



## Getting Services

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In this chapter, we provide information on getting services for a child with an autism spectrum diagnosis. This chapter includes a discussion of legal rights and some of the key concepts relative to rights to educational services. It is important that parents and teachers have some basic understanding of these rights and concepts. We also discuss some of the issues involved in seeking insurance reimbursement for services. In the next series of chapters, we'll talk about overall approaches to programming and then more age-specific issues for infants and young children, school-aged children, and adolescents and adults. Keep in mind that, as in other areas, parents and parent support groups may be good sources of information. Also keep in mind that things can change—either through changes in the laws (by Congress) or new judicial decisions (by the courts)—so it is important that everyone involved be aware of current requirements.

### THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

In thinking about getting services for any child, it is important to know a little bit about the history of educational services for children with autism (and, for that matter, other disabilities). Before 1975 only a small number, maybe around 20%, of children with disabilities received an education within public schools. In many schools, parents would be turned away and were often told to put their children in institutional settings where there was little proactive programming or education. As a result, many individuals with autism were placed in these institutions; probably not surprisingly, the major function of such placements was that it helped them learn to live in (i.e., remain in) institutions, and outcome was often poor. There were, of course, exceptions but these usually were situations where parents wouldn't accept a lack of services and advocated for, or sometimes started, their own private schools or programs. Many of the earliest schools for children with autism in the United States were started this way, and some remain active to the present. All this changed dramatically in 1975.

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In 1975, Congress passed the Education for All Handicapped Children Act, also known as Public Law 94-142, which mandated school services. This law has been revised and amended many times. The current version is called the **Individuals with Disabilities Education Act (IDEA)**. (The IDEA is an alphabet soup of lovely acronyms that we will introduce to you in this chapter). This law applies to several areas, including early education as well as school-based and transition services and mandates meeting the educational needs of children with disabilities from the time they are born until they reach 21 years of age. Although the IDEA is thought of as a civil rights law, it technically does not require states to participate; rather, it gives them incentives to do so by funding programs when states meet certain requirements. All the states now participate. The IDEA was most recently amended in 2004.

## KEY CONCEPTS AND TERMS

IDEA	The Individuals with Disabilities Education Act—an act of Congress giving specific rights to children with disabilities for educational services.
PL-94-142	Public Law 94-142—the original (1975) law passed by Congress mandating school services to children with disabilities.
FAPE	Free and appropriate public education
IEP	Individualized education plan
LRE	Least restrictive environment
ADA	Americans with Disabilities Act
504 Plan	A plan developed to accommodate the special needs of a child with a handicap.
IFSP	Individualized family service plan—a plan similar to the IEP but for younger children (under age 3).

It is important for parents and teachers to understand what the law does and doesn't require. There are some key concepts that we'll review shortly. Also, it is important to realize that the age of the child has some relevance here. For example, after age 21 the IDEA does not apply, but other laws, such as the **Americans with Disabilities Act (ADA)**, may apply. The requirements for early intervention (before age 3) programs are different from those of public schools, and some of the terms and concepts will vary depending on the age of the child; some aspects of procedures may vary a bit from state to state. Also keep in mind that a vast number of children, over 6 million in 2006, were educated under the provisions of this law. This number includes children with a range of disabilities, not just autism. Autism is, however, mentioned specifically in the law as one of the conditions that meet the requirement for disability. As we discussed in the previous chapter, this can be one area where diagnostic labels are very important. Regardless of labels, parents and teachers should keep in mind that the intent of the law is to identify children whose disabilities interfere with their learning. Thus,

even if a child with autism has normal cognitive ability (intelligence quotient [IQ]), he can still qualify under IDEA for services. The reading list at the end of this chapter provides information on a number of resources that can be helpful in understanding this law and how it works. Be aware, however, that in the legal arena, changes can happen at any time—these changes can come from changes in the statute (the underlying law), from court decisions (which interpret the law), from regulations enacted by the state and federal education agencies to implement the law, and by the passage of other federal laws, for example, the No Child Left Behind Act. Changes can occur even because of local issues that impact on school services/programs. For example, a gifted director of special educational services in a district can retire or be replaced, and sometimes, literally overnight, there can be a dramatic shift in the quality and nature of programs. This chapter is as accurate about the state of the law as we could make it at the time of publication; however, it is not a substitute for the advice of a lawyer. Do not take action relying on the descriptions of the law in this book. Consult a lawyer with expertise in this area of law.<sup>1</sup> Some states may have additional provisions about regulation of special education services. In general, federal statutes usually supersede state laws and regulations (called *preemption*). However, a state or local education agency may choose to require or provide more services or more protections than are guaranteed by the federal statute.

#### HISTORY OF THE IDEA

##### *Legislative History*

- 1975:** The Education for All Handicapped Children Act (PL 94-142) mandates the right to education for all children with disabilities.
- 1990:** The law is renamed the Individuals with Disabilities Education Act (IDEA).
- 1997:** IDEA was amended in several ways including to provide coverage of delayed children between ages 3 and 9 years, and the use of mediation to resolve disputes was encouraged.
- 2004:** The Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) modified the law to conform with No Child Left Behind and also dealt with disciplinary issues for students in special education.

##### *Supreme Court Decisions*

- Hendrick Hudson Central School District v. Rowley*:** Decision in 1982 (discussed in the chapter) that established the “Chevy, not a Cadillac” standard of an adequate, not optimal, special education program.

<sup>1</sup>For example, the state of the law on reimbursement for unilateral placements by parents in private programs has changed repeatedly in the past 5 years. That is an area where it is very important to obtain legal advice prior to taking action.

**Schaffer v. Weast:** This 2005 decision held that the “moving” party (usually the parent) in a placement challenge had the burden of persuasion.

**Winkelman v. Parma City School District:** In 2007 the Court found that, under IDEA, parents have independent enforceable rights, which are not limited to procedural and reimbursement-related matters but encompass the entitlement to a free appropriate public education for their child. This means that parents can sue “pro se” (without a lawyer or representing themselves) to enforce their own rights, which are the same as their child’s rights.

*Supreme Court’s Restriction of Right to Attorneys’ Fees for Prevailing Parents*

**Smith v. Robinson, 1984:** Attorneys fees are not available under the Education for All Handicapped Students Act (EHA). In response to *Smith v. Robinson*, Congress amended the EHA to explicitly allow for attorneys fees retroactive to the day before the decision.

**Buckhannon v. West Virginia Department of Health and Human Resources, 2001:** Defined “prevailing parties” entitled to attorneys’ fees in certain cases, including IDEA cases, to those awarded some relief *by a court*. This eliminated the entitlement of fees in settlements and fees awarded under the “catalyst theory” (that the filing of the court action was the catalyst which caused the district to change its behavior.)

**Arlington Central School District v. Murphy 2006:** IDEA does not authorize prevailing parents to recover expert fees. The Court held that IDEA provides that a court “may award reasonable attorneys’ fees as part of the costs” to parents who prevail in an action brought under the act. It does not authorize prevailing parents to recover fees for expert witnesses in such actions.

## KEY CONCEPTS AND PROVISIONS OF IDEA

### Evaluation and Identification

The states are required to locate and evaluate children with disabilities who may need special services. This is known as the “child find” obligation. Children can be identified and referred for evaluation by parents or by health care providers, as well as by school personnel. Given the key importance of health care providers, it is especially important that they be aware of these rights, be familiar with programs and services, and be available to advise parents. The “child find” requirement—to **identify** and evaluate—applies to all children, including children attending private schools and children who are homeless or migrant. Special provisions are made for children under age 3. Once a child has been identified, the local school district (called the Local Educational Authority, or

**LEA** in legal speak) must determine whether the child is eligible for services under IDEA. Parents of children under the age of 18 are asked to give their consent for an evaluation. The evaluation should be sufficiently detailed as to provide a determination of whether the child does or does not meet the eligibility requirement of having a disability such that the child requires **special education** and/or **related services** in order to benefit from his/her education. Given the many different manifestations of autism and related conditions, multiple disciplines and evaluations are frequently involved to be able to provide a comprehensive assessment. For example, many children on the autism spectrum require speech and language evaluations as well as psychoeducational evaluations and occupational therapy assessments. The purpose of the assessment is both to establish whether or not the child is entitled to services and to assist the team in planning the educational program (**individualized education plan [IEP]**) that will provide and direct the services.

Parents can, of course, submit their own evaluations. The school district must take the evaluation into consideration, but is not required to accept such evaluations or to follow their recommendations. If the parents disagree with the evaluation provided by the school, they can also request an independent evaluation. If parents are careful to document that they disagree with the school's assessment, the school has to either pay for the independent evaluation or request a hearing (often called *due process*) to defend their evaluation and to show that an independent evaluation is not needed. When would a parent want to ask for an independent evaluation? There are several situations when this would make sense. If a school district does not identify a child as having a disability and the parent disagrees, an independent evaluation can be helpful. In other cases, sometimes the district identifies the child as disabled, but does not offer services because their evaluation does not show that the disability interferes with the child's ability to benefit from education. A review (usually repeat testing) at least every 3 years (triennial review) is required, with additional testing as needed to show continued need for services.

### **Free and Appropriate Public Education**

One of the core key concepts of IDEA is that students must be provided with a free and appropriate public education (FAPE). Note the words *free and appropriate*. The meaning of *free* is clear: that parents do not have to pay. However, the question of what is appropriate for a particular child is often one that turns into a sticking point. Parents, understandably, want the best for their child. The law, however, uses the word *appropriate*, not *best*. Put another way, as set out by the United States Supreme Court in the case of *Board of Education of the Hendrick Hudson Central School District v. Rowley*, a school district satisfies its duty by

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providing an “adequate” education. In that case, Amy Rowley, a hearing-impaired child, was able to advance from grade to grade without the benefit of the requested sign language interpreter. The Supreme Court stated that law required “personalized instruction and related services calculated . . . to meet [a child’s] educational need.” The Court added that, because in this case they were presented with a handicapped child who was receiving substantial specialized instruction and related services, and who was performing above average in the regular classrooms of a public school system, they confined their analysis to that situation. Unfortunately, later court decisions and hearing officer decisions have frequently ignored the Court’s limitation of *Rowley* (that is a situation where the child was performing above the average) and the *Rowley* case has limited the services required by the IDEA to minimally adequate to pass from grade to grade. This issue remains an important one and a source of frequent dispute between parents and schools.

Of course, if states or school districts choose to, they can do more than the minimum required. As a practical matter, there also is considerable regional variation in how services are provided and what services are available. This can be very dramatic across states and sometimes even within states. In our particular state, for example, variations from town to town can be quite dramatic and sometimes moving across the street can result in a major change for the better (or worse) in terms of the quality of the program.

**Eligibility for Services**

The IDEA includes a very specific list of covered disabilities, including autism as well as mental retardation, speech–language impairment, visual impairment, and hearing impairment. In addition, the law requires that the child must, as a result of his condition, require special education services. In other words, simply having a disability or a diagnosis alone does not make a child eligible for special education and related services. So if a hearing-impaired child, for example, could be helped with a hearing aid so that his disability was not interfering with his ability to learn, he would not necessarily qualify for services under IDEA unless some other condition that interfered with educational progress was present.

We want to stress two additional points: It is very important to keep in mind that educational progress is not limited to academic progress. The term *special education* is much broader than *book learning*. It is, under the law, “specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability.” This includes:

- Instruction in the classroom and also in other settings
- Instruction in physical education

- Transition services designed to help the child move from school to employment, vocational school or other postsecondary education, adult services, independent living, or community participation
- Services based on the individual child's needs that take the child's strengths, preferences, and interests into account
- Instruction, related services, community experiences, the development of employment and other postschool adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation

This is a broad definition of education, well beyond academic subjects, and covers areas of critical importance for children with autism spectrum disorders (ASDs). Transition services also are available, and usually are delivered, after a child has completed and graduated from high school.

The second point is that even if a student doesn't technically qualify under IDEA, there are other federal laws, notably the ADA and section 504 of the Rehabilitation Act of 1973, which may apply, and the child may qualify for some accommodations or services under these laws. Both of these laws prohibit discrimination based on a person's disability, and require equal access to services. The ADA applies to public accommodations and governmental services, and the Rehabilitation Act to recipients of federal funds. Thus, it is likely that almost every public school system would fall under both acts. Both laws require that entities make reasonable accommodations, which are modifications to their policies and procedures that are required to permit a person with a disability to access the services or benefits provided. This applies in schools and means that even if it is determined that a child with a disability does not need special education in order to make progress in school, if she needs another modification to receive equal access it must be provided. Such modifications can be modified curriculum or transportation, preferential seating, or even being permitted to enter and leave classes early to avoid the difficulties of the crowds and disorder of the halls between classes. One important difference about accommodations under these acts from special education mandated under IDEA is that reasonable accommodations must be requested by the student or her parents—there is no requirement to seek out eligible students and offer such accommodations.

Autism is specifically mentioned as one of the eligible categories under IDEA. For young children, the possibility of a "developmental delay" category is given for children between 3 and 9 years of age so that children with developmental delays do not have to have a specific disability label. As a result of the emphasis on autism, there is often pressure to have children on the autism spectrum (more broadly defined) included within the autism category. Practices vary considerably from state to state and sometimes within states. It is also possible for children

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with ASDs to qualify under different categories, for example, speech and language impairment, intellectual delay, even “other health impaired.” In theory the emphasis should be on the child’s needs and not the child’s label.

**Individualized Education Plan (IEP)**

The IDEA requires schools to create an individualized education plan for any child who is eligible for special education. This is required for any student who qualifies and is the most important element of the student’s intervention program. This document is developed by parents and teachers and others (an “interdisciplinary team”) using the information gathered by all of them and discovered in the evaluation. The document will be the guide for the school program and should set out exactly what kinds of services are to be provided, including the number of hours of each service, how much of that service will be provided in a setting with nonhandicapped peers, and what special arrangements or accommodations are made for the student. It should also include measurable goals and objectives (the term *goals* now includes the concept of objectives). We will discuss the IEP in much greater detail shortly.

It is important to understand that the purpose of the IEP is to be an individualized plan—a blueprint. The child should not be pigeonholed into whatever autism classroom the school or district has. Rather, the IEP should reflect the unique needs of the child. In theory, the IEP will include long-term goals, and short-term objectives should be developed without regard to what is available in the district’s existing programs.

Parents should understand that the IEP is developed by an interdisciplinary team (called by different names in different states, i.e., planning and placement team [PPT], committee on special education [CSE or CSPE], or in many states simply IEP team), which includes mainstream and special education teachers, specialists (i.e., school psychologist, **social worker**, speech–language pathologist) and parents in a process that aims to achieve a consensus. The IEP is not something you vote on like a committee meeting. While the school can and should have regular meetings and deliberations among all the staff involved in working with the child, the law requires that parents (and older children) be invited to all formal meetings and be able to participate in a meaningful way. It is also important to realize that the IEP can include provisions for extending the school day or school year if that is necessary to the child’s education. This is available particularly (but not only) if there is risk of regression for the child. The IEP also can include transition services even beyond high school graduation until the age of 21 (in many states, until the end of the school year in which a child turns 21.)

## **Special Education and Related Services**

IDEA encompasses both special education and “related services.” The latter includes the range of other interventions designed to meet the child’s needs and enable him or her to participate in and benefit from special education, for example, speech and language therapy, occupational and physical therapy, or the services of a psychologist or an aide or paraprofessional. Assistive technology is also included. Transportation also falls into this category, for example, a special bus to and from school. However, most medical services are specifically excluded. We’ll talk about insurance coverage of medical issues at the end of this chapter.

## **Least Restrictive Environment (LRE)**

The law mandates that children be educated in the least restrictive environment appropriate to the child’s learning. The intent of the law is for children to be educated in settings that are normative, that is, where they are with typically developing, nondisabled peers. This issue has been the focus of much litigation, and in many states the standard is now twofold: (1) can the child be adequately educated in the general classroom setting if additional services are provided, and (2) if the child is in a more restricted setting, how can he be integrated into mainstream settings to the maximum extent appropriate? This right not to be segregated is considered a civil rights issue, although some parents believe that their children will receive better or more appropriate services in separate specialized settings.

Several different and sometimes competing considerations can apply here. These include the benefits to the student of being in a regular classroom with support versus a self-contained special education classroom or other more segregated classroom, the benefits to the students/peers who don’t have disabilities of being in an integrated classroom, and the disruption to the education of other students, if any, caused by the student’s behavior. A child cannot be placed in an inappropriate setting because it is less costly.

## **Participation in Decision Making and Legal Protections**

Families are specifically included in the decision-making process under IDEA. Parents and, to the extent possible, students should participate in meaningful ways in decision making. Parents have an important role in the entire process, and a series of safeguards are in place to protect their rights and those of the child. In reality, of course, many different things can impact on parents’ abilities to be strong advocates, for example, their levels of sophistication, language barriers, and other competing concerns. Protections written into the law include the

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right of parents to review and receive copies of records, to attend IEP meetings, to participate in decision making, and to consent (or not) to the proposed program (IEP). There are specific requirements about notification of meetings, rights to request independent evaluations, and the provision to parents of notice and explanation of their rights. There is also a procedure to resolve disputes between parents and schools that is designed both to promote agreement among the parties and to protect the rights of the student. These dispute resolution mechanisms are mediation or what are called *due process* hearings. Due process is what the United States Constitution requires before depriving anyone of life, liberty, or property. By calling the special education appeal hearing *due process*, Congress was emphasizing the importance of the right to an education and of the process used to develop the plan. The courts consider adherence to these rights to due process as important as the content of the IEP and the nature of the educational program. In fact, ironically, the courts and hearing officers are more likely to reverse a decision of a school district because of a failure to provide due process safeguards than because of an educational decision. The hope and expectation is that a fair and open process should produce an appropriate educational program. The box below summarizes some of the key concepts in this area.

### RIGHTS AND SAFEGUARDS UNDER IDEA

**Notice requirements:** The school must give written notice to parents of proposed changes (e.g., in placement or program) and of the parents' rights (e.g., to voice complaints or contest a planned change).

**Consent of parents:** Parents must give consent for an evaluation to be done or if reevaluation is done; schools have the right to seek such an evaluation if parents don't consent but must go through due process procedures or mediation to do so.

**Mediation:** Rather than go through due process parents and schools can use the more informal mediation process to resolve disputes.

**Due process:** Parents or the school can initiate a due process hearing to resolve disputes at any stage in the process (from evaluation, planning and placement, and review). Parents must be informed of their rights and the possibilities for free or low-cost legal representation. The due process hearing is similar to a regular court hearing (but less formal) and parents and/or the school may be represented by attorneys. An entire appeals process is also available.

**Stay put:** The stay put provision means that if a child is in a program and there is a dispute about moving the child to another program this cannot be done until a placement decision is reached, that is the school

cannot unilaterally remove a child from a program (parents, of course, can). Practically, this usually means that when a dispute is under way, the child stays where he or she is until the dispute is resolved.

## YOUNG CHILDREN: SPECIAL CONSIDERATIONS

IDEA requires that special education services begin at age 3 years and also provides a program to support early intervention services in children from birth to 3. These programs (sometimes called “birth to three” as well as “early intervention” services) provide a range of services. The focus of this part of the law is on enhancing development of children with disabilities and enhancing the ability of families to meet their needs. This was intended to be a very comprehensive program of services. In reality, the degree of sophistication and intensity of these services again varies considerably from state to state and even town to town. Some young children with autism may require and may be entitled to more intense services than are typically offered in these programs.

Young children also present special issues for “mainstreaming.” It is *not* usual for children younger than age three to be in group (school) settings. Sometimes parents have arranged for a home-based instruction program that is more typical for young children and a number of intervention programs have a strong home-based component (see *Educating Children with Autism*, 2001). Early intervention services are, accordingly, often provided in the home and a 1997 modification of the law included the term *natural environment* to be consistent with this idea.

In contrast to the IEP a different kind of plan is developed for young children. This plan is called the individualized family service plan (IFSP) and, in contrast to the IEP, it is meant to be oriented around the family. There is explicit recognition of the importance of the family in the development of very young children and that the family also needs support. So, for the IFSP, there may be specific attention focused on helping siblings or in helping parents learn ways to promote the development of their child.

Finding eligible children is a major concern of this program. The law mandates that an assessment be completed promptly and a meeting with the family to develop the IFSP be developed within 45 days of referral. The IFSP should include a discussion of the child’s development, parental concerns, and a discussion of how service will be delivered and progress monitored. Unlike the IEP, the IFSP is reviewed every 6 months. As the child nears his third birthday, a written transition to school-based (preschool) services is required, and the IEP process may begin. The IDEA requires states to ensure that the process is

completed by the time the child reaches his or her third birthday. For that reason, many states begin the process when the child is  $2\frac{1}{2}$ . The variability of programs from state to state and often within states makes it important for parents and health care providers to know what is available locally.

## DISCIPLINARY ISSUES

Special issues arise if students with disabilities are disciplined by the school. Under IDEA, it is important that the child's disability be taken into account in disciplinary matters, and even under section 504 and the ADA, reasonable accommodations may be requested (and such requests should normally be granted); for example, a child with autism who is sensitive to loud noises should not be suspended from school if he has a panic attack and runs out of school during a fire drill. Schools should have appropriate behavioral intervention programs in place; if they don't, they can't suspend the child. If a student has a behavioral plan and problems still occur, the team needs to review the behavior plan. There are very specific issues, including consideration of whether the behavior is a manifestation of the disability, that must be considered before a student can be suspended, and lengthy suspensions particularly require careful review under IDEA. Even if a student is suspended, the school is usually obligated to continue to provide educational services. Suspension is not an excuse for excluding children with disabilities from school.

For very serious situations (e.g., involving guns or danger to other students), the child can be placed in an alternative setting for up to 45 days, during which time the IEP team will review the IEP and placement. There are special aspects of the "stay put" provision of the law and specific consideration for situations where the child's behavior is a danger to self or others. If a student's educational placement is being changed as a result of code-of-conduct violations, there must be a "manifestation determination" in order to determine whether the behavior was a result of the child's disability or of the district's failure to provide an appropriate educational program or an appropriate behavioral intervention.

## THE IEP—PROCESS AND CONTENT

As noted earlier, the IEP is, as its name implies, designed to meet the individualized needs of the child for a free and appropriate public education in the least restrictive environment. Once a child has been deemed to qualify for special services, the IEP team is assembled to work on the plan. Usually, a report with a diagnosis of autism will be sufficient, but frequently the school will state that its staff is required to conduct its own assessment. Sometimes, no previous assessments will have been conducted. In these cases, with permission of the parents,

the school can (and must) conduct its own assessment or refer the child for an outside assessment at the school's expense. For younger children (e.g., those moving into school from birth-to-three programs), a formal diagnosis may not be needed initially by the school. In any case, the results of this assessment should be shared with the parents and the IEP team. Similarly, for older children, the IEP should address needs relating to transition from school to work, vocational training programs, college, or other post-high school activities. (We discuss issues relevant to adolescents and young adults in chapter 9).

The team to develop the IEP should include the following:

- The parents and the child as he or she gets older
- At least one regular education teacher—preferably the child's teacher
- At least one special education teacher
- A school psychologist or another professional who can help interpret evaluation results
- An administrator who is familiar with the range of available services
- Others, including, for example, the speech-language pathologist, behavior therapist, occupational or physical therapist, or the school nurse

Parents are also free to bring advocates to the meeting. This could be a friend, another parent, an attorney, or professionals (physicians/psychologists). It is always a good idea to bring along another set of ears to these meetings, where a large amount of information is being discussed.

The IEP covers the range of services the child needs. This includes whatever it takes to help the child benefit from special education including, but not limited to speech-language services, occupational therapy, physical therapy, psychological services, counseling, and assistive technology. School health services as well as social work services in school are also covered, as are transportation services. Any accommodations or modifications the child needs to benefit from the program should be spelled out; this includes any accommodations for standardized district or state tests. Extended-day or extended-school-year services, if needed, should be addressed in the IEP as well. The IEP is a written document, and parents should always have a copy.

Children on the autism spectrum have, of course, many of the same needs as other children. They also have some special issues, and it is important to keep these in mind. Academic goals should be reasonable relative to levels of cognitive ability. It is important that parents and teachers not be misled by the sometimes isolated special abilities seen in children with the autism spectrum disorders: some children may be able to read to “decode,” but it is a mistake to program to this level of ability in general and even for reading in particular if the ability is an isolated one (that is where reading comprehension—understanding what is

being read—is at a much lower level). In contrast to typically developing children, isolated areas of ability are fairly common in children with autism spectrum disorders. Occasionally, people assume that the isolated ability represents a general ability level and then program as if the child were functioning at that level in all areas. This can cause considerable frustration to the child. **Social skills** should be explicitly targeted. This can be done in a variety of ways, both in the classroom and through use of special supports like individual or small group work, for example, with a speech pathologist or psychologist, or in a social skills group, or both. If properly supported, opportunities for mainstreaming are very helpful. A common mistake is to mainstream older school-aged children into settings where they are most vulnerable, such as cafeteria, recess, or gym; these can be some of the *worst* settings for children on the spectrum because of the lower level of structure and lack of adult support and monitoring. Often, more academic settings or music or art can be better choices for social skills development. **Communication** needs to be encouraged, starting at whatever level the child is functioning at. Some individuals with Asperger's syndrome and higher functioning autism have better vocabulary abilities that may mislead school staff into thinking the child does not need to work with the speech pathologist. In fact, it is *communication* and not just vocabulary work that these children need. **Daily living skills** become increasingly important determinants of self-sufficiency and independence as the child gets older. An explicit focus on making skills functional, on having the family involved, and in working on generalization of skills is important. Sometimes an extended-day program is necessary to generalize daily living skills in the home. **Motor** and **sensory** issues can be addressed with the help of occupational and physical therapists. Consideration can be given to providing additional supports, for example, assistive technology such as computers, for children with fine motor coordination issues. Behavior issues/challenges need to be viewed in the context of the overall goals of the program and the safety of the child and classmates. This is an area where the efforts of behavioral psychologists can be extremely helpful and where objective data can really be helpful in informing the intervention plan.

Medical problems/issues are, strictly speaking, not part of the IEP plan, but obviously if there are major issues or problems, it is important that the school know about them. For example, if the child has seizures, is allergic to a food, or is receiving medications that impact on behavior, it is important that school staff be adequately informed. Appropriate accommodations can be made for medical problems. Vocational planning should start as children move through high school. We'll discuss this further in the chapter on adolescents and adults (chapter 9).

Given that often many different people and specialties are involved in the child's life at school, it is good to specifically address issues of coordination of

services and communication between service providers. How (and how often) will the team pass information back and forth to each other? How will they communicate with parents? Who will be the point person in talking with the parents? Who should parents primarily communicate with? When parents are appropriately involved and knowledgeable, the system can work well to help the child learn to generalize their knowledge from school to home and other settings.

The IEP fulfills several functions. First and foremost, it should be a plan for action with a reasonable presentation of the child's various abilities. Based on these strengths and needs, there should be an explicit statement of goals for his educational program—along with short-term goals and benchmarks for reaching those goals. The IEP should be explicit about what services will be provided including how frequent these are and their form and duration (e.g., 30 minutes of individual speech–language work with the school speech pathologist and one 30-minute group three to four students and speech pathologist—session each week). The goals should be operationalized in some way, that is, so you will know when the goals have been met. The law requires measurable goals, and therefore the IEP should set out how progress will be measured. This can be done in a number of different ways, but it is important that the IEP be explicit about how this is to be done. The degree to which mainstream activities are planned should also be made clear and what plans are in place (if needed) to help the student to be successful in mainstream settings. The IEP usually states the amount of time spent with typically developing peers.

The parents should be active participants in the process of developing the IEP. There are a number of excellent books/resources available to guide parents and educators in this process; many of these are listed in the reading list at the end of this chapter.

Regardless of whether the evaluations are done as part of the IEP process (i.e., by the school) or parents have independent evaluations, it is important that the evaluator understand the question(s) being asked. For example, is this an assessment primarily focused on diagnosis and eligibility or is the main goal to establish patterns of strength and weakness and to make program recommendations or primarily to monitor progress? Independent evaluations are most often needed in situations where parents and schools see a child and her needs so differently that they cannot agree on an appropriate program. School staff may have less experience with some of the intricacies of assessment of children on the autism spectrum. You want the evaluation (whether from within or outside the school district) to translate into goals that will move the child along the developmental line toward as independent an adulthood as possible and objectives that can be measured in order to monitor the child's progress toward the goals. Goals should

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cover academic and nonacademic areas: that is, in addition to progress in core academic areas such as math or writing, goals can include skills in the area of socialization, communication, self-help, and physical skills. As children become older, vocational and independent living skills may become important and should be addressed in the IEP goals.

The IEP should provide a summary of current skill levels in relation to the goals. The goals in the IEP should be written in a way that all involved can understand. Parents should always ask questions if something is not clear or does not sound like an accurate description of their child. (You know the saying that the only stupid question is the one you do not ask!) It should be clear how the goal is to be achieved and who will be monitoring progress. In general, being specific and precise is better than being diffuse and general. A goal that can be measured is better than one that can't. It is perfectly fine to have some big overarching goals ("Jimmy will improve his communication skills") as long as there are then very specific targets for assessing how this will be measured. Sometimes goals will be broken down into a specific time frame. While an appropriate goal is to improve reading comprehension, it is better if it is to improve reading comprehension by a particular amount, for example, one grade level. The objectives might be broken down to learning a certain amount of vocabulary or decoding accuracy as necessary components to improving overall comprehension. The long-term goals and short-term objectives must be measurable and should set out the methods of assessment: test scores, work product, teacher observation. This is particularly helpful when you are trying to build up ability (e.g., reading vocabulary or math) where it is possible to document progress in a very clear way. As students turn 16, the IEP should specifically address transition issues.

There are some things parents can do to be effective participants in the IEP process. First, they can bring (or, even better, supply ahead of time) any reports or documents relevant to the meeting, for example, reports from a private speech pathologist or documentation that the child has a need for occupational or physical therapy. Sometimes a pre-IEP meeting is helpful to review results of assessments or discuss preliminary plans. This can give parents an opportunity to digest the reports and discuss them with each other and any outside professionals before the planning meeting takes place. Parents can always bring someone to the meeting; this can be the other parent, an advocate, a professional, or an attorney. If appropriate, the child can also be part of the meeting. Parents can keep their own notes of the meeting and should remember to always have everything put down on paper—a verbal promise without written documentation won't work so well as a written promise. After the IEP meeting, the parents should receive a copy of the IEP and any documentation from the meeting. When it arrives, parents should read it carefully and submit additions or

corrections, if there are any, in writing. Parents should try to participate actively in the meeting—they are the people who know the child best and who are in the best position to speak for him or her.

It is important for parents to keep a couple of things in mind. As we have emphasized, the legal standard is *appropriate* education, not the *best*. Also keep in mind that the school is *not* required to provide the specific method of instruction that you chose; for example, they do not have to provide only applied behavior analysis (ABA)-based instruction. It is the school's responsibility to be sure that parents understand the range of programs and services potentially available to their child. This may include private schools or even residential programs. The fact, by itself, that the school has, for example, an "autism classroom" does not mean that this will always be the right placement for a child with autism. Consistent with the law, the goal should be the least restrictive placement possible, and restrictiveness is measured by time spent with typically developing peers. Therefore, private schools and, particularly, residential programs are often tried only after other placements have not worked out. Remember as well that you don't have to have only a single meeting; if need be, multiple meetings can be held throughout the year to fine-tune the program.

Buddha supposedly once said that if we lived long enough and stayed in one place, we'd see everything; there is undoubtedly much to this. One of us has attended many meetings over the years and has reviewed thousands of IEPs. While things often go well, sometimes they don't. A few examples can illustrate this. The child can have a wonderful IEP, but if the school doesn't follow it, this won't be much help. On rare occasions, we've been surprised that the IEP was pretty poorly done but the school program was very good. We've also seen occasions where, in the attempt to capture every possible issue, the IEP was over 100 single-spaced pages long; in this case, the attempt to get everything right resulted in a document that was too complicated to be useful.

## PRIVATE SERVICES

Parents can withdraw their child from a school program they do not believe is appropriate. They can provide home-based instruction along with services such as occupational or speech therapy on a private basis. Schools may be liable for reimbursement of parents' costs if the IEP is found not to be appropriate and if the program provided by the parents was beneficial educationally. Parents should understand that there is no guarantee that they will be reimbursed—only that they can ask for reimbursement. A decision by the U.S. Supreme Court in 1993 said that parents could be reimbursed for a child's placement in a private program that was not state certified; this was in an instance where the local school's program was judged to be inappropriate.

## DEALING WITH INSURANCE

The current crisis in the American health insurance system has an unfortunate impact on the quality and, for that matter, the quantity of care provided to individuals with all kinds of disabilities. Unfortunately, despite the considerable hype in advertisements about various insurance and health maintenance organization (HMO) programs, all of which seem to emphasize the word *care*, caring is often minimally available; unless parents and others are willing to act as strong advocates for obtaining quality care, such care often is neither available nor provided; in considering insurance plans, you should look at what the plan will provide in terms of continued care for developmental disorders, as well as for so-called “preexisting” conditions. Sometimes parents discover that insurance companies stop providing care when they switch insurance plans because the new insurance company claims the child was born with autism and had a “preexisting” condition. Another unfortunate tactic that insurance companies use is to try to avoid paying for ancillary but important services such as occupational or physical therapy or speech/language services; they may say these should be provided by the schools and not paid for by the insurance company, which may attempt to effectively limit access to more specialized care providers. This is unfortunate because even when primary care providers are very interested, often they need to have the option of asking very experienced specialists for help when problems arise.

As with anything else, if you do more homework in selecting an insurance plan, you are much more likely to be satisfied with it. It used to be the case that there were relatively few options available, and most provided about the same kinds and levels of insurance coverage. This is no longer the case. There are now many plans from which to choose—in some ways, too many. People are often not happy with their coverage but don’t always know what to do about it. While the United States has, in many ways, the most advanced health care system in the world, we still do not have universal health coverage. Complexities with insurance arise because of understandable efforts on the part of both the government and the insurance industry to save money by making insurance plans efficient and cost-effective. On the other side, these efforts can also complicate your task in getting the best coverage for your child. The effort to save money also means that insurance companies may not be as interested in having individuals with chronic problems. Probably the first things to know about are the various kinds of insurance, which ones are available to you, and what their advantages and disadvantages are.

In selecting insurance you can easily feel overwhelmed by the range of choices. It is indeed the case that selecting the best program for your child and family can be a challenge. Given that in most situations you are selecting a

program that everyone in the family must use, you have to consider everyone's needs. Therefore, you will have to keep in mind many factors. Relative to your child with special needs, it is very important to realize that often life is lived "in the fine print"; that is, you should be very careful to read all the details of descriptions of the programs. You have to be educated as a responsible consumer for your child. Do not be afraid to ask questions. You have to remember the level of needs that your child has in terms of medical care, as well as the potential for additional needs in the future. Sometimes what seems like a great option in terms of low-cost medical care does not, in fact, seem so great in reality when you spend hours on the phone arguing with the insurance company over obtaining basic services.

### **Kinds of Insurance**

Several different kinds of health insurance plans are now available. These include HMOs, fee-for-service insurance plans, preferred provider plans, government-sponsored programs, and self-insurance.

**Health Maintenance Organizations** The basic idea of an HMO is that you (and/or your employer) pay a certain amount (the premium) each month for a specified range of services. Essentially, you are paying in advance for the services regardless of whether you use them; the idea of these prepaid programs is that the costs of all the various participants will average out over the month. One great advantage of these programs is that, in theory, you should not see another bill for medical services, having paid your monthly fee. Some plans, however, charge an out-of-pocket copay for certain services and/or for prescription medications. An HMO offers several advantages: it is—at least in theory—comprehensive, with a panel of possible caregivers, and it centralizes care and the finances. Having a centralized medical record, which occurs in some HMOs, can be a great help, as is having a primary health care provider who knows you and your child well. Another great advantage of the HMO is that preventive care such as regular checkups and so forth are well covered; this offers many advantages for parents of autistic children, as it gives you and your child time to know the doctors and staff in situations where your child is not acutely ill. This will help your child be more comfortable in seeing the doctor at times when she is not feeling well. HMOs are often somewhat less expensive than other plans. The HMOs do, however, have some limitations.

Problems with HMOs arise due to the basic structure of this form of health insurance. Given that health care is centralized within a specific system, you usually can see only doctors and other health care providers who are part of the HMO. Sometimes this is not a problem, as there may be many doctors on the

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staff from which to choose, including some who have experience in caring for children with autism and related conditions. However, in some plans, there may not be people who know much about the problems of autistic children or, for that matter, children with developmental difficulties. This can be a complication when you need additional services. For example, you may be perfectly satisfied with your pediatrician but then not like the choices available to you for a neurologist, ear doctor, or **psychiatrist**. In such cases, you may be able to ask if you can use “outside” care providers (i.e., providers who are not part of the HMO), but you may not be entitled to this and might have to pay out of your own pocket if you decide to use such a physician. This may also be a problem if you want the HMO to cover related services, such as speech therapy or occupational therapy. The HMO may tell you that these services should be offered by your child’s school or that such services are not covered by your plan since this is not what it regards as part of routine, regular medical care. Because the HMO can be a relatively “closed” system, it may be hard for care providers to have access to the most advanced specialists who know about autism and similar conditions. Many HMOs have a point-of-service (POS) option. This costs a higher premium and, perhaps, higher co-pay per visit but allows you to see experts not on the HMO panel—a great advantage.

If you choose to use an HMO, it will be important for you to do some research in advance. You should find out exactly what services are covered, whether they have any doctors with special expertise in children with autism, whether you can use specialists who are not part of the HMO, how referrals to other doctors are made, and whether the program has any special exclusions that are relevant to your child. It is important that you look not only at the up-front cost (i.e., your monthly premium), but also the hidden costs, that is, the money you may have to pay for services that are not covered by the HMO, for example, costs to you for outside specialists or prescription drugs or for a psychiatrist or child psychiatrist to talk with you about medications for behavioral problems. It is also the case that the HMO may decide not to let you enroll if it is aware that your child has a chronic disability. One of the most important things to find out is whether any of the primary care staff (pediatricians and family care providers) know much about autism or are willing to learn and what specialized services the plan will cover. Sometimes, particularly in rural areas, the HMO may not give many choices for your primary care provider. You should also know that some programs, called combination programs, have features both of the HMO-type plan and more traditional insurance programs; in some cases, these may be particularly good choices for your child.

**Fee-for-Service Insurance Plans** Fee-for-service plans are the “traditional” kinds of health insurance. For many years, only such plans were available.

Typically, these plans, which are now rare, are available either through your employer or are ones you can purchase yourself. These plans usually, but not always, give you greater flexibility for deciding what doctors (or hospital) you wish to use. This, in turn, may give you the greatest flexibility in finding a physician who has the greatest compatibility with you and your child. With these plans, you pay for the service and then you are reimbursed by the insurance company, or sometimes the insurance company gets the bill directly from the doctor. In either case, the doctor gets paid for the services provided. In contrast to the HMO, you may more often have to pay some costs out of pocket over and above the cost of the premium; this can include things like copays, deductibles, and some bills for services the plan doesn't necessarily cover. It is important to realize that "out of pocket" may not mean small change and that the costs can sometimes add up quickly. The definition of what is medically necessary can vary; sometimes it may refer only to acute care, and important aspects of routine care such as checkups or hearing aids may not be covered. For children with developmental difficulties, the lack of coverage of such basic services can be a problem.

As with the HMO, it is important in selecting a traditional fee-for-service plan that you know exactly what your policy will actually cover. Look especially under the section of the policy called Limitations or Exclusions. You should never just assume that all the services your child will need will automatically be covered.

Traditional fee-for-service programs are often provided by group plans to members or employees. The thought is that, as with the HMO, there is strength in numbers and group plans have some advantages in terms of lower costs given the larger number of persons covered. Copayments may also be lower with such plans. One of the problems with group plans is the enrollment period. Sometimes you can sign up for the plans only at a certain period in time. At those times, you may not have to fill out a health history, so the insurer may not necessarily know that your child has a disability.

Traditional fee-for-service plans can also be purchased on an individual basis, that is, for a person or family. This approach is often much more expensive than coverage provided by group plans.

**Preferred Provider Organizations (PPOs)** The PPO is a variation on the HMO and is the fastest growing type of coverage. In this program, your employer or insurance company essentially makes a contract with a group of doctors or hospitals to provide care for you and your child; typically, the hospital or doctor agrees to take a reduced fee in return for the PPO sending more patients. PPOs have many of the same advantages/disadvantages as HMOs. Again, you have to be very careful to read the fine print to be sure that the particular plan is going to meet your needs.

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**Public Insurance Programs** Various public programs provide health care coverage for families who cannot afford other insurance. Such programs are funded by the federal government; the government of the individual state; a pool of funds; or some combination of state, federal, and private insurers. These include **Medicaid** or what sometimes is called medical assistance or Title 19. Medicaid is a program funded both by the state and the federal government. It provides medical care for individuals with low incomes, as well as individuals who are eligible for **Supplemental Security Income (SSI)** or people who receive what is now called Temporary Assistance to Needy Families (TANF). If you are enrolled in a Medicaid program, you receive a card that you must show every time you visit your doctor or receive medications or other medical supplies. Since the mid-1990s, most states administer Medicaid through managed care organizations.

A range of services are provided under Medicaid, including both in- and out-patient hospitalization services, laboratory services, services from physicians and laboratories, and x-rays. Although states generally must make some services available to individuals within certain groups, there is some variation from state to state. Usually, the primary care provider must ask for authorization for more specialized services; the range of choices of such services may be more limited than for other kinds of insurance.

In some cases, even if your income is a bit higher than would typically be allowed, you can still qualify for support through this program, particularly if you have a child with a disability. This can also happen, for example, if large medical bills reduce your family's income. Eligibility for such programs varies from state to state, and it is important that you check the requirements in your state.

**Medicare** is a federal government program that covers a range of services. It applies to individuals who are senior citizens (over age 65) and to some people with certain disabilities. Although Medicare and Medicaid have similar names, they are in fact very different programs.

**Health Savings Accounts** Health savings accounts were created by public law 108-173 in 2003. Any adult who is covered by a high-deductible plan can establish one of these accounts. The person or family can make contributions to this account (and these are deductible), and so can the employer.

**Self-Insurance Plans** Sometimes an employer may be large enough to set up its own insurance plan. These so-called self-insured programs may seem in many cases very similar to either HMOs or private traditional insurance plans. However, the kinds of services provided may not be as extensive as those provided by other kinds of programs. Sometimes states mandate certain benefits. It is sometimes the case that individuals in self-insured plans are not given all the mandates available. Another problem with self-insured plans has to do with denial of

benefits. With the traditional programs or with HMOs, you often can file a complaint. The complaint is dealt with at the state level by the agencies that regulate these programs. Because self-insured plans are private, filing a complaint is more complicated, and you have to be very careful to understand what is entailed in filing a complaint or using the so-called appeals process before you make a decision.

**State Children's Health Insurance Program (SCHIP or CHIP)** This is a federally sponsored, state administered program, created in 1997 to provide health care subsidies to children whose families earn too much for Medicaid, but who cannot afford other health insurance. The majority of states accept families who earn 200% over the federal poverty level. Information can be obtained from your state department of social services. The rules for this vary from state to state, and you must check with your state to see whether you qualify. Usually, the family pays premiums as in traditional programs and, as with the traditional programs, there may also be deductibles, other kinds of copayments, and various health care options.

### **Preventing and Dealing with Insurance Problems**

**Be an Informed Consumer** As the saying goes, an ounce of prevention is worth a pound of cure. Do as much work as you can before selecting an insurance policy. If you use benefits provided by your employer, see exactly what plans are available. If both parents are employed, you may have even greater access to a range of choices in insurance. Unfortunately, reading the description of an insurance plan, much less the policy itself, can be very confusing. Feel free to ask for help. For example, your employer may have an insurance office that can help answer your questions. If you are using a private insurance agent, this person can also answer many questions. Your current health care provider may be able to give you good information; parents of other special needs children, particularly if they also are employed by your company, can be good sources of information as well. It is very important to educate yourself about what is covered—you want to be sure that you do not have an unexpected surprise in discovering that the plan won't cover services your child needs. Be sure to understand exactly what is covered, your deductibles and copays, and what the exclusions are. Be careful not to be misled by what appear to be lower deductibles. Sometimes it will cost you more to have a plan that has a lower deductible than a higher one.

Particularly if you are using a group insurance plan provided by your employer, you may not always have easy access to the actual insurance policy or agreement between your employer and the insurance company. In this situation, what you often see is a fancy-looking brochure; although this may be beautifully

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done and seem very reassuring, please remember that this brochure is *not* the policy and is not what is legally binding. Always ask to see the actual insurance policy or contract to look at and feel free to ask your employer's benefits office for help in understanding it.

In looking at the insurance policy, be careful to look at what is *not* covered (excluded services). Looking at this section of the policy will give you a lot of information about what is not covered. These exclusions often include medications or certain therapies and specific services, such as mental health services or occupational or speech therapy. Check to see whether "preexisting conditions" are excluded, since autism and related disorders are always going to be preexisting because you already know your child has a problem. Sometimes there is a waiting period for so-called preexisting conditions. You might have to wait six months or sometimes even as much as a couple of years before you can receive reimbursement for some services.

Remember that insurance companies also must abide by the laws, which vary from state to state in terms of kinds of benefits that must be made available. Some states mandate certain services that must be available for children with autism. Look into other questions such as whether there is a cancellation provision to the policy, that is, whether the insurance company can decide to cancel your plan either for you as a group or for your individual child. Look to see whether there are rights of so-called conversion, that is, whether you can take a group policy and change it to an individual policy. This is important to know when your employer decides to change the group policy. It may be very difficult for your child to be enrolled in a new program, but it would then be important that you could continue the old policy as an individual policy.

There are some other things to check as well. Look to see what the maximum liability of the policy is. Sometimes insurance policies have a clause that states the total amount of money the insurer will pay over the life of the child. This may also include a certain maximum amount for a year's coverage. Check to see whether there is so-called coordination of benefits. This applies when both a mother and a father receive different insurance programs through their employer. It provides rules as to whose insurance is used to cover certain services.

It's important not to let yourself be caught by surprise, for example, when you discover that the doctor you have used for years does not participate in the plan you have just joined. Sometimes, even when you have done all your homework, problems will arise. You might, for example, discover that a private insurance program has changed its policy so that a previously approved service is no longer covered or that the care provider you really wanted is no longer participating with the insurance plan. Sometimes you may want services that the insurance plan says are not covered but that you feel should be either because you have

read the policy or because you know that in your state such services are mandated, by law, to be covered.

### Dealing with Disputes

Even when you have done your homework well, problems may arise. Keep in mind that a basic motivation of the insurance company is to make money and avoid spending it. Also keep in mind that a large insurance company may have a large staff with a fair amount of turnover (always try to talk to the same person if you can, and in any case, always keep a record of whom you talked to). Some insurance plans will have specific ways for dealing with disputes. There may be a person with the insurance company or HMO that you can use. This person may be called a patient representative or counselor or benefits coordinator; often, particularly if you are dealing with a large company or HMO, this will be the one person you can expect to be able to call on over time and who can help you deal with problems from within the system.

In dealing with disputes with the insurance company, you'll already be in a stronger position if you have done your homework—both on the specific insurance policy and what is legally mandated in your state. You should be careful to know the name of the office in your state that regulates insurance programs; this office can also help you know your rights and sometimes may be helpful in resolving problems with the insurance company. The kinds of problems you'll face will vary somewhat depending on your insurance coverage. For an HMO or PPO, for example, the problem may be in getting the plan to approve a service so that your child receives it; with the more traditional plans, the problem may be getting yourself (or your child's doctor) reimbursed once your child has received a service. It will be very helpful to you to know, in advance, how your plan is set up to deal with problems. Each plan should have a method for dealing with problems and complaints.

The following are some of the principles that can guide you in resolving problems:

- *Be an effective advocate for your child.* Always remember that you are your child's best advocate. You will know what your child needs and should not be shy in asking for it. While you should be assertive, try not to be angry or confrontational. Being assertive means you should be knowledgeable but also willing to listen. You should not be content to have a problem or complaint swallowed up in red tape.
- *Keep a record.* Always keep a record of whom you talked to and when and what you were told. Keep in mind, however, that while you are keeping a record, the HMO or insurance company may as well—including a

computer record of each time you talk with someone at the company. Keep copies of any letters or other materials that support your request. Also keep copies of any information or correspondence from the insurance company. After you have a phone conversation, make a note to yourself or write a short letter that summarizes your discussion and send it to the insurance company or HMO (but keep a copy for yourself). It may be easiest if you keep a notebook and then put things in chronological order so you can easily find them.

- *Be prepared.* You should know, in advance of talking with the company, exactly what you want and what the problem is. Be prepared ahead of this call with all the basic information such as policy number, claim number, and so on. If you have any additional information that supports your request, be prepared to share it, for example, additional supporting letters from doctors or copies of articles that support the use of the treatment you request.
- *Make good use of others.* Particularly if you are using a group insurance plan, the insurance office in your company may be helpful in dealing with the insurance company. Your health care provider may also be very helpful. Sometimes the support of other parents or other individuals who have had experience within your organization with the same insurance program can also be helpful. Use parent advocacy groups at the local, state, and national levels as sources of information as well.
- *Know the system and try to work with it.* You should know what your rights are within your state and within the insurance company. You should try to move your dispute through the system as quickly as you can. Sometimes you will discover that the person you are talking to at the insurance company is not the person who will actually make the decision about your request—if this is so, ask to speak with the person really in charge. Also think about asking your child's doctor to write a letter or offer to speak with the person in charge. If things seem to have stopped dead in their tracks, call or write again; sometimes the insurance company may hope that your complaint will go away if it takes its time responding to you.
- *What to do when the system doesn't work.* Usually, you will not want to file a complaint with the state insurance agency until you have used all your options in dealing with the insurance company or HMO. However, too many parents do not realize that they do have the right to file a complaint with the state. Similarly, you usually should not immediately think about a lawsuit; this is very expensive and there is no guarantee that you'll win in the end. However, for some parents, there may be legal advocacy groups who could help you on a reduced fee basis.

Parents should carefully consider insurance plans and the special needs of their child when they consider relocating or changing jobs. Until the time that we have universal health care coverage in this country, such concerns should, unfortunately, be central in the minds of parents.

### **Coordination Between School and Private Providers**

Occasionally, parents will be able to obtain insurance coverage for some ancillary services. At other times, parents pay out of pocket. It is important to realize that if multiple care providers are involved, there is the potential for either duplication (which is not always bad) or therapies that are in competition. For example, a child might be getting one approach to stimulating vocabulary development in school and a very, very different approach in private speech therapy. Keep in mind that sometimes this can be a good thing, but what is really critical here is to have the two professionals (school and private) have some discussion with each other. This is also very important if they are doing their own assessments. There is some potential for scores to be inflated if the child is unwittingly given the same assessment instrument more than once within a short period of time; this can mislead clinicians about what is actually going on.

### **SUMMARY**

In this chapter, we have reviewed some of the issues involved in getting services for children on the autism spectrum. In the United States, the passage of Public Law 94-142 and its various successors marked a turning point in our approach, as a society, to children with disabilities and resulted in a much greater effort to include children with autism in the lives of schools and communities. One important result of this effort has been the general trend toward improved outcome. Despite its many advantages, IDEA is not perfect. Schools understandably complain about paperwork and lack of funding from the federal government, which has never lived up to its original commitment. Parents complain that the law is not fully implemented and that procedures aren't followed. They also complain that they want the best for the child, not just what is appropriate. Although the schools aren't required to pay for medical treatments, there are some treatment modalities (e.g., speech therapy, physical therapy, occupational therapy) that clearly fall into a gray zone of being quasi medical and that the schools are required to provide as related services. However, as we've discussed, medical insurance coverage is often minimal, so if parents pursue additional ancillary services outside the school setting, there may be little if any reimbursement.

At the time this chapter was written, Congress had just passed a new law requiring parity for mental health benefits to take effect in 2010; this law would

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require that limitations for mental health coverage be no more restrictive than those for other medical problems. This may increase access to some services for children whose families have private insurance.

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## ■ WEB SITES

[www.autism-society.org/site/PageServer?pagename=life\\_edu\\_IEP](http://www.autism-society.org/site/PageServer?pagename=life_edu_IEP)

[www.ed.gov/policy/speced/guid/idea/idea2004.html](http://www.ed.gov/policy/speced/guid/idea/idea2004.html)

<http://idea.ed.gov>

[www.504idea.org/idearesources.html](http://www.504idea.org/idearesources.html)

[www.ldanatl.org](http://www.ldanatl.org)

## ■ QUESTIONS AND ANSWERS

1. **My child has been diagnosed with PDD-NOS, but the school has given him the label of autism. Is this okay?**

Labels used by schools often differ somewhat from those used by medical professionals. These labels also vary considerably from state to state and sometimes within states! Often, for purposes of getting appropriate services, the label of autism is used very broadly, so in this case, it may be perfectly fine for your child. Keep in mind that you need to evaluate labeling issues in the context of your child's particular needs and that you can always ask to discuss the label and change or drop it.

2. **My daughter had a diagnosis of PDD-NOS when she was younger. Now she is 10 years old and has been included in a regular class for 2 years. She has not needed special services. Can we now drop the label that used to get her special services that she no longer needs?**

Yes, you can indeed drop the label. If it turns out, for whatever reason, that she needs some special services in the future, you can revisit this issue with the school.

3. **My husband and I are having a disagreement with the school district. We think the goals are too broad and want something where there is something more objective, like actual data on something, but the school seems to want things very general (“Jimmy will improve his math skills”). Who is right on this, and do we have to wait until next year to fix this?**

We'd want to know a bit more about the particulars of the situation, but we agree with you that the goals objectives need to be stated in such a way that they can be monitored. Some goals can be fairly broad (to indicate areas that need to have work), but having some specifics is helpful. This can also help to connect them to specific services/service providers; for example, communication goals might be monitored by the speech pathologist. You should ask for a meeting to review this issue. You do not have to wait for an annual meeting.

4. **We have already had some trouble with our school district not following the IEP. When should we get a lawyer?**

In general (with exceptions), we would encourage parents to try to work with the school in as cooperative a way as possible. It is possible to have another parent or an advocate come with you to meetings with the school and this may well help the process. It also is the case that you can talk with other parents ahead of time in an effort to discover if there is anything special you need to know about the school or program and to learn from their experience. Getting a lawyer will typically make the process much more of an adversarial one and, in the early stages, this may actually slow things down. However, if you have what you think are serious problems and if your concerns are not being heard or you feel your child's rights are being violated, it may be very appropriate to consult an attorney. Indeed, once you are at the point of starting "due process" proceedings, having a lawyer may help move things along. Keep in mind that you need to do some homework yourself to be sure the attorney is experienced with special education cases (you can often ask other parents and you can talk to the attorney about this as well). Also keep in mind that lawyers are expensive, and you can discuss costs with him or her, but it may be that just visiting the lawyer to go over your case and seek advice may itself be very helpful. There are some provisions in the 2004 amendments to IDEA that discourage claims that are not well founded. The school district should give you a list of low-cost legal services. Parent groups, including local autism groups and the Learning Disabilities Association of America, often have lists of advocates you can work with.

5. **We have just moved to a different state. When we went to enroll our 12-year-old in school, the school social worker said he was "too high functioning" to have an IEP and that he could have a 504 plan instead, but he has never had one of these and I'm not sure what it means.**

Your question brings up several different issues. First (and probably most important), having an IEP does *not* have to do with being low (or high) functioning; rather, it has to do with meeting the requirements of IDEA and needing special interventions. A 504 plan refers to section 504 of the Rehabilitation Act and the Americans with Disabilities Act and has to do with not excluding children (or adults) from participating in programs that are federally funded based on a disability (this includes schools). A 504 plan might be written, for example, if a child had an illness like diabetes and needed some special accommodations (such as monitoring his blood sugar during the day). Similarly, if a student had

significant grapho-motor (writing) difficulties, it would support providing a keyboard or laptop for taking notes. In contrast, the IEP is an educational plan that outlines what the child needs over and above the regular program provided by the school. A 504 plan does not primarily have to do with special educational services. Sometimes students will start with a 504 plan, but if it becomes clear that special services are really needed, parents and school will move to develop an IEP. Basically, if the child needs special instruction and services, an IEP is the way to go—it is more involved than a 504 plan, but that may well be appropriate in this instance. If the school is telling you that your child has sufficiently improved and that an IEP is no longer necessary, we'd say to be careful that this is discussed thoroughly with you, and remember that even if you agree to this, you would have the option, if this doesn't work well, to ask for a meeting and talk about reimplementing an IEP.

Your question also raises the issue of what to do when you move. This happens frequently in today's world. If possible be in touch with the school or district well ahead of time—that way, they have a chance to meet you (and maybe your child) and see past records. Be sure they have copies of all the relevant materials, including the IEP. While the school can just adopt the old IEP, they may want to do their own assessment and may want to meet with you to develop a new one.

6. **The speech pathologist in school seems to be doing things very differently from everyone else. This is causing my son to be confused. When I asked for a meeting to discuss this, I was told I had to wait for another year for a review. What can I do in the meantime?**

It isn't quite clear from the question whether the problem has to do with differences between the speech pathologist and other school providers or outside providers. Regardless of which is the case, you can ask for a meeting *anytime*. If an outside provider is involved, then invite them to the meeting. You do *not* have to wait for another year to go by.

7. **I just found out that the school changed my child's program dramatically (they eliminated speech-language services) but we didn't know about it. What can I do?**

First, be sure that your information is correct. If so, then you should contact a parent advocate or an attorney. Your input is required, and the school can't arbitrarily change the IEP.

