



CONNECTICUT
BIRTH TO THREE SYSTEM

PRESCHOOL SPECIAL
EDUCATION

WORKING TOGETHER FOR CHILDREN WITH DISABILITIES

BIRTH through 5 NEWS

INFORMATION FOR FAMILIES AND PROFESSIONALS • VOLUME 4, NUMBER 1

SIBLINGS: Precious Members of the Family

By Judy S. Itzkowitz, Ph.D.
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South Windsor, CT

Sibling relationships are especially powerful and important. They provide the foundation for a wide array of learning opportunities involving cognitive, language, social, motor and moral skills. Children develop their unique sense of identity, attitudes, beliefs and values through their experiences with their siblings. Brothers and sisters learn to express love, affection and intimacy together. When one child has a disability it is important to remember that brothers and sisters are first and foremost siblings. Their relationship comes with the same range of experiences inherent in all sibling relationships. Siblings of persons with disabilities share the same kinds of experiences as siblings where no child has an identified disability. The primary difference is the degree of those experiences and the range of emotions experienced.

This article is translated into Spanish on page 2. Ver la versión española de este artículo en la página 2.

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COOPERATIVE EXTENSION SYSTEM
College of Agriculture and Natural Resources

“My experience with my retarded [sic] sister has been one of the most important in my life. It has at times been stressful and emotional, but ultimately a very positive influence. It has definitely shaped my life and channeled my interests in ways I would otherwise have not pursued” (Itzkowitz, 1989, p. 188).

Siblings are often curious about their brother or sister’s disability. They benefit from having accurate and age-appropriate information. Not only are children interested in the specific disability, they also may be curious about the professionals who work with their brother or sister with special needs and the specific therapies in which the child participates.

Brothers and sisters of children with disabilities experience the same range of feelings that parents of children with disabilities experience. This mirroring experience often can be challenging for both parents and siblings. Children with brothers or sisters with disabilities may experience anger, sadness, guilt or disappointment. Sometimes, young people may feel separate, alone or different as a result of having a brother or sister with a disability. It is important to support siblings in recognizing that they are not alone; there are other people who are going through similar kinds of experiences in life.

As parents, family members, friends and professionals look to strengthen the sibling bond, the following themes can be used as a guide:

Have your family be a place where “brave” conversations are respected. Research suggests that families who

communicate effectively are more resilient to life’s challenges. These families solve problems, make decisions and resolve conflicts. Encourage open and honest communication among all family members, even when the feelings are labeled by society as negative and seem to be unjustified. Actually, all feelings are valid; they have a purpose or desired outcome. Encourage children and other



family members, through your modeling, to express the full range of feelings.

Take the time to take care of yourself. Surround yourself with people who genuinely care about you and your family, who respect you, understand you, and support you; make sure that you have a circle of support, people you can go to when you want to talk, when you need someone to listen. Take time for yourself, for your relationships and for your family. Look for ways to make sure that your family comes first rather than the child with special needs. Think about something that brings you joy or comfort and then do it. By taking care of yourself, you are able to support your

family and be a model for your children.

Foster the individuality of each sibling as well as their relationship. Each child is a unique individual with his or her own strengths, needs, experiences and contributions to make to the family and in life. Each young person shares his or her special gift with others. Each person in your family needs to be treated like an individual. Support siblings in having a life that reflects what is important to them, rather than having their life be solely about the child with special needs. Taking a "holiday" where the sibling and the parent do something special together can be a way to reassure siblings about their importance in the family and respect their individual needs and preferences.

"Walk a mile in the sibling's sneakers." Siblings remind us how important it is to really listen to their unique concerns, experiences, needs and ideas. Listening is about hearing not only the words that are spoken but also the affect and the underlying message of the communication. Listening involves hearing the person's story through his or her own eyes and life experiences. Do we truly listen and really hear even when the message is one that is uncomfortable? Do we listen to and value the perspective of that sibling? Given their unique experiences, siblings have invaluable ideas about solving problems and addressing concerns. Encourage children to express themselves fully; respect what you hear. Acknowledge the feelings that your son or daughter

has as well as their experiences.

Each moment of life offers a choice point about how to respond to the circumstances of our life and our attitude. We can choose joy or sorrow, ease or struggle. In any circumstance the choice is a personal one: the glass is half empty or half full. When siblings learn that everything that happens in life can be an opportunity to learn and grow they acquire a life-long skill that will enable them to persevere, to be resilient, and to effectively manage life's challenges. Casteneda (1972) wrote, "The trick is in what one emphasizes. We either make ourselves miserable or we make ourselves strong. The amount of work is the same." Humor and laughter are healing mechanisms; laugh a lot and love often.

LOS HERMANOS: preciosos miembros de la familia

Por Judy S. Itzkowitz, PhD., Consultora educacional, South Windsor, CT

Las relaciones entre hermanos son particularmente poderosas e importantes. Aportan el fundamento de una amplia gama de oportunidades de adquirir aptitudes cognitivas, de lenguaje, sociales, motoras y morales. Es por sus experiencias con sus hermanos que cada niño desarrolla su sentido de identidad y sus actitudes, creencias y valores. Hermanos y hermanas aprenden juntos a expresar amor, afecto e intimidad. El que en una familia un niño tenga alguna incapacidad no impide que su relación con sus hermanos sea fundamentalmente la natural entre hermanos, con la misma variedad de experiencias inherentes a tal relación. Los hermanos de los niños con incapacidades comparten los mismos tipos de experiencias que los de niños sin incapacidad identificada. La sola diferencia es el grado de tales experiencias y la variedad de emociones que experimentan.

"Mi experiencia con mi hermana retar-



dada ha sido una de las más importantes de mi vida. A veces ha sido estresante y emocional, pero en definitiva una influencia muy positiva. Ha modelado mi vida y canalizado mis intereses de formas que de otro modo yo no habría intentado" (Itzkowitz, 1989, p. 188).

La incapacidad de un niño puede suscitar curiosidad en sus hermanos. Es beneficioso que éstos tengan información exacta y proporcionada a su edad. No sólo se interesan específicamente en la incapacidad del hermano, sino también en los profesionales que trabajan con él y las terapias que le aplican.

Los hermanos y hermanas del niño con atraso experimentan la misma variedad de sentimientos que los padres, sentimientos que pueden ser desafiantes tanto para éstos como para aquéllos; pueden sentirse enojados, tristes, culpables o decepcionados. Los niños de corta edad pueden sentirse aislados, solitarios o diferentes por tener un hermano o hermana con incapacidad. Es importante ayudarlos a entender que no están solos, que muchos otros pasan por lo mismo.

Los siguientes temas pueden servir de guía para los padres, el resto de la familia y los amigos y profesionales que tratan de fortalecer y estrechar los lazos entre los hermanos:

Haga que en su familia se respeten las conversaciones "bravas." La investigación sugiere que las familias en que la comunicación es más completa son más fuertes ante los desafíos de la vida. Estas familias resuelven problemas, toman decisiones y solventan conflictos. Estimule la comunicación abierta y sincera entre todos los miembros de la familia, aun cuando se expresen sentimientos que la sociedad tacha de neg-

ativos y parezcan injustificados. Realmente, todos los sentimientos son válidos; tienen un propósito o representan un deseo. Anime a los niños y demás miembros de la familia, con su ejemplo, a expresar una amplia variedad de sentimientos.

Tómese el tiempo necesario para ocuparse de usted. Rodéese de gente a quienes genuinamente les importan usted y su familia, que los respetan, comprenden y apoyan; cerciórese de contar con un círculo de apoyo, con personas a quienes usted puede acudir cuando tiene necesidad de hablar, de que lo escuchen. Saque tiempo para usted, para sus relaciones y para su familia. Busque maneras de asegurarse de que primero está su familia, antes que el hijo con necesidades especiales. Piense en algo que le pueda traer alegría o confort, y persígalo. Ocupándose de usted, se está capacitando para dar apoyo a su familia y ser modelo para sus hijos.

Fomente la individualidad de cada hermano y la relación entre ellos. Cada hijo es un individuo impar, único, con sus propias fortalezas, necesidades, experiencias y contribuciones potenciales a la familia y en la vida. Cada niño o adolescente comparte su don especial con los otros. Cada miembro de la familia debe tratarse como el individuo que es. Que la vida de cada hijo refleje lo que es importante para él, que no gire alrededor del hermano con necesidades especiales. Un día de vacación en que hermanos y padre o madre hacen juntos algo especial puede ser una manera de inculcar en los hermanos su importancia en la familia y de respetar sus necesidades y preferencias individuales.

“Camine una milla en los zapatos del hermano.” Los hermanos nos recuerdan cuan importante es realmente escuchar las inquietudes, experiencias, necesidades e ideas de cada uno. Escuchar es oír, más que las palabras, el afecto y el mensaje implícito en la comunicación. Escuchar implica oír a través de los ojos y experiencias de quien nos habla. ¿Escuchamos y oímos realmente si el mensaje nos incomoda?

¿Escuchamos y valoramos la perspectiva de quien nos habla? Dadas sus experiencias únicas, los hermanos de niños con incapacidades tienen ideas valiosas para resolver problemas y enfocar inquietudes. Estimúelos a expresarse plenamente, y respete lo que escucha. Expresé su comprensión de los sentimientos y experiencias de su hijo o hija.



En cada momento tenemos opciones para responder a las circunstancias de la vida, para nuestra actitud. Podemos escoger entre alegría o pena, calma o agitación. En cualquier circunstancia la elección es personal:

podemos ver la copa medio vacía o medio llena. Cuando los hermanos del niño con atraso aprenden que todo lo que pasa en la vida puede ser una oportunidad de aprender y crecer, adquieren una habilidad permanente que les permitirá perseverar, ser flexibles y enfrentarse adecuadamente a los retos de la vida. Casteneda (1972) escribió “El secreto está en lo que uno enfatiza. O nos hacemos miserables o nos hacemos fuertes. Da el mismo trabajo.” El humor y la risa son mecanismos de curación, ría mucho y ame a menudo.

Learning Opportunities

FOR PARENTS AND PROVIDERS:

- **Orientation to the Birth to Three System**
September 10, 2002 9AM – 12 noon
Rensselaer, Hartford or
November 1, 2002 9AM – 12 noon
DMR Office at The Exchange,
Farmington or
January 14, 2003 9AM – 12 noon
DMR Office, Long Wharf, New Haven

No registration fee
Contact Kathy Granata at (860) 418-6146 or kathy.granata@po.state.ct.us
- **Educating Children with Autism – Samuel Odom**
October 31, 2002 Contact SERC at (860) 632-1485 ext. 269
- **Strategies for Addressing Challenging Behavior – Mary McEvoy**
November 12, 2002 Contact SERC at (860) 632-1485 ext. 269
- **Strategies for Addressing Challenging Behavior: A Follow-up – Mary McEvoy**

November 13, 2002 Contact SERC at (860) 632-1485 ext. 269

Save the Dates:

- **Together We Will**
April 11, 2003 Contact SERC at (860) 632-1485 ext. 269
- **Together We Will Post-Conference for Families**
April 12, 2003 Contact SERC at (860) 632-1485 ext. 269

FOR PROVIDERS:

- **Service Coordination Training**
September 10, 18, 26 & 30, 2002
Rensselaer, Hartford or
November 1, 6, 14 & 22, 2002
DMR Office at The Exchange,
Farmington or
January 14, 22, 30 & February 6, 2003
DMR Office at Long Wharf,
New Haven
9 AM to 4 PM each day

Contact Kathy Granata at (860) 418-6146 or kathy.granata@po.state.ct.us

Birth to Three Program Update

By Linda Goodman

Birth to Three services are family-centered, and brothers and sisters are certainly a big part of the family. While early intervention is time-limited, a child's relationship with his or her family lasts a lifetime. It is the job of early intervention home visitors to ensure that older brothers or sisters are included in the visit, lest the fact that someone is coming weekly especially to play with their younger sibling causes resentment that can damage the relationship. Working early intervention techniques into regular family routines is another way to demystify services and get older brothers and sisters to see that it is not something that has to interfere with everyday life.

Providers should, in conjunction with parents, be prepared to answer questions that siblings may ask them, as siblings are included in home visits and they are trying to understand the nature of their sister or brother's disability or developmental delay. They may worry that it is contagious or that they are responsible in some way. Although we like to say that parents are a child's first and best teacher, it is not a stretch to say that older brothers and sisters run a close second.

As the school year begins, battles over the reauthorization of the IDEA (Individuals with Disabilities Education Act) will continue in Washington. The IDEA is the federal law that governs both special education (ages 3 to 21) and early intervention (birth to age 3). Although many bills were proposed over the summer, if the Congress does not act on them before they adjourn in October, they will all have to be resubmitted when the next Congress convenes in January 2003. Proposals include expanding early intervention to include children who are at risk of developmental delay due to maternal

depression, substance abuse in the family or family violence. It would be a challenge for Connecticut to find the funding to offer services to all of these children (probably double the number currently receiving services). Another proposal is to create a "seamless" birth to 21 system, something that could also be quite a financial challenge for Connecticut, since currently the funding for these services is divided among state, municipal and federal sources.

As I write this, it is unknown exactly what Congress or the

Administration means by this proposal. The point is that big changes are in the wind, and families who are concerned should try to keep informed about them. We will keep current information on the Birth to Three website (www.birth23.org) and the addresses of other websites where you can get information about the various proposals and how to make comments.



Preschool Special Education Update

By Maria Synodi

Wishing you good beginnings and a successful school year. Some news and resources to start the year include:

On June 6, 2002, the U.S. House of Representatives unveiled a new website called Great IDEAs. Given that the Individuals with Disabilities Education Act (IDEA) is in the process of reauthorization, Congress is asking parents, teachers and others for recommendations about how to strengthen and improve the law. Congress is looking for information on the impact of specific provisions of the IDEA and aspects of the law that need to be added, changed or eliminated and why. For more information go to: <http://edworkforce.house.gov/issues/107th/education/idea/ideacomment/index.htm>.

There is a newly funded center providing information on infants, toddlers and preschoolers with disabilities called NECTAC (National Early Childhood Technical Assistance Center). NECTAC provides information on special education law, provides access to literature and resources and provides a number of publications and links to relevant topics in the field of early intervention and early childhood special education. For more information go to <http://www.nectac.org>.

A website for early childhood professionals and parents is New Assessment: Early Childhood Resources. The site contains a host of information related to the provision of comprehensive family-centered and culturally responsive services through a framework for the assessment of young children. The site also offers an online course of study. For more information go to <http://www.newassessment.org>.

Now to the topic... This first newsletter of the year is devoted to siblings, a fancy term for brothers and sisters. Schools, especially preschool special education programs, focus their services and supports on the developmental, social and educational needs of young children with disabilities. As educators, the importance of working with and partnering with families cannot be overstated. We, as educators, need to be reminded that children usually spend more time with their brothers and sisters than they do with their parents. The relationships that children have with their brothers and sisters will probably be the longest and most lasting relationships that they will have in life. Schools should consider how to include families, parents, and siblings of a child with a disability when planning curriculum, school events, training topics and other activities.

There are some wonderful resources listed in the web resources section of this newsletter. I hope the topic of this newsletter and the resources identified provide you with a good start to new and interesting activities that can be incorporated into the wonderful things happening throughout the state. Wishing you a happy Fall.

“SNIPPETS”

The Parent Perspective

Good Night; I Love You Little Brother

By *Jacqueline A. Cantoni, Parent of Jimmy and Nathan*

“Good night, I love you little brother.” Why does it seem so special for a mom to hear her older son say, “good night, I love you little brother,” at bedtime?

For many parents this is so important, and it touches their hearts to know their children love and care for each other. Love between siblings is important in every family. We have two beautiful sons; Jimmy is 7 and Nathan is 4 1/2. Nathan requires a little different care as he has special needs. When Nathan was three months old, we learned that he had epilepsy, at six months that he was legally blind, and at nine months that he had cerebral palsy. We are hopeful that some day Nathan will sit, stand, walk, talk, see, feed himself and hear without aids. Some people call these his disabilities. We like to think of them as his “different abilities,” which are secondary to the fact that he is first a beautiful little boy.

Throughout the years there have been four principles that helped us in raising our boys: (1) Show by example; (2) Set expectations; (3) Give yourself permission not to feel guilty; and (4) Make time together.

Show by Example and Set Expectations

As a mom with two sons, one with special needs, I consciously try to instill specific values that build a solid foundation between my children – a foundation that instills a strong love for one

another. I have found most children learn by example. My husband and I try to show that we love both our boys equally. Jimmy hears phrases like “How are my two beautiful boys?” He sees us kissing and tickling Nathan and making him laugh. He understands how Nathan is included in family activities just like everyone else. As he sees loving behavior day in and day out, Jimmy learns how to act towards his little brother. As different as they may appear, they are both very similar. They are both in a family that treasures and loves them. They both must take turns and share. Sometimes Nathan is the center of attention and other times Jimmy is. At times neither of them is



the center of attention and that is okay, because that's the reality of our life. They know how much they are loved and how special they are.

Give Yourself Permission Not to Feel Guilty

At times, when a parent has a second child, guilt may come along: the guilt from spending too much time with one child and not enough with the other; the guilt resulting from not spending enough time with your spouse; the guilt from not spending enough time for yourself. As a parent, one of the most rewarding and uplifting things I did was eliminating this guilt.

Early on I was concerned and weighed down with guilt that Jimmy was not getting enough attention when I was working with Nathan's therapists (PT, OT, Speech and Vision) or taking extra time to feed Nathan as it is difficult for him to swallow. I finally realized that setting expectations, eliminating any

feelings of guilt and reaching a balance was important to our family. If Jimmy wanted to play a game while Nathan was having therapy, I gave myself permission – guilt free – to go upstairs with Jimmy and leave Nathan with the therapist. If I wanted to concentrate on Nathan's therapy session it was okay to ask Jimmy to entertain himself. What now seems like a simple solution originally came as guilt for focusing on one child over the other.

Make Together Time

We try to do as much together as a family as possible. We have two-on-two basketball games. Jimmy sees and learns how Nathan is included in and dribbles, passes and shoots the ball. We have family game night. Everyone including Nathan gets a game piece and takes a turn. If we play charades, Nathan gets a turn to act out his word. (All with a little help of course.) If Jimmy has a tee-ball game we like to include Nathan.

It is instilled in Jimmy that Nathan is his biggest fan. Or as Jimmy says, “Nathan is my biggest and littlest fan.” He enjoys having his little brother at the game to cheer him on. Nathan enjoys the crowd and the excitement of the game. Jimmy learns, accepts and understands the importance of including and loving his little brother in each aspect of his life.

Many times a child's love for a sibling is expressed in their words. A child's words mean so much to a parent. As I tuck my boys into bed at night, my heart smiles when I hear, “Good night, I love you little brother.”

Teens And Siblings:

A conversation with Jessica Coggins, age 16, a junior at Danbury High School and Taya Wilson, age 15, a junior at Danbury High School

By Claudia Anderson, Danbury Public Schools, Special Education Teacher

Jessica's brother Joshua (age 6) was born with multiple disabilities. He is fed through a G-tube and has an illiostomy. He has a seizure

disorder and has spent long periods of time at Yale-New Haven Hospital. This past spring his leg broke in several place requiring a rod and pins to be placed. Jessica also has a brother Robert who is 12.

Taya was born with a birth defect that left her arms shorter than normal and without five fingers on her hands. Taya has a sister 12 and a brother 14.

Q: Do you ever get mad at your brothers or sister?

J: Josh can upset me, especially at night when he doesn't sleep and he is bouncing around in his bed, but I can't get mad at him because I know he doesn't do it on purpose.

T: My sister is pretty nice, but my brother can be bossy at times.

Q: Are you embarrassed in public or with friends?

J: I'm not embarrassed. People look at Josh, but that is their problem. I care for him no matter what. I won't give up on him and they wouldn't either.

T: I'm not embarrassed; people have to accept me for who I am. My brother embarrasses me sometimes when he is really loud.



Jessica and Josh

Q: Do you ever feel ignored?

J: I don't because I realize he needs a lot more attention than me.

T: My brother and sister get lots of attention; we're a normal family.

Q: What is the best thing about being a sister?

J: Josh is always happy except for when he is sick and can't be so bouncy. I also like seeing how much he's improved since he was a baby.

T: My brother is very protective of me and will help me out when I need it. My sister and I have a lot in common and talk a lot to each other.

Q: What is the worst thing?

J: Seeing Josh go to doctor visits, especially when they have to draw blood and he gets so upset. Or when he is sick and the doctors can't find the cause and he has to go to Yale and my mom has to stay down there with him.

T: Sometimes my brother and sister do what they want and can be selfish.

Q: What can't you do because of your sibling?

J: My parents are overprotective; someone always has to be with Josh. Because of all his medical problems it is difficult to get sitters and to do family things.

T: There is really nothing that they can't do.

Q: How do you handle the responsibility?

J: It doesn't seem like a lot of work because I am used to it. I can start/stop feeds, give meds into his lines, know which toys are his favorite – he's my brother and I want to do all I can to help him.

T: There is no extra responsibility, but everyone has jobs to do.

Q: Do you ever wish you were an only child?

J: No, but I wish I had a sister.

T: I'd like to be an only child to have more space and privacy.

We're Special Too!

By Christina Mace, Program Coordinator at We're Special Too

We're Special Too! is a volunteer-based community program which brings together brothers and sisters of children with special physical or developmental needs as well as those with chronic or terminal illnesses. The program acknowledges the unique challenges facing these siblings. Sponsored by the Friends of Yale-New Haven Children's Hospital, the sibling program offers supportive workshops on the second Saturday of every month to brothers and sisters between the ages of 5 and 15 years.

These workshops combine informal discussion with interactive games and activities in a fun-filled, age appropriate environment that emphasizes a "kid's-eye-view." Some of the activities include tree climbing at The Adam Kreiger Adventure Course, creative woodworking, yoga for children, photography, and a trip to the Operating Room. A team of specially trained volunteers, who give of their time willingly, facilitates the workshops.

It is well documented that the longest lasting relationship in the family is the sibling relationship. Yet, brothers and sisters of children with special needs have, compared to their parents, fewer opportunities for peer support and

We're Special Too! continued on page 8.



Taya

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For more information about Local
Interagency Coordinating Councils,
contact the person listed in your area,
the Child Development Infoline at 800-
505-7000, or visit the Birth to Three
website at www.birth23.org.

BIRTH through 5 NEWS

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Web Resources

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National Information Center for Children and Youth with Disabilities has a number of related resources that can be accessed through their website at www.nichcy.org. NICHCY also has a publication entitled, *Children with Disabilities: Understanding Sibling Issues*.

The Sibling Support Project is a national program for brothers and sisters of individuals with disabilities and special health care needs. The goal of this resource is to provide access to peer

support, information and resources for siblings with a brother or sister with a disability. This resource can be accessed at www.thearc.org/sibling-support/.

University of Michigan Health System answers questions about siblings of children with disabilities and provides fact sheets at their extensive website at www.med.umich.edu/1libr/yourchild/spcneed.htm.

Educational Resources Information Center (ERIC) has suggestions to help parents minimize sibling concerns at their website at www.ericec.org/faq/siblings. The ERIC Clearinghouse on Disabilities and Gifted Education is part of the National Library of Education, Office of Educational Research and Improvement, U.S. Department of Education.

Pediatric Physical Therapy, Inc. offers suggestions and additional resources on their Living with Disabilities page at www.pediatricpt.com/articles/siblings.htm.

SibKids is an Internet list serve for young brothers and sisters of children with special needs and is available through www.yahogroups.com.

Exceptional Parent Library at www.eplibrary.com can provide a list of books and publications that focus on sibling and family relationships for families that have a child with a disability.

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education. Siblings need to express their feelings and concerns as well as have them respected and validated. They often need attention and assistance in dealing with the whirlwind of emotions that naturally arise as a result of their family dynamics.

Through participation in the sibling program brothers and sisters are able to share their feelings with peers in a positive way as they realize that their experiences are not unique. They learn ways to cope with their particular situations and they are recognized for the contributions that they make to their families. Most importantly, siblings are made to feel that they are special too.

For more information or to refer a child to We're Special Too! please contact **Christine Mace**, Program Coordinator at (203) 688-6880.

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