

Developmental Disabilities Resource Guide for Healthcare Professionals

"Beauty is in the eye of the beholder, and so is disability."

-parent

Healthcare professionals play a critical role in ensuring that children with developmental disabilities and their families receive appropriate, timely, and effective supports and services. This includes providing all families with information on developmental milestones, listening when families express concerns about any aspect of their child's development, and providing medical and educational referrals when concerns arise. Following a diagnosis, additional supports may include sharing resources on developmental disabilities and available community supports and services, partnering with families and educational professionals, and using family-centered practices and disability-specific strategies to provide appropriate care.

Early Identification

Learn the Signs. Act Early., Centers for Disease Control and Prevention

<http://www.cdc.gov/ncbddd/actearly/index.html>

This site provides information, materials, and free resources for healthcare professionals and families related to typical and atypical child development and the early warning signs for developmental disabilities including autism spectrum disorders. Use this site for information on developmental screening, to find educational materials for families, and to help you play a key role in identifying developmental disorders early so that children receive essential early intervention.

Milestones of Child Development: A Guide to Young Children's Learning and Development from Birth to Kindergarten, Virginia Department of Social Services

<http://www.dss.virginia.gov/family/cc/publications.cgi>

Find this resource as well as information for families about selecting high quality child-care on the Virginia Department of Social Services website. Share the Milestones publication with families to help them become educated about developmental milestones so that they can be active partners in monitoring their child's progress and proactively addressing developmental concerns.

"Respect how overwhelming it is for parents."

-parent

Educational Referral

The National Early Childhood Technical Assistance Center (NECTAC)

<http://www.nectac.org/default.asp>

Use the *Contact Lists and Finder* link for contact information for the appropriate early intervention or educational agency in order to make a referral.

National Dissemination Center for Children with Disabilities (NICHCY)

<http://www.nichcy.org/Pages/StateSpecificInfo.aspx>

Use this site to find contact information for the appropriate early intervention or educational agency in order to make a referral.

Developmental Disabilities

American Association on Intellectual and Developmental Disabilities (AAIDD)

<http://www.aamr.org/>

The AAIDD is an organization for professionals who work with people with intellectual and developmental disabilities. The site provides information for professionals interested in the field of intellectual and developmental disabilities as well as policy-related information and links to a variety of disability-related national organizations.

Developmental Disabilities, CDC, NDBDDD

<http://www.cdc.gov/ncbddd/dd/default.htm>

Use this site to learn about various developmental disabilities and to find resource kits specifically designed for healthcare providers to share with families.

Mental Retardation & Developmental Disabilities (MRDD) Branch, National Institute of Health and Human Development, NIH

<http://www.nichd.nih.gov/about/org/cdbpm/mrdd/index.cfm>

This site provides information on the NIH's recent research efforts related to individuals with intellectual and developmental disabilities.

Partnership for People with Disabilities

<http://www.vcu.edu/partnership/>

Learn about the programs and services available to professionals and families through this University Center for Excellence in Developmental Disabilities located at Virginia Commonwealth University.

"You have to have respect for the disability before you can have respect for the disease process."

-parent

Autism Spectrum Disorders

HANDS in Autism

<http://www.handsinautism.org/toolkit.html>

This is a toolkit developed for use by medical professionals to help them provide responsive high quality care to patients with autism spectrum disorders.

Autism Spectrum Disorders (CDC)

<http://www.cdc.gov/ncbddd/autism/index.html>

This site provides information from the CDC on autism spectrum disorders including a free toolkit and other resources for healthcare professionals and families.

Children's Health Topics: Autism, American Academy of Pediatrics

<http://www.aap.org/healthtopics/autism.cfm>

Find autism-related information and resources for healthcare professionals including

Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians.

Autism Spectrum Disorders Knowledge Path, Maternal & Child Health Library at Georgetown University

http://www.mchlibrary.info/KnowledgePaths/kp_autism.html

This knowledge path provides autism-related information and resources on topics for professionals and families. This is a useful source for current information and resources on a variety of autism-related topics.

"There are a lot of resources out there and it can be overwhelming. My pediatrician listened to my major concern and suggested just one book or local organization that could help me get started."

-parent

Family Support and Resources

Medical Home Plus

<http://www.medhomeplus.org/>

This site provides information on Virginia's medical home program and can be a valuable resource for families. Families can contact Medical Home Plus to get assistance finding community resources and services, or browse the Family Resource Center online.

Parent Educational Advocacy Training Center (PEATC)

<http://www.peatc.org/>

Virginia's Parent Training and Information Center, PEATC provides services and support to families and professionals in order to improve educational opportunities and outcomes for children with disabilities.

PACER Center

<http://www.pacer.org/>

Minnesota's Parent Training and Information Center, the PACER Center, provides information, programs, and resources to families of children with disabilities across the nation.

The Arc

<http://www.thearc.org/>

The Arc is a national organization that includes, advocates for, and supports individuals with intellectual and developmental disabilities. The Arc's website is a source of information and resources for individuals with disabilities and their families including the arc link, <http://www.thearc.org/>, which allows users to search for providers by state.

Wrightslaw Yellow Pages for Kids

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

This website allows families to search for contact information by state for Departments of Education, Parent Training and Information Centers, legal and advocacy resources, disability-related organizations, and more.

Autism Source, Autism Society of America

<http://www.autismsource.org/>

Families can search for professionals from various disciplines located in and around their community who work with individuals with autism spectrum disorders.

Autism Speaks

<http://www.autismspeaks.org/>

This organization provides information, support, and resources to families, in addition to funding autism-related research. Information on autism is presented in family-friendly language and includes a video glossary, resource library, and resource guide searchable by state and zip code.

"Give the child the chance to be an individual."
-parent

Medical Home & Respect for Individuals with Disabilities

***The National Center of Medical Home Initiatives for Children with Special Needs,
American Academy of Pediatrics***

<http://www.medicalhomeinfo.org/>

Use this site to link to your state's Medical Home page, and to find information and resources on the principles of the medical home model, resources for families, screening initiatives, disability-related health topics, and publications including fact sheets on topics such as family-centered care.

Disability is Natural

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

This website provides information by Kathie Snow regarding language and attitudes related to people with disabilities. Whether or not you agree with Snow about People First Language, take time to understand the debate and to consider whether your language use matches the language chosen by the families who you work with and communicates respect and a positive attitude toward individuals with disabilities.

Additional Tips from Families:

- Have a handout with the names and phone numbers of private related-service providers (Occupational Therapists, Physical Therapists, Speech/Language Pathologists, Psychologists, and Psychiatrists) in your community that you can provide to families.
- Respect parents as the authority on their children.
- Avoid telling parents that "your child will *never....*" or "your child will *always....*"
- Describe the child's needs for support instead of his or her problems or disabilities
- Ask parents if they know of any accommodations that help their child tolerate medical exams or procedures more easily

Abigail K. Vo, M.Ed.

klassai@vcu.edu

VA-LEND, 2009