

CONNECTIONS

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FAMILY SUPPORT NETWORK OF THE HIGH COUNTRY

Information & Support

for Families of Children with
Special Needs in Alleghany,
Ashe, Avery, Mitchell,
Watauga, Wilkes, & Yancey
counties

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It's natural for parents to focus their energies on children with special needs, health problems or exceptional abilities -- and feel the personal effects of raising them.

But it's also important not to overlook how their siblings are faring. On the sidelines of all that extra attention, these siblings can come under some major pressures, says pediatrician Scott Steinberg, MD.

"Parents are often

Sibling Rivalry

emotionally drained or stressed, especially about the uncertainty of a diagnosis. They may be angry and frustrated that it happened," says Dr. Steinberg, with Northeast Cincinnati Pediatric Associates in Mason. "But the healthy child also has to adjust -- both to a sibling taking up more parental time and resources, as well as to a parent who's tired and stressed."

Siblings of children with special abilities or needs may act out to get

parents' attention. But the impact on family dynamics can go much deeper, he says, particularly with siblings of special-needs children, who may:

- Feel alone or jealous about extra attention for their sibling and interpret it as rejection
- Wish they had medical problems to get more attention
- Worry they might "catch" what their sibling has

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Mental Health Transitions

There has been a major transition in North Carolina mental health, developmental disability and substance abuse services. Many of the services have changed. There are new services, blending of services, new ways to qualify for services and some services no longer exist. At the same time services changed, families and consumers were asked

to choose, very quickly, who they wanted their service provider to be. It has been a challenging time for families, consumers, service providers and our area Mental Health programs who have been trying to focus on providing smooth and seamless transitions.

Choosing a provider can be hard and confusing. The NC

Department of Health and Human Service offers families and consumers guidance on choosing providers.

General Consumer Guidance on Choosing Providers

One of the goals of the changes being made to the public mental health, developmental disabilities

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- Be overly helpful or noncompliant for attention
- Try to ease parents' burdens by not making demands or feeling guilty if they do
- Feel guilty for their own good health or have negative thoughts about their special-needs sibling
- Feel embarrassed or resent having to involve their sibling with neighborhood friends
- Resent having to care for a sibling or worry about their sibling's future

Tactics for Reducing the Rivalry

Dealing with misperceptions and emotional responses starts with fostering communication, Dr. Steinberg says. "Try to be a good listener. Encourage siblings to express themselves, including negative feelings. Ask them what they like best and least about each other. Let your children know it's okay to get mad at their special-needs sibling and not to feel guilty if they sometimes resent the extra attention."

One good way to combat misperceptions, he says, is to describe to children their sibling's special needs or abilities, starting with simple explanations around ages 5 or 6. "Share with them how a health condition is evaluated and treated and what to expect. Talk about their sibling's strengths and weaknesses and the best ways to interact with that child."

It's impossible to treat all children equally, he says. But parents should be as fair as possible and take steps to prevent sibling rivalry.

"Have special-needs children do as much for themselves as they can and assign them tasks so everybody has responsibilities. Do chores together as a family."

Dr. Steinberg suggests setting siblings up to cooperate rather than compete, for instance by having them race against the clock as a team rather than individually to complete chores. He recommends devoting time to family activities that everyone enjoys.



"Let each child know he or she is special," he says. "Make sure they're able to develop their own interests and identity. Try to get a few minutes a day alone between each parent and child." Exclusive time with parents will be especially valuable to the sibling of the special-needs child. He also cautions against overburdening older children with care duties for their siblings. However, all siblings of the special-needs child can be enlisted as "partners" with parents in understanding and addressing their sibling's requirements.

When to Seek Help

If sibling rivalry gets out of hand or parents see signs of depression or anxiety, counseling may be in order for children or the family, he says. Signs to watch for include sleep or appetite disturbance, hopelessness, poor concentration, low self-esteem, talk of hurting oneself, loss of interest in activities, frequent crying or worrying, difficulty separating from parents, perfectionism, or what can be physical symptoms of emotional distress, such as headaches or stomachaches.

"If you see these behaviors for more than a few weeks, seek counseling," Dr. Steinberg says. Sibling support groups can connect children with others who have similar experiences. Despite the potential problems, being the sibling of a special-needs child can have pluses, too, he says. Research indicates they're more likely to develop such positive traits as maturity, social competence, ability to get along with others, insight, empathy, tolerance of differences between people, pride in family accomplishments and loyalty.

"They have more issues to deal with," he says, "but they have opportunity for personal growth and character development."

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Early Intervention Update

By Douglas Galke, Director
Children's Developmental
Services of the Blue Ridge

The Early Intervention Branch continues to implement changes in the structure of the NC Infant Toddler Program to ensure that infants and toddlers most in need of early intervention receive services as mandated by federal and state legislation. Among these changes are the following:



The Early Intervention Branch has been reorganized to better support the

Children's Developmental Services Agencies (CDSAs). The quality improvement unit, responsible for ensuring that the CDSAs meet performance expectations has been expanded to nine employees (7 with regional responsibilities). A Resource and Information Unit has been created to ensure consistent communication with partner agencies and the public, coordinate personnel certification, support the Regional Interagency Coordinating Councils, and provide technical assistance related to the public reporting of early intervention data.

The NC Interagency Agreement for Provision of Services to Children With or at Risk for Developmental Disabilities Ages Birth Through Five and Their Families Under Parts C and B of the Individuals Education

Act has been revised and has been posted at www.ncei.org for public comment through April 30th. The agreement outlines the responsibilities of the Division of Public Health and Division of Public Instruction to ensure the availability of a coordinated network of services.

The proposed eligibility definition (see below) for the Infant Toddler Program was approved by the NC Commission for Public Health and is now awaiting final approval by the US Office of Special Education Services. A tentative implementation date for the new definition has been set for the summer. Children enrolled in the program under the current definitions will not be impacted by the new definition and can continue to receive early intervention as long as a need as expressed on their Individual Family Service Plan exists.

In order for the CDSAs to appropriately respond to referrals **after the new definition has been implemented**, a new referral process will be implemented that is flexible and supports the parent's role in determining how they would prefer to proceed with entrance into the Infant Toddler Program. Referrals will continue to be made to the CDSA by the parent or other concerned community agencies and service providers.

Essentially, the role of the CDSA will be to assign a

service coordinator within two days of receiving a referral and have that service coordinator contact the family as soon as possible to discuss the parent's concerns and those of the referral source (if someone other than the family made the referral). The parent may choose to ask for a screening, a single evaluation, or a multidisciplinary evaluation at that time. Based on the information obtained by the next step, the family would then choose to continue or exit the process. If the family chooses to exit the eligibility process they would be offered a referral to other programs that would better meet their needs at that time. In all cases, the CDSA must be able to offer the family the opportunity to have an IFSP developed within 45 days of referral for children determined to be eligible for the program.

The CDSA of the Blue Ridge already uses a referral process that is very similar to the one described above so families living in our seven counties should see little difference in the way we respond to a new referral.

10A NCAC 43G .0110 ELIGIBILITY DRAFT 3/6/06

(a) Children from birth to age three (3) are eligible for early intervention services under the provisions of this subchapter and under Part C of the Individuals with Disabilities Education Act (IDEA) if they have been

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Early Intervention... continued from page 3

determined to meet the criteria of one of the two following categories:

- (1) developmental delay;
- or
- (2) established conditions.

(b) Developmental Delay.

(1) A child is considered to have developmental delay if the child's development is delayed in one or more of the following areas:

- (A) Cognitive Development;
- (B) Physical Development, including fine and gross motor function;
- (C) Communication Development;
- (D) Social-Emotional Development; or
- (E) Adaptive Development.

(2) The specific level of delay shall be:

(A) documented by scores of 2.0 standard deviations below the mean of the composite score (total test score) on standardized tests in at least one of the above areas of development; or

(B) documented by a 30 percent (30%) delay on instruments which determine scores in months in at least one of the above areas of development, or

(C) documented by scores of 1.5 standard deviations below the mean of the composite score (total test score) on standardized tests in at least two of the above areas of development, or

(D) documented by a 25 percent (25%) delay on instruments which determine scores in months in at least two of the above areas of development.

(c) Established Conditions. A child is considered to have an established condition if the

child has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay. Specific conditions through which a child may be deemed eligible in the established conditions category are as follows:

(1) Congenital Anomaly/ Genetic Disorders/Inborn Errors of Metabolism. These are children diagnosed with one or more congenital abnormalities or genetic disorders with developmental implications. Some examples are Down Syndrome, Fragile X Syndrome, familial retardation syndromes, and fetal alcohol syndrome.

(2) Congenital Infections. These are children diagnosed with congenital infections with developmental implications. Some examples are toxoplasmosis, rubella, cytomegalovirus, and HIV.

(3) Autism. These are children diagnosed with autism or autism spectrum disorders.

(4) Attachment disorder. These are children with a diagnosed attachment disorder.

(5) Hearing Loss. These are children diagnosed with unilateral or bilateral permanent hearing loss.

(6) Visual Impairment. These are children diagnosed with a visual impairment that is not correctable with treatment, surgery, glasses, or contact lenses.

(7) Neurologic Disease/ Central Nervous System Disorders. These are children diagnosed with a disease or disorder known to affect the nervous system with developmental implications, such as Cerebral Palsy,

Spina Bifida, Epilepsy, and Microcephaly.

(8) Neonatal Conditions and Associated Complications. These are children diagnosed with one or more of the following neonatal diseases or disorders known to have developmental implications:

(A) Gestational age less than 27 weeks or birth weight less than 1000 grams;

(B) Neonatal encephalopathy with neurological abnormality persisting at discharge from the neonatal intensive care unit.

(C) Moderate to Severe Ventricular Enlargement at discharge from the neonatal intensive care unit or a ventriculoperitoneal shunt;

(D) Neonatal seizures, stroke, meningitis, encephalitis, porencephaly, or holoprosencephaly;

(E) Broncho Pulmonary Dysplasia requiring supplemental oxygen at discharge from the neonatal intensive care unit;

(F) Intrauterine Growth Retardation;

(G) Necrotizing enterocolitis requiring surgery;

(H) Abnormal neurological exam at discharge;

(I) Intraventricular hemorrhage III or IV; or

(J) Periventricular leukomalacia.

Q & A

I feel I have to constantly worry about money. Where can I find more information on financial literacy?



Program has very helpful learning modules like *Saving for your Future*, *Developing a*

Spending Plan, Taking Control of Your Debt, and *Car Insurance*. To learn more, check out their website at www.financialmentoring.net.

The Financial Mentoring

Mental Health... continued from page 1

and substance abuse services is to increase the number of qualified providers that are available to serve you and your family. You may begin to hear from providers interested in providing services to you. When making a choice of service providers, one of the things you should think about is the ethics of your provider. A provider's ethics are often an indication of the quality of care that they provide. The World Book Dictionary defines ethics as "formal or professional rules of right and wrong" and a "system of conduct or behavior." Consumers and families will usually receive higher quality services from providers that hold themselves to high professional standards and ethics.

Look for service providers who are willing to spend the time to talk to you about what you can expect if you choose that agency. Be an informed consumer and base your decisions on facts and on the history of the provider agency, not on their promotional activities:

- Listen for opportunities to be involved. Does the provider promise you that you'll be able to have input into decisions about your care while you are

receiving services? That is critical.

- Does the provider give you plenty of time to ask questions?
- Is the provider connected to the community and does the provider use a team approach? Bonuses and free gifts are a one time event and may be offered to compensate for a lack of quality services.
- It is never OK for a provider to try to recruit you when you're receiving active treatment from another provider, i.e.; during a counseling session.
- Trust your own judgment and if you have questions or concerns, contact your LME's customer services staff. When something about the way a provider tries to get your business doesn't feel right, it probably isn't.

Contact information

New River Behavioral HealthCare Customer Services Office 828/263-5656, 877/391-1705 (toll free outside Watauga & Avery)

Western Highlands Network

828/225-2800,
Toll free 800/951-3792



Want Your Ideas/Concerns to be Listened to? Want to Advocate? Please Attend!

North Carolina's leading disability agencies want to listen to YOU!

People with developmental and other disabilities, their families, service providers, and the general public are invited to provide feedback and ideas for the latest state plan to support people with disabilities and their families. Please join the North Carolina Council on Developmental Disabilities, the Governor's Advocacy Council for People with Disabilities and the UNC Center for Development and Learning at a FREE LISTENING SESSION: Thursday, March 30 from 2:30-4:30 pm at Ashe Services for the Aging in West Jefferson OR Thursday, March 30 from 6:30-8:30 pm at Broyhill Inn and Conference Center in Boone. For more in Ashe call: Mary Whittington at 246-2461 x224 or for the Boone session call: Parent to Parent Family Support Network at 828-262-6089 or Toll Free 866-812-3122.

Upcoming Events

Fostering the Sexually Abused Child:
MARCH 29, 6-8 PM at Large Conference Room, Watauga County DSS. To Register Contact Roberta Yates – 265-8100.

Free listening session on Thursday, March 30 at 6:30 pm at Broyhill Inn and Conference Center in Boone. People with developmental and other disabilities, their families, service providers, and the general public are invited to provide feedback and ideas for the latest plan to support people with disabilities and their families. There will also be a session in Ashe County in Jefferson at the Senior Center on March 30th from 2:30-4:30. Contact person is Mary Whittington.

Challenging Behaviors & Medically Fragile Share Groups meet the second Friday of each month at the Boone Unitarian Universalist Church (381 E. King St, beside the Playhouse). Dinner provided & Child Care provided if a space is reserved in advance.

KIDSTOCK Family Festival May 20th. Put it on your calendar! Fundraiser for Parent to

Parent FSN-NC and Western Youth Network (WYN) Come with your family/PLAY/HAVE FUN/Volunteer to help staff an activity or booth. Call Parent to Parent FSN-HC for more details.

HATS OFF!



Hat's Off to Earth Fare for supporting community non-profits. Each month they feature an organization and the group gets to put up a display in the store and gets 10 cents each time a customer uses a recycled grocery bag. We were the highlighted program in February.

Thanks to the Blue Ridge CDSA for contributing to our newsletter each month.

Thanks to the Avery County Partnership for putting an article in their newsletter about us.

Thanks to all the Foster Families who give so willingly of their time and love.



Please support our projects so that we can continue to serve our parents and the community. Detach this form and send donations to the address below and help continue this much needed program. All donations are tax-deductible.

Name _____

Address _____

City _____ State _____

Zip Code _____ Amount \$ _____

Name of Honoree(s) _____

Thank you for your valuable contribution.



FSN-HC
150 Den Mac Dr.
Boone, NC 28607