

Getting Started: For Families of Young Children with ASD

You have just been told by the medical-educational team your child has an Autism Spectrum Disorder (ASD). What do you do now? Your first steps should include getting more information about ASD, getting services for your child, and getting support for you and your family. These steps are outlined in detail in the First 100 Days Kit from Autism Speaks Family Services, http://www.autismspeaks.org/docs/family_services_docs/100_day_kit.pdf

Your child may already be seeing a Speech Therapist or already receiving Early Intervention (EI) or Early Childhood Special Education (ECSE) services. The EI program in your community will be a critical part of your child's treatment program. **Share information about your child's diagnosis with your therapist or EI staff member and schedule an appointment with your child's health care provider in the next week or two.** These professionals will help you understand your child's diagnosis and needs and will help you find the services recommended by the medical-educational team.

Behavioral and educational programs are the primary treatments for children with ASD. In general, 20-25 hours or more per week of structured services is recommended. This includes the services provided by Early Intervention, other community services and structured activities you can do at home. You can incorporate many of these activities into your daily schedule, for example, during play time, when getting dressed and when meeting people.

As you read more about ASD and talk to other parents you will learn there are many different intervention programs for young children with ASD. Many of these programs are based on applied behavior analysis or ABA principles. The Early Start Denver Model and Pivotal Response Training (PRT) are two such programs. In general, these programs teach skills by breaking them up into small steps and teaching one step at a time. Each child with ASD is different and needs a treatment program designed for them. Details on many of the programs are included in the Autism Speaks First 100 Days Kit.

A good place for you to start with treatment at home is to imitate what your child does in play. This also has been called following your child's lead. This very simple play strategy is the basis of Stanley Greenspan's Floortime, <http://www.stanleygreenspan.com>, and has been incorporated into other intervention programs such as a program to teach social communication to young children with autism developed by Brooke Ingersoll and Anna Dvorschak. This curriculum is now available online as the IMPACT Online program. Ask for a flyer from the assessment team. Early Intervention (EI) programs in Oregon incorporate parts of many different treatment programs including treatments based on ABA and the social

communication curriculum. Your EI/ECSE provider will help you learn how to work with your child during typical daily routines at home.

Several community programs may be helpful to you and your family. The public health nurses of Oregon's CaCoon program can help you find needed services and give you support in navigating what at times can be a confusing system of services. CaCoon nurses are available through your county health department. In your county, call _____.

You and your child also are likely eligible for Developmental Disability (DD) services. Community Developmental Disability programs are present in each county. In your county, call _____. Services include care management, family support, and other supports available through the new K plan and the children's intensive in-home services (for children with challenging behaviors).

Your child and family also may be eligible for supplemental income through the Social Security program, <http://www.ssa.gov/applyfordisability/child.htm>. Eligibility is based both on your child's medical diagnosis and family income.

Finally and most importantly find the support you need as a parent and an individual. Initially you may be surprised and confused by the diagnosis. You may have questions about how to tell other family members about your child's diagnosis. Take time for yourself and your family. Share with your family's traditional support persons. Talking to other parents of children with ASD also may be helpful. Many communities have organized parent groups for parents of children with ASD or parents of children in EI programs. Ask your EI provider or health care provider for information about local parent groups. Information about parent groups also is available through the Autism Society of Oregon, <http://autismsocietyoregon.org>

There is a great deal of information on autism spectrum disorders (ASD) on the Internet. Some of it is very helpful and other information can be misleading. If you have questions about the information you have read, discuss it with your child's primary care provider, therapist or EI staff person. The following are some websites which may be helpful to you in learning more about ASD, planning activities with your child, and how-to information on construction of visual schedules, social stories and related materials:

Autism Society of Oregon, www.oregonautism.org

Autism Speaks Family Services, <http://www.autismspeaks.org/family-services>

Autism Spectrum Disorder Resource Site for Oregon, resource library with articles and books for families, and information on teaching communication, visual and social story resources, and

understanding behavior. Click on "for parents and families" under Autism Services menu,
<http://www.nwresd.k12.or.us/autism/VisualStrategiesI.html>

Autism Hand in Hand portal is a special education resource designed for parents and teachers which provides information, examples of play date activities and materials to construct visual schedules and social stories, <http://www.autismhandinhand.com/welcome.htm>

Resources in Spanish

Autism Speaks Family Services (multiple documents)

<http://www.autismspeaks.org/family-services/resource-library/material-en-espa%C3%B1ol>

For example, Manual de los 100 Días,

Manual de 100 Días de Autism Speaks

NICHCY's National Dissemination Center for People with Disabilities (information on autism and other chronic conditions/developmental disabilities and other disability related subjects)

<http://nichcy.org/families-community/spanishresources>

For example, NICHCY's Fact Sheet on Autism,

<http://nichcy.org/espanol/discapacidades/especificas/autismo/>

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