Picking Professionals

Working with doctors you trust can help you parent with confidence. Here's how to find the best team for your child. BY PERRI KLASS, M.D., AND EILEEN COSTELLO, M.D.

In a perfect world, you would rely on an erudite and sensitive team of experts who would come to your child without preconceptions and take the time to get to know him. Their recommendations would be realistic and practical, and the evaluation and follow-up appointments would be fully covered by your insurance. Sorry-we don't have the map to that world. As you've perhaps discovered, with so many diagnoses to choose from, and a dizzying lineup of specialists to do the choosing, parents of quirky kids can lose time, money, and sleep and still find themselves knowing no more than they knew at the beginning-and perhaps trusting their instincts less.

Well, we may not have a map, but our goal here is to help you get most, if not all, of what you need as you put together your team of experts. Whether you're still looking for a diagnosis that makes sense to you, or are well down a treatment path, the following advice will help you make informed choices about your child's professionals.

The Starting Point

Parents typically start with their child's primary health-care provider-usually a pediatrician, family practitioner, or nurse practitioner. Some pediatricians have additional training in behavior and development, and many others have at least a special interest in the area. But every pediatrician spends much of his time looking at babies and young children and probably has some idea of the range of normal-and of the varieties that lie on the fringes of that range.

If you've expressed a concern about your child to your pediatrician-and he has listened carefully, interacted with your child, and examined him, but is not alarmed-consider letting yourself be reassured. It's not a guarantee, of course, but it may well mean that what you're looking at is more in the going-through-a-phase category. It can be hard to judge whether a two-year -old is off the charts in oppositional behavior and tantrums, especially if the two-year-old is your first child. If you like and trust your doctor, you might consider letting it rest here, at least for a few months. There is probably no single vital test that needs to be done as soon as possible to get anyone essential answer. (Obviously, we're not talking about diagnosing a child who's deaf or a child with classic autism or seizures. It is always important that children with major psychiatric or medical disorders be diagnosed-and treated-as rapidly as possible.)

But if you're really worried about your child's development, communicate that to your pediatrician. Stop him, look him in the eye, tell him you're worried, and tell him exactly why. Then schedule a visit to talk about your concern. Don't try to discuss it during, say, a visit for an ear infection.

Your concerns should prompt your pediatrician to do some kind of systematic developmental assessment, not just "eyeball" your child. If you don't feel you're being listened to, get a second opinion. Most pediatricians will be open to referring your child to a behavioral and developmental pediatrician if you are truly worried.

Finding a Specialist

When faced with a pediatrician who keeps telling you there's nothing to worry about, you should probably request a referral to a specialist in child development and behavior, so your child can be fully evaluated. Depending on your financial situation and your health insurance, you may prefer to locate a specialist or clinic on your own and make the appointment yourself. But if your health

insurance requires a referral from your primary care pediatrician, as many plans do, remember that you are completely within your rights to request it.

A reliable place to look is at the nearest children's hospital or major university medical center. Most metro areas should have at least one or the other, if not both. There will be a Pediatric Developmental Assessment Clinic at either type of facility. If you're looking for a recommendation to a certain type of specialist, and your pediatrician can't or doesn't provide one that satisfies you, try networking. Ask an official at your child's school or a neighbor with a child who has learning differences or someone else you trust who has experience in developmental issues

It won't take long for you to discover that there is a broad spectrum of help available. There are many kinds of specialists-with different training, different orientation, and different assessment tools-who can offer you different kinds of information. Some may be more oriented toward practical, everyday function, others more attuned to recognizing syndromes and making diagnoses. You can find experts in a school setting or at a medical center, working alone or as part of a larger organization.

Early Intervention programs, federally funded services for children with developmental needs in the first three years of life, are available in every state. For children under age three, your insurance company may insist on an EI evaluation before it will pay for any other kind of testing.

Another option is to pursue a school evaluation, either because you think it will help provide some answers or because your insurance company requires it or because the school usually covers the expense. School evaluations are often reasonable places to start, but we offer several cautions: Waiting lists can be long; the quality of the evaluators varies immensely; there is no guarantee that anyone of the evaluators will have experience with the needs of the quirky child.

We have heard parents complain about school evaluations that seemed rushed, or superficial, or focused on fitting every child into one of a few categories. On the other hand, we have also worked with plenty of gifted school-based professionals who have helped many families enormously. The school-based perspective can direct the evaluation specifically at learning issues that are vitally important for children.

Bottom line: Although you may need or want to start with a school evaluation, and it may yield valuable information, you might need to go further in your quest.

Managing the Maze

As you move through this maze of experts, your job will be to track and evaluate the information offered and to make important decisions about when to look further and when to pause.

- Understand the cast of characters. Ask the specialists you see about their qualifications and their particular fields of expertise. It's important to know whether you're dealing with a neurologist or a neuropsychologist. Even if you aren't completely sure how to integrate the specialist's background with the assessment and the advice you receive, your pediatrician and the other specialists you see may better understand the opinions you've already collected if you can fill them in on who was doing the evaluating.
- Talk! Ask questions! Take notes! Some parents just don't, or can't, get their questions answered in detail by the professionals evaluating their child. Sometimes this happens because there are still tests to be scored or conversations that need to take place among members of the evaluation team. At the very least, you should come away knowing when you will hear and how you will hear assessment results.

Someone who has just spent some time with your child should be able to give you a few reactions. It is reasonable to let evaluators know that you'd like a few minutes at the end of the session to get a sense of what they think. Take notes, so you don't have to remember exactly what you did or didn't hear. Ask to have unfamiliar terms spelled out and explained, and request sources of information you can consult. If you've had a multispecialty evaluation done, consider making an appointment to come back in and discuss the results.

- **Keep a notebook**. As time goes by, you will think of questions you want to ask, observations about your child that seem significant, ideas for further assessment. Write them all down in a notebook. There you can also make note of the specialists you see, the tests they perform, the information they give. Jot down phone numbers of programs you learn about from other parents, as well as contact data for someone who isn't that helpful now but may be in a few years. A notebook will help you track your child and your own understanding. It will also help you use your time with the specialists to ask the questions you've wanted to bring up.
- Trust your instincts. Go into this process with an open mind but also with a healthy degree of skepticism. If someone tells you something that absolutely does not fit with your sense of your child, consider it objectively. If it's nonsense, forget it. Don't let someone who can't answer questions to your satisfaction pursue a long-term therapeutic relationship with your child, no matter how grand or glorious his degrees or reception room.
- **Don't expect a "eureka" moment**. We'll say it again because it's so important: By and large, quirky kids don't fit neatly into diagnostic categories. The ongoing process of having your child assessed and considering different diagnoses can be valuable if it points the way to helping your child. Still, it's probably not going to yield a single, illuminating conclusion when you find out what's "really" going on.

Some specialists or clinics will give almost anyone a diagnosis. If you look hard and long enough, you will come across someone who will pin a label on your child-perhaps because it's the same label everybody gets at that particular clinic. Be especially wary of labels that carry immediate recommendations for expensive therapists. Don't let anyone prey on your desire to help your child. It's worth getting a second opinion or discussing the recommendation with your own pediatrician.

Most of the professionals you will encounter as you look into assessment and diagnosis will be honorable. It must be said, however, that there is something of an industry out there in providing diagnoses and therapies to kids with developmental variations. This brings us, once again, to our preference for the academic medical center.

Finally, don't forget that the point of all this-the workup, the testing, the consideration of your child by multiple experts-is not to come up with the right label, the right name, the right answer on some cosmic medical-student exam. It's to help your child-as well as to help you help your child.

Choosing a Course

Ask these questions as you consider potential therapies and therapists:

1. Does the therapy target the problems that are getting in my child's way? Keep in mind what you are targeting. What skills do you want him to gain, or which behaviors would you like to decrease?

- 2. How will we know if it's working? Ask this question during an initial evaluation. How does the therapist decide? What kinds of assessments are done at the beginning, and how often is the child reassessed?
- 3. What if it isn't helping? Can you trust the therapist to let you know if she believes that the program isn't working or that she and your child aren't a good match?
- 4. How much commitment is required? Is there any danger in stopping the program cold turkey if it isn't effective? If it's group therapy, how important is it for your child to stick it out for an entire semester or year? How would it affect other kids in the group if she didn't?
- 5. How long will it take?
- 6. Is my child the right age? There is good evidence to suggest that, the younger the age you start addressing troublesome behaviors, the more progress the child will make.

Who Can Diagnose-and Treat-ADHD?

Choosing the appropriate professional for diagnosis and treatment can be hard. Each specialty has strengths and weaknesses. Here is a short list of who does what when it comes to diagnosing ADHD.

Psychiatrist

A psychiatrist, an M.D. who treats the brain, may prescribe medication or other treatment.

ADVANTAGES

- Trained in diagnosis
- Able to diagnose, prescribe medication, and treat.

DISADVANTAGES

- Fees usually start at about \$200 an hour and go up from there.
- While psychiatrists can diagnose and treat, they may not be trained in counseling, especially in the areas of day-today life skills that may be needed by the person who has ADHD.

Psychologist

A psychologist understands how the mind works, but is not an M.D. and cannot prescribe medications. If the psychologist feels that medications are called for, he or she will have to refer the patient to either a medical doctor or a psychiatrist.

ADVANTAGES

- Trained in diagnosis
- Trained in counseling.
- Costs less than a psychiatrist

DISADVANTAGES

- Cannot prescribe medications.
- Patient must be referred for an MRI or any other test that could assist in diagnosis.

Family Doctor

Most family physicians know of ADHD but may lack the extensive knowledge of more specialized professionals

ADVANTAGES

- Is already familiar with you and your medical history.
- Is usually easier to see for an appointment.
- Can prescribe medications if needed.
- Less expensive than a psychiatrist.

DISADVANTAGES

- May have limited experience with ADD, especially in adults.
- Cannot offer counseling.
- Brief office visits often mean a hurried diagnosis.

Neurologist

A neurologist is a doctor who specializes in treatment of the brain and central nervous system.

ADVANTAGES

• Can determine if other conditions, such as seizure disorder, are present.

DISADVANTAGES

- Expensive
- EEG testing for ADHD isn't needed for diagnosis or treatment
- Patient must be referred for any counseling or therapy

Master Level Counselor

A master level counselor has a master's degree in psychology or counseling. They may be able to do an initial assessment if they have the appropriate training.

ADVANTAGES

- Is able to provide counseling, behavior management, and problem solving.
- Less expensive than psychiatric care.

DISADVANTAGES

- May have trouble with a differential diagnosis (identifying other possible problems).
- Will need to refer patient to a doctor or other professional.
- Cannot prescribe medication.

Social Worker

A Master of Social Welfare (MSW) or a Licensed Clinical Social Worker (LCSW) is often employed by an agency (for example, public health care resources) to provide counseling to people served by the agency.

ADVANTAGES

• Inexpensive.

DISADVANTAGES

- May have trouble with a differential diagnosis (identifying other possible problems).
- Will need to refer patient to a doctor or other professional.
- Cannot prescribe medication.

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