Support for Siblings

Many factors, such as a sibling’s age and the family atmosphere and attitude, impact the issues that siblings deal with in relation to their brother or sister who has a disability. Concerns and needs of siblings may include over-identification (thinking that they will “catch” their brother or sister's disability), embarrassment, guilt, isolation, sense of loss, resentment, increased responsibilities, and a pressure to achieve. Although there are concerns and needs to address, siblings often turn out to be some of the most caring and compassionate people with an increased tolerance for negative people and situations because of the insight they have into the value of life.

Siblings tend to show a greater sense of maturity and often demonstrate a great sense of loyalty and appreciation for their family as a whole. Parents need to be in tune to the needs of their children without a disability by providing information, support, and opportunities to be their own person. The following are some tips for how to accomplish this.

- **Provide information:** All siblings need some level of information about their brother or sister's disability. How detailed the explanation is depends on the age and level of understanding of the sibling. Knowledge helps siblings cope more effectively with their brother or sister's disability.

- **Alleviate fears:** Siblings sometimes fear that the disability that their brother or sister has might happen to them, too. Help them to understand that they won't "catch" their sibling's disability.

- **Treat all children fairly:** Parents should treat all of their children fairly, but must recognize that it may not be possible to treat each child equally. This can be difficult, but try to treat each child with the same standards for their behavior, even though those standards may not be exactly the same. Explain to the sibling about these differences in expectations to help them to try to understand. Remember that, in cases where the child's disability is severe, it appears to the sibling that their brother or sister is not able to do anything wrong.

- **Be aware of their drive to succeed:** Many siblings, once they have grown into adults, express that they felt pressure to achieve and had higher expectations than their friends who did not have a brother or sister with a disability. The expectations, though, were set by themselves in an effort to help compensate for the loss that they think their parents feel for the child with a disability. Parents should be aware of this and help their child balance the priorities in their lives.
• **Monitor their independence:** Because of the demands of a child with special needs, siblings often think that they need to take care of their own needs, such as making lunch or entertaining his/herself, in order to help out the rest of the family. Although this lends to the development of mature and responsible behavior, siblings need to know that they are not expected to be independent. Using respite care and help from extended family members can help.

• **Openly communicate:** Siblings need to feel free to express their feelings without guilt. Emotions they feel can include sad, mad, loss, isolation, resentment, guilt, and confusion. Parents can help by opening displaying their own emotions in an appropriate manner and explaining to their children that it is all right to show emotions.

• **Watch for warning signs:** Be aware of emotional and physical signs that the sibling is not doing well. Some warning signs are a decline in academic performance, sleep disorder, appetite problems, headaches, stomach aches, and preoccupation with their own health. If communication with your child does not seem to help, seek help from a physician, counselor, or other professional.

• **Create special times:** Siblings often feel that their parents do not spend as much time with them as their brother or sister who has a disability. They often recognize their parents’ preoccupation with their brother or sister and the absence of their parents during hospital stays and numerous appointments. Try to create special times to be with the sibling and to create regular rituals, such as reading every night together, to create a personal bond.

• **Teach social coping skills:** Some siblings have problems with the reactions of people to their brother or sister when they are out in public. Explain to the sibling why people react the way they do and appropriate ways to respond to them. Rehearse how to answer questions that friends or strangers might ask.

• **Involve siblings when making decisions:** As siblings get older, they should be encouraged, but not forced, to be involved with the medical, financial, educational, and daily living decisions in regard to their brother or sister’s care.

• **Understand sibling rivalry:** Parents should recognize that sibling rivalry exists, even when one of the siblings is disabled. If issues seem to be developing beyond the parents’ control, though, professional help should be sought.

• **Plan for the future:** As siblings get older, they may begin to realize that they might be their brother or sister’s caregiver one day. As mentioned earlier, involve the sibling in the decision making process and help them learn more about their brother or sister’s options for the future.

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For past editions of our newsletter, visit our website.
http://www.unr.edu/educ/ndsip
We are pleased to announce that the 14th Annual Nevada Dual Sensory Impairment Project Parent Conference will be held May 25 & 26. The conference will take place at the University Inn, located across the street from the University of Nevada, Reno. All parents of children who are involved with the Nevada Dual Sensory Impairment Project are welcome to attend. Service providers of children involved with project can also attend if they are invited by the parents.

Although the conference agenda has not been finalized, some of the potential conference topics include: communication, recreation and leisure, preparing for the IEP / IFSP, sibling issues, inclusion in family activities, assistive technology, and stress management.

If you are a parent or service provider with a child involved with the Nevada Dual Sensory Impairment Project, you will receive the conference information in the mail. Any questions about the conference can be addressed to MaryAnn Demchak or Marty Elquist at 784-6471 in the Reno area or 1-877-621-5042 (toll-free in Nevada). We hope to see you at the conference.

Deaf Education Strategies for General Educators

1 Semester-hour credit course, S/U graded, self-directed

This course will provide an opportunity for general educators and other interested professionals to learn about hearing loss, its potential impact on student learning and behavior, and appropriate services for students who are in the general education setting. This information will enhance the educators' professional skills in creating and implementing quality educational programming for students who are deaf or hard of hearing. An end-of-class project will give each educator resources and practical materials for future use.

When & Where: May 15, 2006 through June 23, 2006 (6 weeks)
Online Course through University of Northern Colorado’s Office of Extended Studies

Tuition: Approximate Cost: $175

Registration & Contact Information: You must register for this course through the University of Northern Colorado’s Office of Extended Studies. Visit the Extended Studies Website: http://www.unco.edu/center/es/pro_dev/prov_index.htm or call (800) 232-1749. Registration begins March 1, 2006
For more information, contact the instructor: Ann Sebald, Ed.D. ann.sebald@unco.edu 970-351-1853 or 1-800-395-2693

10 Ways to Reduce Stress

1. Eat and drink sensibly. Alcohol and food abuse may seem to reduce stress, but it actually adds to it.
2. Assert yourself. It’s okay to say “No.” Being assertive allows you to stand up for your rights while respecting those of others.
3. Stop smoking or other bad habits. Aside from the obvious health risks of cigarettes, nicotine acts as a stimulant and brings on more stress symptoms.
4. Exercise regularly.
5. Practice relaxation techniques. Deep breathing, meditation, and other techniques can be done throughout the day.
6. Take responsibility. Control what you can and leave behind what you cannot control.
7. Reduce stressors (cause of stress). Too many demands and too little time? Most demands are ones that we have chosen. Effective time-management skills involve asking for help when appropriate, setting priorities, pacing yourself, & taking time out.
8. Examine your values and live by them. The more your actions reflect your beliefs, the better you will feel, no matter how busy your life is. Use your values when choosing your activities.
9. Set realistic goals and expectations. It’s okay, and healthy, to realize you cannot be 100% successful at everything at once.

www.clevelandclinic.org
What is CRS?
Rubella is a virus that usually causes a mild illness in children or adults; however, if a pregnant woman contracts rubella, the consequences for the unborn child can be severe. Rubella, and subsequently congenital rubella syndrome (CRS), is a vaccine preventable disease.

What causes CRS?
CRS is caused when the rubella virus is passed from the mother to her developing fetus. Up to 90% of infants born to mothers who contracted Rubella during their first trimester develop CRS (Mayo Clinic, 2005; Zimmerman & Reef, 2002). CRS can vary according to the developmental stage of the fetus. Infection during the first trimester affects more developing organs than later in pregnancy; therefore the symptoms are more severe for infants who contracted the virus at an earlier gestational age.

What are the Symptoms?
Rubella is characterized by a distinctive red rash, swollen glands, low-grade fever, runny eyes, sore throat and joint pain in children and adults. Rubella is generally a mild infection. Up to half of those infected with rubella do not have symptoms (Immunization Action Coalition, 2005).

Delayed Symptoms:
While medical professionals are aware of early problems associated with CRS, the delayed problems are not widely known. It is important to note that most people with CRS will not develop any of the late symptoms.

• Diabetes,
• Underactive or overactive thyroid,
• Growth hormone deficiency,
• Glaucome (disease of the optic nerve),
• Changes in seizure disorder.

What are the Implications for Hearing?
Hearing impairment is the most common disability resulting from CRS. Hearing loss can range from mild to severe and can both decline or improve in the first few years of life (Parker, n.d.).

What are the Implications for Vision?
The vision of individuals with CRS can range from normal to total blindness. Some common visual abnormalities include:

• Pigmentary retinopathy (progressive vision loss),
• Cataracts (clouding of the lens) in one or both eyes,
• Retinopathy (inflammation of the retina),
• Nystagmus (uncontrollable movement of the eyes),
• Microphthalmia (one or both eyes are small),
• Optic atrophy (deterioration of the optic nerve),
• Congenital glaucoma (disease of the optic nerve that happens prior to birth resulting in large globes and clouded corneas).

What is the frequency in the U.S.?
Between 1964 and 1965 there was a worldwide epidemic of rubella. In the U.S. alone, approximately 20,000 were born with CRS. Thousands of these individuals were reported to be deaf-blind (Helen Keller National Center, 2005).

Today, rubella cases are at a record low in the U.S. Only 9 cases of rubella were reported in 2004 and only 4 cases of CRS were reported from 2001-2004. Worldwide there are still an estimated 100,000 infants born annually with CRS (Centers for Disease Control, 2005).

Is there a treatment?
There is a vaccination for the rubella virus that causes CRS. The mumps, measles, rubella (MMR) vaccination is generally given during childhood in two doses; the first between 12-15 months-old and the second between 4-6 years-old.

There is not a treatment to “cure” CRS. The treatment of CRS focuses on treating associated problems if needed (e.g., cataract surgery, hearing aids, seizure medication).

Additionally, it will be determined on an individual basis whether or not special education and related services (e.g., physical therapy, occupational therapy, speech therapy) are needed. These educational services are determined by the individuals’ needs and are intended to assist the child in receiving an appropriate education.

References


Center for Disease Control (2005). Congenital rubella syndrome: Health care needs and are intended to assist the child in receiving an appropriate education.

By: Marty Elquist
The Nevada Dual Sensory Impairment Project thanks our generous donors for their support:

The Leonette Foundation has encouraged inventive solutions to problems in contemporary society focusing on children and seniors in northern Nevada since 1994.

The Chartrand Foundation is a generous supporter of education and youth services in Reno, Nevada.

Both of these Foundations were instrumental in assisting the Nevada Dual Sensory Impairment Project in enhancing the lives of children who have vision and hearing impairments in northern Nevada.

Thank you for your generosity!

Website

Dragonfly Toys
www.dragonflytoys.com

Dragonfly toys is a toy company for children with special needs. This website is full of great products for children of all abilities. The site contains a Child Profile search where you can search for toys based on your child's developmental profile.

The site includes Play Tips that contain great ideas for including children with special needs. There are also Play Pen articles that contain great information for parents and teachers on a variety of disability-related topics.

This site is more than just a toy store. It is a great resource for parents and teachers of children with a wide range of abilities.

"I was, on the whole, considerably discouraged by my school days. It was not pleasant to feel oneself so completely outclassed and left behind at the beginning of the race."

~Sir Winston Churchill
Promoting Literacy through Emergent Writing

By MaryAnn Demchak & Marty Elquist

Literacy is important for everyone including individuals with dual sensory and multiple impairments. Literacy is comprised of word knowledge, reading, communicating and writing. Just as teachers and families should provide children a variety of experiences with books, stories, printed word, Braille, and so forth, they should also provide experiences with writing. Children go through developmental stages in learning to write, beginning with random drawing or scribbling and progressing to proficient writing. It is important to incorporate “writing” experiences into the daily schedule.

Unfortunately, we have not always provided children with disabilities, especially those with significant disabilities that include sensory impairments, the opportunities to experiment with and explore the writing process. Beginning emergent writing activities typically involve providing opportunities for creativity through manipulating a variety of conventional and non-conventional writing tools, crayons, painting tools, stamps, and other art materials.

This “Tips for Home or School” column provides suggestions for involving children with significant disabilities in emergent writing activities. The use of various grasping aids might be needed for some children with motor impairments. (See our Fall 2005 Tips for Home or School column on assisted grasping.) The intent is to help you think of ways to encourage drawing, scribbling, etc. as emergent writing.

- **Crayola Slick Styx** ("creamy," twistable crayons that require very little pressure to use).
- **Twistable crayons.** Good for children who break traditional crayons.
- **Jumbo crayons** (fatter crayons for children who use a wider grip. Also come in anti-roll style).
- **Stumpy crayons** (short chubby crayons for children who use a whole-handed palmar grasp).
- **Finger crayons** (crayons that fit over the fingertip).
- **Pencils, pens & markers come in a variety of shapes and diameters.** Some come with built-in grips and others can be used with grasping aids.
- **Paint brushes** also come in a variety of sizes with a variety of handles to accommodate many grasping needs.
- **Sponge paint rollers** come with textured or smooth rollers.
- **Cut a sponge** into different shapes or purchase shaped sponges, which come in letters and numbers.
- **Finger paint.**
- **Stamps & stamp pads.** Stamps can be adapted or purchased with large grips.
- **Wood, felt, or foam shapes, letters & numbers** that can be glued to paper for 3-D art work.
- **Wiki Stix** can be used to create raised pictures. Children can “draw” or “write” by bending the self-sticking sticks.
- **Dish brushes** or a make-up brushes.
- **Spray bottles** to spray thin paint.
- **Toys with wheels—run wheels through paint and then on paper.**
- **Cookie cutters.**
- **A ketchup dispenser or mustard dispenser** is also a handy way for kids to dispense their own paint.

For many children these emergent writing activities will be more meaningful by drawing or writing on a textured surface. A textured surface can be created by placing any of these items under the paper: Non-slip shelf liner, rough sand paper, plastic craft canvas, wire mesh.

Some children might require use of an easel on a stand or a table top easel for easier access motorically. Paper may need to be held in place with tape or clips. If children are unable to participate physically, then they can be offered choices about tools, color, paper, placement, etc.

It is also important for children to understand that “writing” is a way to share ideas and communicate. Thus, emergent writing products can be used as a basis for children to make greeting cards, banners for the school hall, notes home, gift bags, etc.

Young children can do such work through art centers while older children might have a Publications Center, Media Center, or Graphic Arts Center (in order to be age appropriate). Within the center children could have access to various types and colors of paper. Not all materials need to be available at all times. Children can be motivated to participate on a regular basis by varying available materials.

Nonconventional art tools can allow for various patterns or designs to be created as well as accommodate various types of grasps or grasping aids. Nonconventional art tools can include:

- **Potato mashers**—in different mashing styles with different handle types.
- **Wire whisks**—most have long, sturdy handles.
- **Plastic sponges/scrubbers**—some provide a nice handle for gripping.
- **Pouf mesh body sponges.**
- **Shaving brushes or a make-up brushes.**
- **Dish brushes** — with or without soap compartment (which could be used for dispensing paint).
Parent Education & Support Group Meetings

- Meet other families
- Learn about sensory integration
- Explore a therapeutic environment
- Receive Support

Sat., April 29th 10:00am—11:00 am
Sat., May 27th 10:00am—11:00 am

Meetings are in Las Vegas. For more information:
702-735-6223 or www.nvblindchildren.org

American Association of the Deaf-Blind Conference

June 17-23, 2006
Towson University • Baltimore, Maryland

For more information: http://www.aadb.org

Nevada Department of Education

State Mega Conference
May 5-7, 2006
Green Valley Ranch • Henderson, Nevada

For more information http://www.doe.nv.gov/schoolimprovement/mega.html

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