So your child was diagnosed with ASD: What comes next?

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Receiving an ASD diagnosis for a child may be accompanied by a variety of reactions. For many parents and caregivers, the diagnosis may confirm what they had suspected. For others, it may come as a shock. Parents commonly note whether they had expected an ASD diagnosis or not, they often hoped they would have been told that there was nothing wrong. Remember to ask for and accept help.

While it may take some time to deal with the emotional reaction to an ASD diagnosis, action is needed to ensure the child receives appropriate services. The actions can be broken down by category and potential resources.

* *Develop an action plan*- The action plan outlines first steps in securing services. Helpful resources include the Autism Speaks First 100 Days tool kit geared toward children under four years old: [100 day tool kit for < 4 years old](file:///C%3A%5CUsers%5CJHarris%5CAppData%5CLocal%5CMicrosoft%5CWindows%5CTemporary%20Internet%20Files%5CContent.Outlook%5CJUYSZ4NL%5C%E2%80%A2%09https%3A%5Cwww.autismspeaks.org%5Cdocs%5Cfamily_services_docs%5C100day2%5C100_Day_Kit_Version_2_0.pdf) and Autism Speaks First 100 Days tool kit for school-aged children: [100 Day Kit – School Age](https://urldefense.proofpoint.com/v2/url?u=http-3A__www.autismspeaks.org_family-2Dservices_tool-2Dkits_100-2Dday-2Dkit-2Dschool-2Dage&d=DwMFAw&c=LfJFs5tz11XIvZ1zGnYRWYcpprcdQWHKbyr0OjT-Gjk&r=mlOz4i1yeEY9BYiJ8xtuGodGaliT0ALO1MXoD5xuOw-9HXYs-Yqq3D9hjUaLMkZi&m=ccihwHcHW9JpUGHdA3DVKnPzK2XiYTXlw3aayMittTs&s=jCkKPFLQTi0LZNFqaCBjR7JcXF476IOPoAdvO1r3MYg&e=)

Autism Speaks also operates an Autism Response Team at 888-288-4762; En Español: 888-772-9050 for information and resources local to the area.

* *Find out about the diagnosis*- Free parent/caregiver workshops may be offered through diagnostic centers or ASD support groups. This provides not just an overview of ASD diagnostic and treatment services but also an opportunity to connect with other families who are also newly diagnosed to share tips and support. For example, Children’s Specialized Hospital provides “Navigating the Journey” workshops that include multidisciplinary experts discussing social, behavioral, medical, communication, occupational therapy, educational advocacy issues as well as a panel of experienced parents of children with ASD.

The internet can be helpful but make sure the source is reliable, evidence-based and relevant for your child.

Additional resources:

* Autism Speaks website has information as well as toolkits on topics including dealing with challenging behavior, sleep issues, dentist and doctor visits, etc. For lists information regarding local services: www.autismspeaks.org
* The Autism Society website has general ASD information as well as information on many topics ranging from legal resources, understanding research and advocacy. www.autismsociety.org
* Children’s Specialized Hospital Real Life Tips “Understanding the Diagnosis of ASD” Tip sheet:

<https://www.childrens-specialized.org/Content/Uploads/Childrens%20Specialized/Files/Real-Life-Tips-for-Kids-with-Autism-Understanding-Diagnosis-ASD.pdf>

Video: [www.youtube.com/watch?v=9S4Y4V0Oe4c](http://www.youtube.com/watch?v=9S4Y4V0Oe4c)

* *Obtain intervention*- For children from birth to age three, Early Intervention (part C) programming can arrange a free screening to confirm eligibility and to develop an individualized family service plan. EI services vary from state to state but are typically home-based with focus on training the parent/caretaker to implement the intervention with the child. Depending on the state, the services may be free or provided on a cost-shared basis. Contact number in NJ is 888-653-4463

For children 3 or older, contact the local school district to request evaluation and services. It is important that the parent/guardian submit the request in writing in order start the clock ticking to ensure a timely response from the district.

It is important to ensure that all intervention is evidence-based, individualized, data is recorded and that progress is being measured and analyzed.

Additional resources:

Wrightslaw site has information about educational services including early intervention <http://www.wrightslaw.com/>

Autism Science Foundation has information regarding ASD treatments <http://autismsciencefoundation.org/what-is-autism/treatment-options/>

For information re: evidence-based interventions: The National Autism Center’s National Standards Project <http://www.nationalautismcenter.org/resources/for-families/>

Or The National Professional Development Center’s Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder: [http://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/fi les/imce/documents/2014-EBPReport.](http://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/fi%20les/imce/documents/2014-EBPReport.)

* Care for the caregiver- When a child receives a diagnosis of ASD, it likely affects the whole family and may feel overwhelming. It is important for caregivers to try to get rest, exercise and take a break when possible. In addition to your existing sources of emotional support, you can build a new support system through local support groups (in person or online), or with a professional therapist or counselor. Statewide ASD information and advocacy organizations may have local resources. In New Jersey, a 24 hour hotline, Mom 2 Mom is manned by trained parents and other family members and is monitored by a trained mental health professional. [www.mom2mom.us.com](http://www.mom2mom.us.com)

Autism Speaks Family Support tool kits: [Family Support Tool Kits](https://urldefense.proofpoint.com/v2/url?u=http-3A__www.autismspeaks.org_family-2Dservices_tool-2Dkits_family-2Dsupport-2Dtool-2Dkits&d=DwMFAw&c=LfJFs5tz11XIvZ1zGnYRWYcpprcdQWHKbyr0OjT-Gjk&r=mlOz4i1yeEY9BYiJ8xtuGodGaliT0ALO1MXoD5xuOw-9HXYs-Yqq3D9hjUaLMkZi&m=ccihwHcHW9JpUGHdA3DVKnPzK2XiYTXlw3aayMittTs&s=PD1s5yxiIqP62Z-RRmhWl5QY4F-YMAUevQ3OCxGVcxE&e=)

* Explore disability eligibility- Children and adults with ASD may be eligible for Social Security Disability services if there is documentation of serious limitation in understanding, remembering, or using information; interacting with others; focusing on activities; and adapting or managing oneself. In NJ, determination of developmental disability services for someone under age 18 is through PerformCare 877-652-7624

Additional resource: [Social Security Administration SSI overview](https://www.ssa.gov/pubs/EN-05-10026.pdf)

* Consider case management support- ASD is a complex condition and often involves services across a variety of providers and settings. Case management can help coordinate care, provide information, assist with applications for services, and advocate with educational, insurance or other service providers. Case management may be available through state developmental disability agencies, county special child health services, insurance (including Medicaid) or other advocacy agencies. In New Jersey, for example, each county has a Special Child Health Case Management unit that assists with linking to services and advocacy. <http://www.state.nj.us/health/fhs/specialneeds/contacts.shtml>

Care managers for NJ Medicaid:

* Consider anticipatory guidance- It is helpful to anticipate developmental progress and to learn which activities may help engage the child and spur development. The CDC Milestone Moments resources are geared to children under five. A developmental tracking app is also available.

Milestone moments birth-age 5years (English):

<https://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/milestonemomentseng508.pdf>

Milestone moments birth-age 5 years (Spanish):

<https://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/LTSAE_Booklet_MilestoneMoments_SPAN-ReaderSpreads_Web-ready_7.22.11.pdf>

* Get involved in recreation- Recreation can provide opportunities for socialization, promote wellness and build lifelong leisure skills. Recreation programs may be under ADA requirements to provide inclusive programming and supports. Some families seek recreation programs that are geared exclusively for children with special needs, while others prefer programs serving all children, with supports as needed. Resources include town and county recreation departments, YMCA/YWCA, scouting programs, and other public and private agencies.
* Sharing the diagnosis with others- Deciding when to discuss the diagnosis with the child is an individual decision and influenced by the child’s developmental age. It may be helpful to shape the discussion around how people have differences and similarities, strengths and challenges. The term for the child’s pattern of strengths and challenges is ASD. While people with ASD have some things in common, they are all different.

It is often helpful to share the diagnosis with relatives, coaches, and others routinely involved with the child to ensure they have accurate information and to enlist their support.

Additional resources: [Partial list of books for children about ASD](https://www.appliedbehavioranalysisprograms.com/30-best-childrens-books-about-the-autism-spectrum/)

* Kohl’s Autism Awareness Community Hub- This site operated by Children’s Specialized Hospital provides a comprehensive variety of videos, resources, educational programs, and apps offering helpful tips and resources related to dealing with challenging behaviors, safety, inclusion, school, recreation, healthcare, and many other areas. Many of the resources are in Spanish as well as English. [www.childrens-specialized.org/KohlsAutismAwareness](http://www.childrens-specialized.org/KohlsAutismAwareness)

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