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Facing Disability Together: Families are more than Moms and Dads

By Vivian J. Carlson, Ph.D., Human Development & Family Studies, Saint Joseph College, West Hartford, CT



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

Produced by the State Department of Education Early Childhood Special Education Program and the Connecticut Birth to Three System in collaboration with the



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“When the doctor told us that Mira has Down syndrome, we were so stunned that we couldn’t hear anything else that she said. As those first days passed and we saw Mira’s quiet determination to survive in spite of her heart surgery and difficulties with sucking and swallowing, we fell in love with her. Our love was mixed with fear, anxiety, and hope. My mother came to the hospital right away, but she was afraid to hold Mira. My father didn’t even come in. Michael’s parents visited once then helped care for three-year-old Robert at home. My sister came to the hospital to hold Mira every night while we went home to spend time with Robert.”

When family members realize that one of their own children has a disability, they begin a process of grieving for the loss of the expected child, learning to understand the realities of their child’s current and future needs, and adapting their daily lives and family roles to an entirely new reality. Family members are challenged to cope with their own emotions and beliefs about disability while trying to maintain positive relationships with one another.

“I was angry with my father and disappointed that my mother still seemed afraid of Mira, even after we brought her home. Michael’s parents were good about helping out with Robert, but rarely paid attention to Mira. My father seemed to be avoiding us.”

The intensity of emotions aroused by the discovery that a family member has a disability can be overwhelming for extended family members as well as parents and siblings. Beliefs about the causes of disability vary widely across generations and among varied cultural and religious groups. Older

generations may believe that they are personally responsible for passing on ‘defective’ genes. In the recent past, many families hid family members with disabilities from others, often by placing them in institutions. The fact that a family member had a disability thus became a shameful and never-to-be-spoken-of secret.

“I decided to talk with my father and try to find out why he was avoiding us. I went to see him when mother was out and tried hard to tell him how sad I felt about not seeing him and worried that my children were going to miss knowing what a wonderful grandfather he is. He broke down and actually cried, telling me that he had a little brother I had never heard about who was ‘never quite right.’ His brother was sent to a state institution and died at the age of 12. I told Daddy that Mira would always stay with the family and be a part of our community. She is a beautiful baby and has already taught us so much about persistence and patience and love.”

Finding a way to talk with family members about their beliefs and experiences with disabilities is not easy. It requires a loving approach without blame or judgment and an open-minded willingness to listen and understand. Encouraging family members to share their emotions and experiences can bring everyone closer together. Acknowledging the past and actively welcoming a more hopeful future is a part of the process of acceptance that will help to lead families towards resilience and unity. Professionals who are skilled communicators can offer empathy and support to families as they struggle to cope with individual fears and adaptations.

“Michael sat down with his parents and let them know that he was puzzled by their lack of attention to our sweet daughter. He asked them what they knew about Down syndrome and how they felt about Mira. His father insisted that there were no genetic problems in his family and that this must have come from some other part of the family. Michael’s mother finally admitted that she was taught that God punishes parents who have sinned by giving them children with disabilities. Michael was stunned and angry at first, but bit his tongue and explained that Down syndrome does not usually run in families. It is an accident that happens when the cells that form the baby first start to divide. He asked his mother to consider that God may have given Mira to our family as a special gift—a child who will teach us many things about what is most important in life. And that perhaps we were chosen because we have the strength and love among us to understand the blessings she will bring to us.”

Changing deeply held cultural and/or religious beliefs is neither a quick nor an easy process. Simply opening up the discussion and beginning to communicate about these ideas is a very important step toward mutually rewarding family roles and interactions. Helping parents understand that extended family members may not share their ways of understanding disability may assist them in their efforts to establish more positive relationships.

“So now my father comes over to the house. He mostly still plays with Robert or helps Michael fix things, but I try to bring Mira to him and show him how she smiles now and loves to cuddle. I can see that he’s starting to relax a bit and smile at her and let her hold his finger. My mother comes over too and will

now sit in the rocker with Mira while I get a few things done around the house. My sister stays with the kids one night every weekend and we visit Michael’s parents every Sunday. We show them all the new things that Mira does and talk about her therapy and Robert’s preschool. I think they’re beginning to get more comfortable with Mira. I guess maybe I expected too much of the grandparents at first. It must be very hard for them to understand that everything has changed for children with disabilities since they were young.”

Early intervention and preschool professionals who understand the interconnectedness of families, the complexity of family efforts to adapt to the presence of a child with disabilities, and the stressors that many parents face will learn to model patient, supportive, and respectful communication and relationship-building skills. Children who participate in programs designed to actively encourage the participation of all important family members will be more likely to experience resilient, positive and mutually supportive family environments.



Afrontar juntos la incapacidad: Las familias incluyen más que papás y mamás

Por Vivian J. Carlson, Ph.D., Estudios del desarrollo humano y la familia, Saint Joseph College, West Hartford, CT

“Cuando el médico nos dijo que Mira presentaba el síndrome de Down nos sentimos tan aturdidos que no podíamos seguir escuchando lo que nos decía. Al pasar los primeros días y ver en Mira una serena determinación de sobrevivir pese a la cirugía del corazón y dificultad para chupar y tragar, nos enamoramos de ella con un amor impregnado de temor, ansiedad, y esperanza. Mi madre vino inmediatamente al hospital, pero no se atrevió a cargar a Mira. Mi padre ni siquiera vino. Los padres de Michael nos visitaron una vez y ayudaron cuidando en la casa a Robert, de tres años. Mi hermana venía todas las noches al hospital a cargar a Mira mientras íbamos a la casa a pasar un rato con Robert.”

Quando los miembros de la gran familia se dan cuenta de que uno de sus vástagos tiene una incapacidad, inician un proceso que incluye aflicción por la decepción, comprensión de la realidad en cuanto a necesidades actuales y futuras de la niña, y adaptación a la nueva realidad. Los miembros de la familia sienten el reto a afrontar sus propias emociones e ideas sobre la incapacidad mientras tratan de mantener entre sí relaciones positivas.

“Yo estaba enojada con mi padre y decepcionada de que mi madre parecía temerle a Mira, aun después de llevarla para la casa. Los padres de Michael eran buenos en lo que ayudaban con Robert, pero rara vez le prestaban atención a Mira. Mi padre parecía que nos esquivaba.”

La intensidad de las emociones que despierta la conciencia de que un miembro de la familia tiene una incapacidad puede ser

abrumadora para los miembros de la familia y también para los padres y hermanos. Las ideas sobre la causa de la incapacidad varían a través de generaciones y entre grupos culturales y religiosos. Los miembros de generaciones anteriores pueden sentirse personalmente responsables por haber pasado genes defectuosos. En un pasado reciente muchas familias ocultaban los miembros con incapacidades, hasta ingresándolos en instituciones. El hecho de que un miembro de la familia tenía una incapacidad parecía ser un secreto bochornoso del que no se debía hablar.

“Decidí hablar con mi padre y tratar de averiguar por qué nos evitaba”. Fui a verlo cuando no estaba mi madre y traté de decirle cómo me entristecía no verlo y que me preocupaba que mis hijos fueran a extrañar su fantástico abuelo. El rompió a llorar diciéndome que había tenido un hermanito menor del que yo nunca había sabido, que ‘no estaba del todo bien’. Ese hermano fue enviado a una institución del Estado y murió a los 12 años. Le dije a papá que Mira se quedaría siempre con la familia y sería parte de nuestra comunidad. Es hermosa y ya nos ha dado lecciones de persistencia y paciencia y amor.”

No es fácil encontrar la forma de hablar con la familia sobre sus ideas y experiencias respecto a las incapacidades. Se necesita un enfoque cariñoso sin culpa ni juicio y una voluntad de escuchar y comprender. Lograr que los miembros de la familia compartan sus emociones y experiencia puede acercarnos más unos a otros. Reconocer el pasado y dar activamente la bienvenida a un futuro de esperanza es parte del proceso de aceptación que ayuda a llevar la familia a tener mayor fortaleza y unidad. Los profesionales que son buenos en comunicación pueden ofrecer empatía y apoyo a las familias que afrontan la situación con temores y adaptaciones individuales.

“Michael se sentó con sus padres y les dijo que estaba intrigado por su falta de atención a nuestra dulce hija. Les preguntó qué sabían del síndrome

de Down y cómo se sentían respecto a Mira. Su padre insistió en que no había problemas genéticos en su familia y que lo de Mira debía provenir de la otra parte de la familia. La madre de Michael finalmente admitió haber oído que Dios castiga a los padres pecadores dándoles hijos con incapacidades. Michael se quedó atónito y furioso al principio pero se mordió la lengua y explicó que el síndrome de Down no suele ser hereditario. Es un accidente que ocurre cuando las células que forman el embrión comienzan a dividirse. Le pidió a su madre que considerara que lo que Dios nos había dado en Mira era un presente especial—una niña que nos va a dar muchas lecciones de lo que es más importante en la vida. Y que tal vez fuimos escogidos por tener la fortaleza y amor para comprender las bendiciones que nos traerá.”

Cambiar ideas culturales o religiosas profundamente arraigadas no es proceso rápido ni fácil. Simplemente traer el tema a discusión y comenzar a comunicar estas ideas es un paso muy importante para lograr papeles e interacciones mutuamente gratificantes en la familia. Ayudar a los padres a comprender que los parientes pueden o no compartir su modo de ver la incapacidad puede ayudarlos a establecer relaciones más positivas.

“Así que ahora mi padre nos visita, mayormente juega con Robert o ayuda a Michael a arreglar cosas pero yo trato de traerle a Mira y mostrarle cómo se sonríe ahora y se acurruca. Puedo ver que comienza a relajarse un poco y sonreírle y dejar que le agarre un dedo. Mi madre viene también y ahora se sienta en la mecedora con Mira mientras yo hago algunas



cosas en la casa. Mi hermana se queda con los niños una noche cada fin de semana y nosotros visitamos a los padres de Michael todos los domingos. Les mostramos las cosas nuevas que hace Mira y hablamos de su terapia y la preesuela de Robert. Creo que comienzan a sentirse más cómodos con Mira. Tal vez al principio yo esperaba demasiado de los abuelos. Debe ser muy duro para ellos comprender que todo ha cambiado para los niños con incapacidades desde los tiempos de su juventud.”

Con los profesionales de la intervención temprana y prekindergarten que comprenden las conexiones internas de la familia, la complejidad de los esfuerzos de la familia para adaptarse a la presencia de un niño con incapacidad y los estresantes que muchos padres confrontan, aprenderán a modelar comunicaciones de apoyo, pacientes y respetuosas. Los niños que participan en programas diseñados para promover activamente la participación de todos los miembros importantes de la familia tienen más probabilidad de experimentar un ambiente de resistencia positiva y de apoyo mutuo.



How Extended Families Can Support Children with Disabilities

By Bethanne Vergean, CRT Early Care and Education

One of the biggest challenges for parents of a child newly diagnosed with a disability is sharing the information with close relatives. While some disabilities are physical and more apparent when interacting with children, some are not. Understanding the disability that is not easily seen may make it harder for siblings, grandparents and other family members to understand the child's disability and know how to help. As parents engage in these discussions,

they should remember that their extended families might experience feelings of ignorance and fear that they themselves may have felt when learning of the diagnosis.

Accepting the diagnosis may be harder for some family members. Some family members may give their opinion: "the professional is wrong," "get a second opinion," "it's your parenting," or "the child will outgrow it."

Extended families may not have access to the information that parents receive from professionals. Sharing this information is key. Explain what help families can give, identify strategies that can be used while the child is in their care, and finally discuss that the disability should not be focused upon at family gatherings.

Getting family members involved is a good strategy to employ. Have them come to a meeting with the professionals, share the IEP and explain what services your child will be receiving. By helping to identify the diagnosis and where the child may struggle you can introduce what strategies will be used at home to support the child.

It's always best to have everyone on the same team. This team approach will provide a positive experience for the child no matter who they are with. The more knowledge the family has of the disability the better, and in the end this will benefit and support the child.



Parents' Perspective

Finding Support from Extended Family Members

By Amy McCoy, parent

Extended family members often want to offer us their support. We, as special needs parents, just have to show them how to help. This can be difficult for a number of reasons. Here are some suggestions of how your extended family can provide support to you and your family.

- Ask an extended family member to volunteer at your child's school, or to watch your other children so that you can volunteer. Becoming more involved in your child's education is important. Having an extended family member in your child's classroom gives him or her a direct view into your child's needs and differences in comparison to peers.
- If your child is receiving Birth to Three services, ask a family member to attend a therapy session in your home. If your child is older than three and is signed up for any community based recreational programs, ask an extended family member to attend the activity with you and your child.
- Any books or articles that you read about your child's disability should be given to the extended family. If the books are lengthy, condense them by highlighting page numbers or even writing a short summary of the book.

Parenting a special needs child requires incredible patience and strength, extraordinary courage and hope. Extended family can be a great support system for you if you give them the opportunity.



Birth to Three Update

By Linda Goodman, Director, Birth to Three System

We feel very fortunate that the Governor's proposed budget for the next two fiscal years supports early childhood programs. While there was no expansion of programs in this very difficult budget, funding for Birth to Three remains intact and the only reductions are those due to plans to capture increased health insurance revenue. We were also very pleased to see that the President's budget proposal for next year includes an increase for IDEA Part C (the federal funding portion of Birth to Three.) That may or may not survive Congress's attempts to pass the next federal budget, but it at least tells us that the administration values Part C in the context of effective early childhood programs that receive federal funding.

The focus of this issue is extended family members of children with disabilities. Birth to Three, as a family-centered program, is especially interested in including all family members in its services and support (the Individualized Family Service Plan is not just intended to cover parents and their children). Brothers and sisters that

are home during visits should become part of the activity, as would any other family members in the home at that time. Visits can be arranged when children are receiving childcare from other family members (if they're not too far away) and service coordinators should be available to talk about the best ways to explain a child's disability or needs to family members who see the child less frequently. Infants and toddlers, unlike school-age children, are uniquely dependent on their family

or other caregivers all-day, everyday. As a result, it is the job of your Birth to Three providers, including your service coordinator, to make all family members comfortable in caring for or playing with the child and knowing what kinds of intervention techniques work best. After all, Birth to Three staff will all be gone when a child turns three, but family is forever. Whatever we can do to enhance, not disrupt, relationships between family members and the child can last a lifetime.



We need your help!

Please send your ideas or suggestions for future newsletter topics to:

german.cutz@uconn.edu
or call 203-207-3266.

Thank you so much for your input.

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Birth to Three State Interagency Coordinating Council Update

By Mark A. Greenstein, MD, State ICC Chair

Families and parents are central to the Birth to Three System, not only as full participants in the Individualized Family Service Plan (IFSP) process, but also in many other ways. They are central members of the State's Interagency Coordinating Council and also represent their own and other's needs in terms of children who are served by the State. We have two new parent members, Corrine Greco and Miriam Martinez, on the ICC, replacing parents whose terms have recently ended. In addition, two of our new members from agencies bring with them experience as parents of children recently in the Birth to Three System or as parents of adults who have special needs who received services decades ago. Each of these members brings their child's and their family's story and perspective to us as we strive to assist and advise the lead agency in terms of services.

In addition, parents worked with support staff and stepped up in the new year, working on the distribution of the Birth to Three annual report (along with a single sheet fiscal update) to legislators at the start of the new

term. Hampered by a blizzard the day before, some were still able to manage the time to show and voice their appreciation for the services they are receiving, and to help legislators understand the role that early intervention plays in helping children and families here in Connecticut. We hope that sharing this year's report with new or returning legislators and their staff will illustrate the role that early intervention plays in families' lives. Our thanks to these parents!

Parents also serve as co-chairs on each of our committees. From the current Vice Chair of the ICC to co-chairs of our Fiscal/Legislative, Communication, and Quality Assurance committees, parents are equal partners in leadership and service.

As I have in the past, I want to thank the parents for the extraordinary effort they make to participate in any and all of these activities outside of their family, and to urge any of you who are interested to contact either me or Anna G. Hollister, RN at 860-418-8716 or anna.hollister@ct.gov about further participation.



Early Childhood Special Education Update

By Maria Synodi, Coordinator

Extended Families... This Birth through 5 News newsletter addresses the importance of *extended family members* in providing support, guidance and assistance to parents who are raising a young child with a disability. For many parents of a child with a disability, extended family and close friends are their greatest resource. For others, we have yet to dip our feet into the well. Sometimes parents may not know how much to share, may fear that judgments may be made by others and/or may have a variety of other reasons for excluding instead of including extended family members into the intricacies of the special education and related services being provided to their child with a disability.

As educators in public schools, our work centers on the child. Teachers direct their primary attention to what a child needs to learn and do. After

all, it's school... Yet we all know that in order for what we teach each day to have meaning, parents and families play a vital role and their involvement is crucial. Many school district staffs have worked to create opportunities to communicate with a child's parents and to afford parents opportunities beyond the planning and placement team (PPT) meeting for activities that foster a school and parent partnership. Opportunities that can include extended family members, with parent permission, are as important as including the child's parents in our work. Schools can consider a variety of options and opportunities to include grandparents and extended family members such as:

- Inviting grandparents and other extended family members to participate in class activities. Use their unique gifts, skills and expertise to contribute to the preschool classroom and school.
- Work with children's parents to provide opportunities to educate grandparents and other extended family members on

how they could help in providing consistency and continuity when they provide care or support for the child.

- Provide resources and information on the particular disability so that grandparents and extended family members better understand the child's strengths and needs.

These are just a few thoughts and considerations. Summer is just around the corner and what better time to work with parents and extended family members to ensure that a child's summer learning opportunities can be carried out by those who know and love the child most—and that it's fun for all!



Resources

Websites:

http://www.familyvillage.wisc.edu/general/frc_sibl.htm.

The Family Village is a web site for children and adults with disabilities, their families, and their friends. Family Village brings together thousands of online resources in an organized, easy-to-use directory.

http://www.familyvillage.wisc.edu/frc_grnd.htm. This is the Family Village site for grandparent information and resources. The site includes lots of great articles.

<http://www.siblingsupport.org/>. The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

<http://www.autismspeaks.org/community/resources/websites.php>. Autism Speaks is an autism advocacy group that has been an important source of funding research into causes and treatment of autism spectrum disorders. It also conducts awareness and outreach activities aimed at families and the public. The web site has an excellent compilation of online resources for families.

<http://astore.amazon.com/thesibsuppro-20>. This site includes information about books related to siblings and families.

Books:

Understanding Your Special Needs Grandchild: A Grandparent's Guide by Clare B. Jones, Ph.D. Specialty Press Publishers, 2001.

Voices from the Spectrum: Parents, Grandparents, Siblings, People With Autism, And Professionals Share Their Wisdom by Cindy N. Ariel and Robert A. Naseef. Da Capo Lifelong Books, 2006.

Grandparenting a Child with Special Needs (2009) by Charlotte E. Thompson, M.D. Jessica Kingsley Publishers, 2009.



University of Connecticut
Cooperative Extension System
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Este boletín está disponible en inglés y en español. Visite el sitio del Sistema para Infantes a Tres Años en www.birth23.org y pulse a Publicaciones o el del Departamento de Educación en www.sde.ct.gov. Pulse entonces el enlace 'Early Childhood' (primera infancia).

CHILDREN'S ARTWORK WANTED!

You are invited to send pictures, drawings or other artwork that your child has done. We would like to start an "art collection" for possible inclusion in future Birth through 5 News newsletters. Please mark the artwork with the artist's first name and age and mail to:

Dr. German Cutz, editor, UCONN CES
67 Stony Hill Rd.
Bethel, CT 06801

or send by email to: german.cutz@uconn.edu

No artwork will be returned. We look forward to receiving your child's works of art!

