

Getting an Accurate Diagnosis for Your Child 10 Steps for Families

Getting an accurate diagnosis for your child can be challenging. Several factors contribute to this challenge, including the following:

- Symptoms – that often include extreme behaviors and dramatic changes in behavior and emotions – may change and develop over time.
- Children and adolescents undergo rapid developmental changes in their brains and bodies as they get older and symptoms can be difficult to understand in the context of these changes.
- Children may be unable to effectively describe their feelings or thoughts, making it hard to understand what is really going on with them.
- It is often difficult to access a qualified mental health professional to do a comprehensive evaluation because of the shortage of children’s mental health providers and some health care providers are reluctant to recognize mental illnesses in children and adolescents.

Despite these challenges, there is still plenty families can do to help their child get an accurate diagnosis and ultimately receive the most effective treatment, supports, and services. Here are ten steps that families should take to help their mental health services provider make an accurate diagnosis:

1. **Record Keeping:** organize and keep accurate records related to your child’s emotional, behavioral, social, and developmental history. The records should include observations of the child at home, in school, and in the community. They should be shared with the child’s treating provider to help in making a diagnosis.

The records should include the following information:

- Primary symptoms, behaviors, and emotions of concern;
- A list of the child’s strengths;
- A developmental history of when the child first talked, walked, and developed social skills;
- A complete family history of mental illness and substance use disorders – many mental illnesses run in families.
- Challenges the child is facing in school, in social skill development, with developmental milestones, with behaviors, and with emotions;
- The times of day or year when the child is most challenged;
- Interventions and supports that have been used to help the child and their effectiveness – including therapy, medication, residential or community services, hospitalization, and more;
- Settings that are most difficult for the child (i.e. school, home, social situations);
- Any major changes or stresses in the child’s life (divorce, death of a love one, etc);
- Factors that may act as triggers or worsen the child’s behaviors or emotions; and
- Significant mood instability or disruptive sleep patterns.

Families know their child best and their expertise is essential in securing an accurate diagnosis for their child.

2. **Comprehensive Physical Examination:** To make an accurate diagnosis, it is important to start the process with the child’s primary care physician. A comprehensive physical examination should be done to rule out other physical conditions that may be causing a child’s symptoms.
3. **Co-occurring Conditions:** Your child should be evaluated for co-occurring conditions, like learning disabilities, sensory integration problems, and other physical or mental disorders, that may cause behavioral problems or poor school performance. If you suspect that a co-occurring condition is affecting your child’s ability to learn, ask the school to perform a psycho-educational evaluation.

4. **Specialists in Children’s Mental Health:** After other physical conditions and learning disabilities are evaluated, it is time to meet with a qualified mental health provider. Your child’s primary care physician may be able to refer you to a mental health professional. You can also ask for referrals from families involved with NAMI or other advocacy organizations.
5. **The Diagnostic and Evaluation Process:** A medical diagnostic tool, like a blood test, MRI scan, or x-ray that will diagnose mental illnesses in children has not yet been developed. Your child’s diagnosis should be made based on professional observation and evaluation, information provided by your family and other experts, and the criteria found in the latest version of the Diagnostic and Statistical Manual of Mental Disorders. This evaluation should include a comprehensive look at all aspects of your child’s life in school, with family, with friends, and in the community. The provider evaluating your child is likely to ask you to fill out a checklist that provides a detailed profile of your child and the challenges your child is facing.
6. **Adjustments in the Diagnosis:** It may take several visits with a mental health professional before a diagnosis is made. The diagnosis may also change as new symptoms emerge or existing symptoms change. A diagnosis must be confirmed over time and thus an ongoing two-way communication between the treating provider and the family is necessary to track and monitor the child’s condition and progress. Families should not hesitate to seek a second opinion if they are not confident in their child’s evaluation and the diagnostic process. Getting a second opinion can be challenging because of the shortage of children’s mental health providers.
7. **Effective Interventions and Outcomes:** If a diagnosis continues to change or cannot be reached right away, it is still important to focus on effective interventions to address the child’s symptoms. The goal should be to achieve the outcomes that are most important to the child and family.
8. **Working with the School:** You should consider meeting with your child’s teacher or other school officials to discuss appropriate accommodations and supports for your child. Families should work with the school to identify effective interventions, accommodations, and supports that promote positive behaviors, academic achievement, and prevent challenging behaviors in school. Families should ask their child’s treating provider to identify interventions that can be used at school and at home to help your child acquire positive behaviors and academic achievement.
9. **Service and Support Options:** Ask your child’s treating provider to recommend effective psychosocial interventions, skills training, support groups, and other options that can help your child cope with symptoms and develop the skills necessary to ultimately lead a full and productive life.
10. **The Importance of Families:** Never underestimate the importance of working with other families. There are many seasoned families who have walked the walk and are happy to share their wisdom and experience with families attempting to secure an accurate diagnosis and effective services for their child.

For some children, having a diagnosis is scary and they may be resistant to accept it. Others are relieved to know that what is happening to them is caused by an illness, that they are not alone, and that there are treatment options that can make them feel and do better. It is important to find ways to use the strengths and interests of your child to help him or her cope with difficult symptoms. Benefits are often derived from aerobic exercise, martial arts, music, and art – whatever it takes to provide your child with a therapeutic outlet. The diagnosis is one piece of a much larger puzzle.

Please visit NAMI’s Child & Adolescent Action Center at www.nami.org/caac.