrated or tired. Importantly, she was beginning to use some words, on occasion, to communicate her needs and was starting to use words with a point to request objects. Her language was mostly single words and continued to have an unusual “robot-like” quality.

Discussion Helen seems to have developed well until shortly after a year of age. Even at the time of her first comprehensive assessment, her presentation was fairly classic for autism. Even though she appeared to have had major losses of skills in some areas, motor and nonverbal problem-solving remained close to age level at the time of our first assessment. She gradually made gains in the areas of socialization and communication, but significant vulnerabilities persisted despite provision of a reasonably intensive program. Her ability to read to decode had emerged as an isolated area of strength but was not matched by her ability to understand what she read. Although provided with reasonably intensive intervention, she had not, unfortunately, made as much progress as we would have hoped.

Helen now, at around 6 years of age, has not made as much progress as her older brother. She is enrolled in a special school for children with autism. She has a few words, but generally her communication skills remain an area of great vulnerability. She has had a number of behavioral challenges and been treated with several medications for behavior problems.

SUMMARY

In this chapter we reviewed some of what we know about autism and related conditions as they appear in infants and young children. As we mentioned, until recently most of the information on this topic came from either parent memories or the retrospective study of children through videotapes. Most parents of children with autism become concerned about the child’s development in the first year or two of life. The earliest features of autism tend to fall into two groups—one involves social engagement and the other relates to early communication abilities. Although unusual sensory interests and motor behaviors develop, they often develop somewhat later—usually by age 3 but can be preceded

by unusual sensory sensitivities that, as Kanner suggested, stand in stark contrast to the child's lack of interest in the social world.

When parents are concerned the health care provider is usually the initial professional to see the child, conduct an initial assessment, and suggest more extended testing. Depending on the results of this assessment, services can be provided even before the child is eligible for school-based programming (at age 3). The unusual profiles of strengths and weaknesses in children on the autism spectrum can present some challenges for intervention. It does appear that, on balance, early and more intensive intervention is the most effective. Parents must negotiate the challenges of dealing with two systems—the early intervention system and then the public schools. A range of well-documented programs are available for slightly older children; as interest in early diagnosis of autism increases, there will undoubtedly be more interest in evaluating programs for children under 3 as well. Overall, it does appear that early intervention makes an important difference for the better; that being said, there are still individual differences, and predicting what will happen to a specific child is often difficult. A major challenge for current research is the development of better tools for screening/assessing children with possible autism or related disorders. Several studies are under way at present in different places around the country, often studying children who are siblings of those with known autism. We hope that this research will lead to earlier and more effective interventions.

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■ WEB SITES

- <http://www.aap.org>
<http://www.cdc.gov/ncbddd/autism/index.htm>
<http://www.firstsigns.org>

■ QUESTIONS AND ANSWERS

1. **My son and his wife have an 8-month-old son, their first. I know I may be an overly concerned grandmother, but I worry that Billy doesn't seem to respond like other children. He doesn't seem as interested in things as my other grandkids. He does not turn when his name is called, and he doesn't seem to smile when we talk to him. He seems to like to stare at things that move. Is this too young to be worried about autism?**

It is not too young. You are absolutely right about the kinds of things to worry about at this age—lack of response to people and a greater

interest in things. While being sure of a diagnosis at this age is not always possible, it is possible to start intervention if there are good reasons to do so. You should express your concern to your son and his wife and ask them to talk to their health care provider, who may want to do some developmental screening and/or refer them to the local early intervention program for an assessment.

2. **Our 4-year-old was diagnosed with autism at age 2. She has made very good progress with an ABA program. This has been fairly intensive and structured with some time each week (and more this past year) in a typical preschool setting. My wife and I are just starting to think about a transition to a typical kindergarten next year (with some supports). When can you tell if a child is “cured”?**

First and foremost, it is very good indeed that your daughter has responded well to treatment. You explicitly ask one question but also raise another important issue: transitions. Changes in program go best when a lot of planning has gone on and the child and program are well prepared. The people who have been helping her already will undoubtedly have a number of suggestions. Having her enrolled in some experience with typically developing children also will make the transition easier. There are a number of things you can do well ahead of time to smooth things along—pictures and visits to the new classroom and teacher. In developing the IEP, look at both where she has come from and where the team would like her to go. It may be easier to have more supports at first, and then if things go well, you can phase them out or cut back. Your explicit question asks about cure. This is always difficult to answer since the answer depends on how you define *cure*. Many children on the autism spectrum are going on to have productive experiences in mainstream settings and sometimes continue to do so even without much in the way of formal support. Often, even the most able people on the spectrum have some residual personality quirks or eccentricities as adults, as do many typically developing people. You should take pride in her accomplishments to date and see how the transition to a typical kindergarten goes. Good luck!

3. **I am a retired pediatrician. My first grandchild is now 15- months old and still not talking. I worry because he doesn't respond to his name and doesn't seem to “click” with people (he won't look at me if I make a funny sound). My grandchild has had a number of ear infections, although once these clear up, his hearing is fine (it has been tested several times now). My daughter-in-law gets very anxious whenever we talk about this and won't agree to pursue an**

evaluation by the local early intervention team. Do you have any suggestions?

You are right to be concerned. The process of coming to grips with a child's developmental vulnerabilities can be a difficult one for parents, particularly if this is a first child and they don't have a good comparison. Obviously, you have a long history of experience but also the complicating role of being the father-in-law. In situations like this it may be worth having a private discussion with your son to share your concerns. It may also be worth suggesting that the parents take the child to a play group or other setting where they will be able to see typical peers and make some observations of what typical behavior at this age is like.