

# A Map for Your Journey

*It is good to have an end to journey toward, but it is the journey that matters in the end. Ursula K. LeGuin*

## A MEANINGFUL DIAGNOSIS

Diagnosis is a critical point on the journey. It can be a useful tool in two ways. First, identifying your child's unique strengths and weaknesses will determine how to best help him or her. Second, a diagnosis can open the door to services. Insurance companies, government agencies and schools use the diagnosis to determine eligibility for programs and benefits. While it is an important point in the journey, **a diagnostic label does not change who your child is as an individual.**

In seeking a diagnosis, your child may be referred to a specialist: a developmental pediatrician, a neurologist, a psychiatrist and/or a clinical psychologist. The type of professional that you see is not as important as the amount of experience they have diagnosing autism. Find professionals who allow you to discuss your concerns: **no questions that you have regarding your child are trivial or unimportant.**

Arriving at a diagnosis sometimes involves medical tests. The tests do not confirm that a child has autism, but may rule out other possible causes for the developmental delay. Before agreeing to testing, you may want to ask how and why the test is performed, and how the test will influence a treatment plan. After testing is complete, ask the professional to explain the results in language that you understand. Ask how the findings can be used to develop a treatment plan. Always ask for a copy of any test result, report or evaluation. Websites to visit: [www.nichcy.org](http://www.nichcy.org)

**Not everything that is faced can be changed. But nothing can be changed until it is faced.**  
*James Baldwin*

## BUILD A TEAM

Developing and implementing a successful treatment plan requires a team approach. Usually, family members and teachers are the core members of the team. Therapists, doctors, day care providers and friends should all be invited to participate as members of the team. In order for the team to be effective, all team members need to show respect for the individual with the disability, regard parents as experts on their children and convey a sense of hope. Working together, team members develop a treatment plan. Team members need to set up a way to share information about which aspects of the plan are working and which need to be rethought. Not all team members will participate in every decision, but all need to be kept informed with phone calls or e-mail. **As much as possible, encourage the person with ASD to participate as a member of the team.**

Websites to visit: [www.mncdd.org](http://www.mncdd.org)

**Nobody can do everything, but everybody can do something.** *Anonymous*

## KNOW YOUR RIGHTS

One of your main responsibilities as a parent of a child with a disability is to be an effective advocate for your child, protecting his/her rights. In order to be a good advocate, you need to know what your child is entitled to by law. Two important laws that concern the rights of people with disabilities are the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). In addition to knowing your rights, it helps to know how to ask for help. Always try to be diplomatic, and keep a record of each interaction. The records will be useful if you need to move up the chain of command.

Websites to visit: [www.advocacycenter.org](http://www.advocacycenter.org), [www.wrightslaw.com](http://www.wrightslaw.com), [www.firn.edu/doi](http://www.firn.edu/doi)

**Diplomacy is the art of letting someone else have your way.** *Wynn Catlin*

## CONNECT WITH OTHER FAMILIES

**It is important to remember that you are not alone.** Many other families have come before you and can share their experiences with you. In addition to providing emotional support, parents can offer insight on many important matters. For example, they know what help is available in your community and how to access it. Parents can also share information on which intervention strategies have worked with their children. Another important reason to develop relationships with other parents is that there is strength in numbers. When government entities are making decisions that affect your child, it is powerful to have a group of vocal parents advocating for their children.

Websites to visit: [fnfll.org](http://fnfll.org), [www.autism-society.org](http://www.autism-society.org), [www.autismfl.com](http://www.autismfl.com)

**Shared joy is double joy; shared sorrow is half sorrow.** *Swedish proverb*

## EXPLORE COMMUNITY RESOURCES

Federal, state and private agencies exist to help families of children with disabilities. Each agency offers different kinds of help, has its own application process and uses different criteria to determine who is eligible. Since many agencies have a waiting list, it is wise to apply as soon as possible, ideally before you really need the help. **Getting help often requires persistence.**

Websites to visit: [www.ssa.gov](http://www.ssa.gov), [apd.myflorida.com](http://apd.myflorida.com), [national.unitedway.org](http://national.unitedway.org), [www.floridarespite.org](http://www.floridarespite.org), [www.rehabworks.org](http://www.rehabworks.org)

**In this age, which believes that there is a short cut to everything, the greatest lesson to be learned is that the most difficult way is, in the long run, the easiest.**

*Henry Miller*

## INDIVIDUALIZE TREATMENT

Each person with ASD has a unique profile of strengths and needs, so treatment must be tailored to the individual. There are dozens of intervention strategies from which to choose. You can learn about your options by going to trainings and workshops, reading books and articles and talking to other parents and professionals. You will want to find out whether or not the treatment has been scientifically validated. Because there is no cure for ASD, you will want to be skeptical of treatments that claim to cure autism. Also be wary of treatments that promise quick results. **Typically, good treatment results in slow, steady progress, not miraculous transformation.**

Websites to visit: [www.teacch.com](http://www.teacch.com), [www.firn.edu/doi](http://www.firn.edu/doi), see CARD website addresses on reverse side

**Many an opportunity is lost because a man is out looking for four leaf clovers.** *Anonymous*

## PRIORITIZE

Perhaps the hardest thing to do is to figure out where to start. It may feel like there is so much to do that it could never all get done; and it is true that there is a lot to do. Overwhelmed by possibilities, you may feel unable to act, but there are many ways to get the ball rolling. Start by asking yourself, your family members and your child with ASD to name the one issue that would improve the child's quality of life. Person Centered Planning is another useful brainstorming tool to help you prioritize and imagine your child's ideal future: is she living at home, with a roommate or alone? Does she have a job? Friendships? Now the Person Centered Planning team works backwards and identifies what steps could be taken now that would help build this ideal future. For example, if friendships are an adult priority, focus on teaching your young child how to share toys and take turns. **The most important thing to remember is to take one step at a time.**

Websites to visit: [www.mncdd.org](http://www.mncdd.org), [www.uvm.edu/~cdc/](http://www.uvm.edu/~cdc/)

**Small deeds done are better than great deeds planned.** *Peter Marshall*