



Who Can Help?

What is this Idea of a Team?

Individuals with autism are often quite complex, so it is helpful to take a broad approach when evaluating concerns, and deciding how to provide appropriate support. In order to meet their various needs, many individuals with autism, especially those with challenging behaviors, need a team to develop specialized and individualized care.

Team Members to Consider

Depending on the placement, circumstances, services, supports and concerns surrounding your loved one with challenging behaviors, the team might include the individuals and professionals from the disciplines outlined below. The actual mix of professionals and titles will vary across situations, but for most people it will be important to have someone in each of the roles described, either as an ongoing advisor, or as a consultant at some point.

- **Individual with Autism:** To maintain a person-centered approach and treat your loved one with dignity and respect, it is essential to include his voice at the table. Keep his wellbeing in the forefront of your mind as you plan and program as a team. Seek his perspective on the behaviors that are concerning, and why they take place. With some kids, it might help to ask, *‘Why do you need to do this? How can we help?’* Wherever possible, involve him in the decision-making. Some individuals will have strong preferences that can greatly affect outcomes.

Even if it seems that your child is not able to understand what you are saying, let alone make decisions about his care, talking to him directly might deliver more information and generate more understanding than you might expect. In addition, a person who does not respond verbally can deliver a great deal of information about his comfort, preferences and dislikes through his behavior. Involving him in the treatment process can help to build his social skills, self-advocacy skills, and independence. Remember to be sensitive to talking about him in his presence, as it is possible that he understands more than he can show.

Below is an excerpt from A Full Life with Autism, from the perspective of Jeremy, a young man with autism who learned to type to communicate:

“I have often times been the victim of ignorance. I think you have to be brave to get over the horrible times people hurt you by talking like you don’t understand the comments they are making about you within earshot. I don’t think people realize the kind of effect they have on nonverbal people. You know that intentional abuse is unforgiveable, but in some cases ignorance is just as painful. I remember when I was in junior high the occupational therapist told the teacher I would never learn and she did not understand why I was in mainstream classes I was so upset because even though I could not talk or type, I could listen and learn. I wanted to die.”

From A Full Life with Autism by Chantal Sicile-Kira and Jeremy Sicile-Kira. Copyright © 2012 by the authors and reprinted by permission of Palgrave Macmillan, a division of Macmillan Publishers Ltd.





- **Parent(s):** You are the key informant and advocate and an absolutely essential member of the treatment team. Outcomes are better with family involvement. No one knows your loved one, his history or the dynamics of your beliefs and your household the way you do. You might need to tell a story or give an example to fully describe the situations you find difficult or the needs you might see in your child.

Be prepared to ask questions, raise your concerns and preferences, and ask for help. Effective communication across the team is essential, and in many cases you may be the one facilitating the sharing of information. Take notes, but also request information, suggestions and treatment plans in writing, since afterwards it may be hard to recall what was said. Ask for referrals to additional resources and share concerns about time and financial abilities. Ask for training and where else you might find help.

If you are asked to do something you cannot do because it is too expensive, too difficult, or you don't understand the objective, speak up and ask for other ideas.

You are likely to fall into a role as the team leader or coordinator, but if this is too much for you to take on, there might be help. Look into finding a case manager (see below), *special needs parent advocate*, family member or friend. Ask for suggestions from a primary care provider. Ask someone to accompany you to medical or specialist appointments to take notes and help you understand the choices and information being presented. You do not need to do this alone, but you may need to seek out and advocate for the level of supports that your family needs.

"When my daughter was moving from 1st grade to a new school, I created a 3-ring binder notebook with plastic inserts and dividers. In each plastic insert, I placed sheets of her school work both good and bad to show her growth. I included artwork, certificates and added a picture to the front. Almost just as important, I included information from her Medical Home and all of the other care providers on her team. This gave each team member and everyone who saw it, the full scope of who my daughter was. That notebook gave me the tools I needed to be the best Team Leader for my daughter. Not to mention, it helped me effectively communicate with our entire team. I still update and use this notebook method for everything from IEPs to Summer Camps...it works!!" - KD, parent

- **Case Manager:** Depending on the age or placement of your loved one, this might be a school case manager, or a representative from a service agency, such as a regional center (in California) or your state's Division of Developmental Disabilities or Department of Child and Family Services. Ideally, this person should be your direct contact, and should be helping to gather resources, team members and ideas. The effectiveness, skill set and time availability of a case manager will vary considerably due to many factors, and in some circumstances, you may not have one. You may have to advocate strongly in order for the case manager to understand the level of your concerns. If you do not have a case manager, sometimes a friend or family member can help you to research, track and organize the body of information that comes with the challenges of your loved one.
- **Medical Professional:** If you do not yet have one, try to build a 'medical home'—a relationship with a doctor who knows your child, and who you know and trust. Involve your primary doctor in evaluations, as he should be able to help when considering medical triggers for behavioral concerns. If your provider does not have a lot of experience in autism, it might help to share the list of Things to Consider in the next section and work through the possibilities together. Your doctor might refer you to specialists in areas of concern, and may be helpful in finding some of the other team members or therapists in the roles described below.





- Among others, referrals to specialists might include:
- hearing assessments (*audiologist*)
- vision evaluation (*ophthalmologist or optometrist*)
- stomach or digestive tract concerns (*gastroenterologist*)
- diet or nutrition issues (*nutritionist*)
- allergies (*allergist*)
- immune concerns (*immunologist*)

Just because an individual has autism, it does not mean that he is exempt from any of the other health concerns that affect any of us.

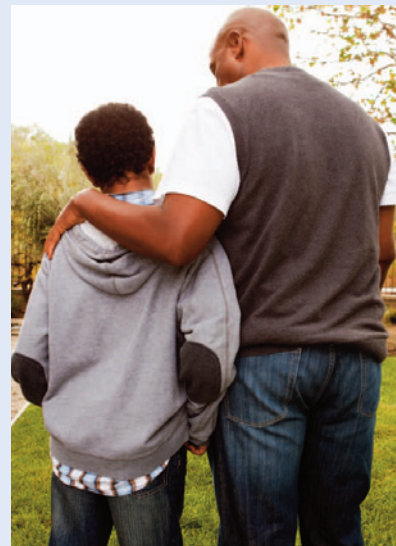
Sometimes doctors try to consider symptoms and signs, relate them back to what they know about autism and write off anything difficult to interpret as behavior. This is especially difficult if your loved one has limited language and cannot describe pain or perception issues. You might have to advocate in order to keep the focus on the individual and your concerns. Just because a broken leg is not associated with autism in the research literature, doesn't mean your child who just fell out of a tree does not have one!

In some states, you might have access to an [Autism Treatment Network](#) site, where the medical concerns associated with autism are being researched and treated according to collaboratively developed protocols with teams who specialize in autism treatment.

Is your loved one an adult or approaching adulthood?

It is important to note that while pediatricians are becoming increasingly aware of some of the issues related to autism, individuals on the spectrum are still relatively rare and novel in the world of adult medicine. Sometimes individuals with developmental disabilities stay in pediatric care far beyond childhood. If a switch to an adult provider is necessary, try to facilitate a transition of medical records as well as conversations with the pediatric caregiver. You may want to pass along this introduction for internists: '[Gently does it,](#)' caring for adults with autism, from the American College of Physicians.

If you find your loved one in the care of an adult doctor new to autism, you may need to share the information and resources provided in this tool kit, or additional general background information such as [Your Next Patient Has Autism....](#)





- **Behavioral Health Provider or Behavior Analyst:** A team member who is trained in behaviorally based evaluations and interventions is often instrumental in understanding your child's challenging behaviors and developing supports and strategies. This might be a school *psychologist*, general psychologist, *Board Certified Behavior Analyst* (BCBA) or other behaviorally trained provider. These providers will use the elements of *Applied Behavior Analysis* (ABA) in supporting your loved one.

ABA techniques involve controlling factors in the environment and monitoring interactions prior to a behavior (antecedents) and responses after a behavior (consequences). These techniques, including using positive reinforcement, are powerful in shaping behavior in individuals with autism. For more information, see the [ATN Applied Behavior Analysis: A Parent's Guide](#) and tips on [Partnering with your Child's ABA Instructor](#).

"I honestly do not know where my son, Tyson, would be today without ABA. I am a true believer, although it was definitely not easy in the beginning. I hadn't realized how much work it was going to be for me and my wife, not to mention for our BCBA, but it was well worth it in the end. We basically started breaking down every task in Tyson's life into very small, manageable steps, and we rewarded him for even his 'smallest' successes. Then the BCBA would have us systematically raise the bar as he did more and more independently. I can say that Tyson is in an inclusive middle school today (with lots of accommodations) because ABA therapy helped him learn how to do almost everything from looking, listening, and sitting in his chair."

– HK, a father

- **Educator/Job Coach/Habilitator:** If your child is under the age of 21, it is likely that he is in a school based program with a teacher. Once he reaches adulthood, instruction is more likely to come through a habilitator or staff member at a day program, or a job coach. In both instances, finding a lead educator with autism experience and background in behavioral interventions will likely be helpful. Schools will require credentials on a state-by-state basis, but there is very little licensing or required training for adult service providers in most states.
- **Mental Health Provider:** Consideration of emotional and mental health concerns, as well as training and supports for the individual and the family, can come from a psychologist, school psychologist, psychiatrist, social worker, or community mental health worker.
- **Speech Pathologist or Speech Language Pathologist (SLP):** A trained speech specialist can evaluate an individual's ability to understand language as well as produce speech. These specialists are trained to see subtle concerns that might reflect communication deficits that an individual might find frustrating. A speech professional can also be invaluable in developing *functional communication* skills.

Sometimes schools or agencies will resist providing speech services for a person who is non-verbal. But it is the development of communication systems (e.g. use of gestures and visuals, *picture exchange systems (PECS)*, sign language, *voice output technology*), not the pronunciation of sounds, that is the target for many speech therapy interventions in autism. Be persistent!

- **Occupational Therapist (OT):** An occupational therapist can help to evaluate concerns with fine motor issues, as well as the sensory and stimulation differences. Many OTs have also been trained in interventions and coping strategies to help make individuals feel more comfortable in their surroundings.





Physical therapists (PT), who generally work on large motor tasks and functions, may also be trained in related techniques. Both OTs and PTs can be instrumental in developing effective exercise programming.

Each of these team members might bring a different view of the same person to the table, providing perspective and expertise in understanding and creating systems of support. It is up to the parent, hopefully with the support of another key team member such as the case manager or doctor, to weigh and prioritize the input from these team members. A combined approach from the team should help to address physical, mental and learning concerns, and create a positive support plan for addressing challenging behaviors and helping you help your loved one with autism to grow and adapt.

Things to Look For in Your Child's Team (and Questions You Might Ask)

It might be helpful if you first go through the list of questions included below so that you have a sense of your own expectations and perspectives and can find a good match. Also keep it mind that certain personalities and styles will fit you or your child better than others.

■ **Person-centered approach:** Professionals who think of your child as a person first—not the disability or the behaviors—will be the most helpful in discovering his strengths and his challenges. A person-centered approach will allow your team to find the tools and strategies that will be most helpful to him as an individual and to you as a family. A family-centered approach is also important, so it is essential to consider the values, priorities and specific needs of your family.

■ *What do you see about my child that you think is meaningful? Helpful? Different?*

■ *What are his strengths? What can you see of his preferences and fears?*

■ *This concern is as much about the questions the provider asks you, as it is about how he answers your questions. Does he try to understand your loved one, family dynamics, priorities, strengths, confounding factors, etc?*

■ **Collaborative:** The challenging behaviors that might develop from a variety of factors will require many points of view. There may be a need for multiple providers or even multiple agencies, and the team will need to work together on the person's behalf. Collaboration also requires good communication between the members of the team. Some parents carry a notebook, an informational sheet and even makeshift brochures regarding their child to share with other team members.

■ *How do we communicate as a team?*

■ *What information can you give me to share with other team members?*

■ *How have you worked collaboratively in the past?*

"I have to say, we were lucky enough from the beginning to have assembled a group of fine people who had the very best intentions of helping my son Eli. But a few months into his preschool year, after Eli's progress seemed to have stalled, the school psychologist realized that we were not communicating well enough with each other. We were a patchwork team in which one hand hardly knew what the other one was doing. Once we started holding monthly





team meetings at the school where we could coordinate what each person found helpful, Eli really started to make a lot of progress. Keeping a daily communication book in his backpack (and now an email chain) was terrific because it kept us all in the loop and it was a way to document everyone's ideas.” – SW, a mother

- **Broad thinking approach:** Given the complexities and variability associated with autism, it is critical that team members think about all of the possible driving and complicating factors that might influence an individual's behavior. (See Things to Consider) Especially when a challenging behavior is new or has dramatically increased, medical issues should be considered early in the evaluation process.
 - *What do you know about other interventions?*
 - *Do you have any suggestions for other team members with _____ expertise who might be helpful?*
 - *Do you think _____ might reflect something physical or emotional? Is there something else we should be considering?*
- **Experience with Autism:** Especially when it comes to challenging behaviors, it is important to try to connect with providers who are experienced with autism. For example, a doctor who understands that a minimally verbal child cannot report pain may have developed other ways of gathering information about possible concerns. A psychologist who understands that sensory issues may cause a child to be more anxious in certain situations may utilize a different approach to evaluation. You can learn about the provider's experience by asking at his office, or by connecting with school or agency staff, other parents, or local support groups for suggestions and recommendations.
 - *What is your experience in working with individuals with autism? This age group? This type of challenging behavior? This intervention plan?*
- **Commitment to evidence-based interventions:** Team members should focus on medications, interventions and programming that research has shown to be effective. However, it is important to remember that each individual should be treated as such. An intervention that has been validated in a diagnosed co-occurring condition, such as depression, should not be tossed aside just because it has not been established as a treatment in autism.

The team should treat the person and the presenting symptoms, not the 'autism.'

In addition, the field of autism is evolving, and for many interventions the research has not been done. A lack of research may not mean a lack of effect or relevance to your child's situation. Consult other team members to help you assess suggestions, but also know that you might not all agree. You should work within your team to weigh risks and benefits. For more on autism best practices, see the National Autism Center's [A Parent's Guide to Evidence-Based Practice and Autism](#) and the [National Professional Development Center on Autism Spectrum Disorders](#).

- *What does the research say about the use of this intervention for _____? What other information is available?*





- **Professional judgment:** While research studies show the general effects of an intervention across a population, an evaluation of effectiveness should take place for interventions used with any specific person. Assessing effects requires set targets, goals and protocols, as well as a plan for collecting and analyzing data. Data analysis is important so that you know what is working, and when and if alternate treatment choices should be considered.
 - *What is the target behavior of this intervention?*
 - *How will we know if it is working? What are we tracking?*
 - *What are the side effects?*
 - *What is our role in the intervention?*
- **Responsiveness:** Providers should give you as much information as you need to understand the intervention and your role in it. They should listen to your concerns and priorities—cultural, familial, financial, etc.—and be able to adjust interventions to make them work for your family, the team, and the individual’s needs. Voice your concerns and challenges so the providers can best support you and your loved one.
 - *What is my role in this plan or intervention?*
 - *How can we adjust _____ to take into consideration our family’s needs? My travel schedule? Our insurance plan?*
 - *This is too hard. Data reflects that it is not working. This medication is making him worse. What do we do now?*
- **Licensing, board certification or other credentials:** It might be helpful to request references and talk to others who have used a provider you are considering. A list of certification and credentials required for the team members above is listed below:
 - **Occupation Therapist/Physical/Speech Therapists:**
 - OT/PT/SLT State Certification Required (available online)
 - [National Board for Certifying Occupational Therapy](#) (voluntary certification)
 - [American Speech-Language-Hearing Association](#) (voluntary certification)
 - **Mental Health Provider:**
 - Psychologist License: State Licensing Board (available online)
 - Psychologist Certification: [American Board of Professional Psychology](#) or [National Association of School Psychologists](#)
 - Clinical Social Worker: State license or certification (available online)
 - **Behavioral Health Provider:**
 - Certification, required for BCBA designation, but not required to use ABA: [Behavior Analyst Certification Board](#)
 - **Medical Professional:**
 - License: [United States Medical Licensing Examination](#)
 - Certification required: [American Board of Medical Specialties](#) or [American Osteopathic Association](#)





How and Where to Find a Team

For school age children, many of these providers will be available through your school (ask your child's teacher or *Individualized Education Plan (IEP)* team case manager), or by referral from your school team or your doctor. Schools are required under the *Individuals with Disabilities Employment Act (IDEA)* to use *Functional Behavior Assessment (FBA)*, and then to support the learning of a child in school using a *Behavior Improvement Plan (BIP)* when necessary. Further information is available [here](#) and [here](#).

Additional case management and referral ideas might come through your state disability agency, county offices, or social services agencies. Often there are printed resource directories or you might search online for your state's agency for developmental disabilities. Check phone books and county websites for government offices that might lead to the right agency. You may need to call several numbers to find out how to get to the right place for what you need. This may be quite frustrating, but be persistent! Public health departments, offices of children and family services, disability services or developmental disabilities may be helpful; sometimes their work is subcontracted to other organizations such as Easter Seals or United Cerebral Palsy, or groups that only exist in your state or city. The Autism Speaks [Resource Guide](#) also contains state information by age.

"Each time we saw a new doctor or therapist, or my daughter joined a new group or activity, I became increasingly overwhelmed. I oftentimes found myself just staring at papers and numbers and not knowing where to start. A friend of mine, whose child is also on the spectrum, suggested I reach out to a case manager to help me sort through everything. I wanted to think I could do this all on my own but decided to call. After an hour-long meeting with a case manager at a local organization I felt much better. There's still so much to do but I feel like I have a clear path to get there now."

– MM, a parent

Some states have *wraparound* programs, designed to build teams of providers, family members and natural supports to help keep complex youth in their homes and communities. In autism, wraparound services can sometimes fund behavioral programming. You can find a Board Certified Behavior Analyst (BCBA) [here](#).

For adults, referrals might come through an existing service provider, medical home or *Medicaid* case manager. Contacting the county or state agencies will be similar to what is described above, but different agencies may be involved in care for adults.

It is important to note that your primary or initial contacts may not have the necessary time or specific skills necessary to fulfill the needs of your child, his evaluation, or ongoing supports and interventions. You may need to ask for additional referrals and supports. Keep asking.

Contacting other parents, often through your child's school, program or local autism support groups, might reveal additional suggestions and resources, especially for providers who are already working in the field of autism. Attend conferences, lectures, or fundraising events such as [Walk Now for Autism Speaks](#). Even if you don't have time for the lectures or the event itself, take a pass through the vendor tables that are often set up just outside to meet area providers who might be able to help.

To access supports or resources specific to your state, please consult the [Autism Speaks Resource Guide](#). If you have found providers that have been helpful, please submit them to the database [here](#).





Funding Sources

Even if you have an experienced professional team assembled, paying for the additional services and supports can be yet another hurdle. Services provided by the school under the stipulations of IDEA are required to be free and appropriate. That means you do not need to pay, and if the school does not have the necessary skills or staff to meet your child's needs, it is their responsibility to pay for the services required to do so. It may require significant advocacy to get them to do what the law requires. More information on your rights under IDEA can be found [here](#).

Ask your Human Resources officer about benefits, or check with your insurance company. Contact the public health department to learn about community plans such as those for mental health or those targeted to children. Funding for medical needs is often covered through health insurance and/or Medicaid. Speech and occupational therapists, as well as medical specialists, are often covered under medical plans. Historically, some of these benefits were specifically denied for autism and developmental disabilities, but as autism has become more common and research and advocacy efforts have increased, coverage for these items is improving.

Some states have mental health parity laws, which indicate that mental health care has to be covered to the same degree as physical health issues. Some insurance plans also have stipulations for behavioral health supports and interventions, and Medicaid programs provide *wrap around* services for behavioral interventions. It may take some significant investigation through your Human Resources department, your insurance company or the Medicaid office to find out the details of the mental or behavioral health coverage available. You may find assistance through your primary care provider or a case manager.

Military families are covered by *TRICARE*, the military healthcare program, which provides for limited ABA coverage for certain beneficiaries under the TRICARE Extended Care Health Option (commonly referred to as the ECHO program). Learn more about TRICARE eligibility criteria [here](#).

Autism insurance legislation is in the process of being enacted state by state, with various terms regarding implementation and coverage. More than 30 states have passed autism insurance laws; they are listed on the [National Conference of State Legislatures](#) website. It is advisable to investigate and understand your coverage so that you know what to expect before beginning services. To find out the status of specific laws for insurance coverage for autism services in your state, visit the Autism Speaks [Autism Votes](#) website and select your state.

Certain state agencies can also provide funding for *respite*, which is helpful in giving you a chance to catch your breath. These agencies, such as Departments or Divisions of Developmental Disabilities or Children and Family Services may have programs, supports or suggestions of resources.





Sources/Resources:

Behavior Analyst Certification Board, Inc. (BACB)

<http://www.bacb.com/>

'Gently does it,' caring for adults with autism

<http://www.acpinternist.org/archives/2008/11/autism.htm#sb3>

National Autism Center's *A Parent's Guide to Evidence-Based Practice and Autism*

http://www.nationalautismcenter.org/learning/parent_manual.php

National Conference of State Legislatures (autism insurance information)

<http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx>

National Professional Development Center on Autism Spectrum Disorders

<http://autismpdc.fpg.unc.edu/>

Special Needs Parent Advocate

www.specialneedsadvocate.com

Wrightslaw (special education and disabilities legal information)

www.Wrightslaw.com

US Bureau of Labor Statistics *Occupational Outlook Handbook*

(Information on practitioner training and qualifications)

www.bls.gov/OCO/

Your Next Patient Has Autism...

<http://www.northshorelij.com/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobkey=id&blobtable=MungoBlobs&blobwhere=1247088820137&ssbinary=true>

