Transforming Common Family Dilemmas

By Andy Miser, Ph.D., Family Consultant, Hartford, CT

While consulting with and supporting parents of children with special needs, I have become familiar with common family dilemmas. The following is a description of some dilemmas and ideas for resolving them.

WHAT IS HAPPENING TO OUR FAMILY?

From the time that parents suspect that their child may have a special need, they deal with a host of feelings and experiences for which they are unprepared. Parents report feeling robbed of the experience of having the healthy child and the future they had expected. They may be anxious about their child's development, health and future. Many families find it difficult to cope with the feelings of loss and uncertainty that accompany the initial suspicion or knowledge of a disability.

Often parents turn to the medical community for answers. Some parents need to push their doctors for the information that will help them understand their circumstances. Others are reluctant to seek information for fear of what they might find out. Many parents find it difficult to put their child through the medical tests that might be involved in the diagnostic process. Repeated doctor visits recreate earlier painful experiences for some parents. Over time, it is common for some parents to distrust their experiences and to feel that the medical experts know what is best for their child.

Parents need support in learning to trust themselves: their needs, the child’s needs and the family needs. They need support so they can foster safe and supportive relationships with medical personnel while developing confidence as the expert regarding their child. And, they need support in recognizing that whatever they are feeling at any particular time is a normal response to a very difficult life situation.

OUR FAMILY AND FRIENDS DO NOT UNDERSTAND

Parents express concern that they are repeatedly asked to explain their child's disability to family and friends. They may feel burdened with the feelings and attitudes of other people regarding their child. Parents sometimes give mixed messages to friends and family. They want others to understand what is going on in their life, but do not want to continually explain their situation, and may end up pushing others away.

Parents need support as they learn to cope with the concerns of extended family and friends. They need to find ways to include others in their lives on their terms. They need to realize that it is okay to be private and to choose not to explain their situation to everyone. They need to understand that their friends and families are acting out of love, concern and a desire to contribute. It can be helpful when parents find ways to request the specific help they need.

WE ARE OUT OF BALANCE

Parents of a child with a disability often find that they are focusing all their time on that child and very little on their marital relationship or other children. They may feel guilty about this imbalance and blame themselves if their other children are having difficulties in dealing with the stresses in the family. Usually parents know that things are out of balance, but do not know how to balance their family needs.

Parents need to find a balance in caring for the needs of the child with a disability, the needs of the marital relationship, the needs of
La resolución de comunes dilemas familiares

Por Andy Miser, Ph.D., Consultor de Familia, Hartford, CT

En mi trabajo de asesorar y dar apoyo emocional a padres de niños con necesidades especiales me he familiarizado con dilemas familiares que son bastante frecuentes. Lo que sigue es una descripción de algunos y de ideas para resolverlos.

¿QUE LE ESTÁ PASANDO A NUESTRA FAMILIA?

Desde el momento en que los padres sospechan que un hijo puede tener alguna necesidad especial, confrontan una multitud de sentimientos y experiencias para los que no se encuentran preparados. Se sienten despojados de la vivencia de tener el hijo saludable y con futuro. El desarrollo, salud y futuro del hijo les produce ansiedad. Muchas familias encuentran difícil hacer frente a los sentimientos de pérdida e incertidumbre que acompañan la sospecha o conocimiento inicial de la incapacidad.

Es natural que los padres acudan a la comunidad médica en busca de respuestas. Algunos se sienten impelidos a presionar a sus médicos en busca de información. A otros los frena el miedo a lo que pudieran encontrar. A muchos se les hace difícil someter al niño a las pruebas médicas necesarias para el diagnóstico. Las repetidas visitas a facultativos pueden recrearles experiencias dolorosas anteriores. Pero con el tiempo es bastante común que desconfíen de sus propias impresiones y lleguen a la conclusión de que los expertos médicos saben lo que es mejor para su hijo.

Los padres necesitan recobrar la confianza en sí mismos, en que pueden satisfacer sus necesidades, las del niño y las de la familia. Necesitan ayuda para promover relaciones firmes y de mutuo apoyo con el personal médico a la vez que desarrollan confianza de expertos en cuanto al niño. Y necesitan ayuda para reconocer lo que puedan sentir en un momento dado, por descabellado que sea, es reacción normal en una situación muy difícil.

LOS PARIENTES Y AMIGOS NO COMPRENDEUN

A los padres les inquieta que parientes y amigos repetidamente les hagan preguntas sobre la incapacidad del niño. Se
pueden sentir abrumados por las mani-festaciones y actitudes de los demás. No es extraño que los padres den impresiones contradictorias a familiares y amigos. Desean que éstos comprendan por lo que ellos están pasando pero no tener que dar continuas explicaciones y puedan terminar rehuyéndolos.

Los padres necesitan ayuda para responder a las expresiones de interés de parientes y amigos. Necesitan incluirlos en su vida pero en sus propios términos. Necesitan convencerse de que no hay nada incorrecto en ser reservado y no dar explicaciones a todo el mundo. Pero también comprender que muchas preguntas de amigos y parientes están motivadas por el afecto, por una genuina preocupación y por deseos de ayudar. Esos amigos y parientes pueden serles útiles en las ocasiones en que los padres encuentren la manera de pedirles ayudas específicas que necesitan.

**“NOS SENTIMOS DESCONCERTADOS”**

Los padres de un niño con incapacidad suelen estar conscientes del desequilibrio que pueda tener a consecuencia de la frecuencia de los problemas que los otros hijos pueden tener a consecuencia de la frecuencia de la tensión en la familia. Los padres suelen estar conscientes del desequilibrio pero no saben cómo resolverlo.

Es preciso que los padres logren dedicar tiempo y atención tanto a las necesidades del niño con incapacidad como a las de la relación marital, a las de los otros hijos y a las de la familia como un todo. Necesitan ayuda para aprender a dedicar tiempo de modo regular a la relación marital, a estar juntos con cierta intimidad. Necesitan encontrar el modo de dar atención especial a cada uno de los hijos y de conseguir el apoyo de otras personas (niñeras, enfermeras, etc.) que puedan ayudar a restaurar la armonía.

**“NO TENEMOS VIDA PRIVADA”**

A los padres puede parecerles difuso su ámbito familiar, sentir que les falta espacio personal y libertad al tener profesionales en su casa habitualmente. Los padres están agradecidos por la asistencia que reciben en los variados programas, pero a veces suelen sentir que no tienen vida privada. Puede parecerles que es obligación de los padres participar plenamente en cada sesión de terapia y ser terapeutas y maestros del niño. Una madre resumía esto preguntando “¿Cuándo paso a ser madre?” A algunos padres les remuerde la conciencia cuando no participan en algún tipo de terapia con su hijo.

Es importante que los padres se sientan al frente de la asistencia que reciben. Su conciencia de que controlan sus ámbito familiar y espacio personal es vital al sentido de salud y bienestar de la familia. Debe alentarse a los padres a participar activamente en la determinación de los tipos de apoyo que recibe el hijo y del papel que deben desempeñar en los mismos.

**“NO SOMOS UNA FAMILIA NORMAL”**

Es fácil que los padres de un niño con incapacidad piensen que no tienen una familia típica y que se sientan solos en sus desafiantes circunstancias. Muchos de esos padres piensan que las familias con hijos que se desarrollan típicamente no comprenden por lo que ellos pasan. Se sienten fuera de la vida de la comunidad.

Las familias necesitan convencerse de que son familias normales que se enfrentan con circunstancias extraordina-rias. La participación en grupos con otros padres que han pasado por circunstancias similares suele ser positiva. Puede consolarles el saber que no son los únicos y que son parte de la comunidad.

**“NUESTRO HIJO ES DIFERENTE”**

Es muy corriente la ansiedad de los padres al comparar el desarrollo de salud de su hijo con el de otros niños. No es raro que encuentren difícil estar alrededor de niños con desarrollo típico.

Con el tiempo los padres llegan a aceptar con naturalidad al hijo como un niño especial que tiene mucho bueno que dar. Necesitan apoyo mientras aprenden a comparar más bien el nivel de desarrollo actual del niño con sus circunstancias similares suele ser positiva. Cuando los padres reconocen que su amor por su hijo es incondicional pueden apreciar los dones especiales del hijo. Entonces pueden experimentar las satisfacciones que su hijo les traerá a ellos, a la familia y a los amigos.

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**Program Updates**

**BIRTH TO THREE UPDATE**

By Linda Goodman

As most of you are working on the holiday shopping and cooking list, we’re frantically working on finishing our self-assessment that is due in Washington on December 22. A big “thank you” to all who participated in any of the public forums that were held at the end of September. When the document is finished, we will post it on the Birth to Three website ([www.birth23.org](http://www.birth23.org)), and you can see for yourself what the steering committee decided were the strengths and areas needing improvement as we do our best to implement the Individuals with Disabilities Education Act in Connecticut.

On a separate track, in October, the University of Connecticut Health Center, Division of Child and Family Studies began a study for us so that we can better measure the effectiveness of early intervention. You probably
received a survey from them and many of you who returned it may have also volunteered to participate in a follow-up telephone interview. Again, thank you for your help. When the study is finished, sometime this spring or summer, we will post the results on our web site.

In September, we issued a Request for Proposals to find a parent organization that wished to create a Family Leadership Initiative within the Birth to Three System. As we had recognized even before our self-assessment, we don’t often have family members “at the table” when decisions are being made about the administration and operation of the Birth to Three System or when materials are being developed for families. We are hoping that this Leadership Initiative can start with a small group of parents who can then begin to recruit other parents so that, if all goes well, we will have a large number of parents involved in all aspects of our System. Those proposals are due by January 5, 2001 and, we will be making a selection by mid-January for a March 1, 2001 start.

One area of family involvement where we have already improved is having parents work with us as co-trainers, particularly as we train new service coordinators. In last spring’s newsletter, we had over 40 responses to our request for co-trainers, and we now have our first group of parents that we can contact when training or other opportunities for participation come up.

I would like to wish a very joyous holiday to everyone and a glorious 2001.

**Preschool Special Education Update**

By Maria S. Synodi

Holidays are fast approaching, and this school year has already whizzed by. The following are updates of some of the Department’s activities:

- On December 22, 2000, the State Department of Education and the Birth to Three System will be submitting a Self-Assessment Report on the status of special education and Birth to Three in Connecticut. The report will reflect the status of the state in relation to meeting the requirements of the IDEA for infants, toddlers, children and youth with disabilities. The U.S. Department of Education, Office of Special Education Programs has required the Self-Assessment of Connecticut. The state will be making the Self-Assessment Report available to the public through its web site sometime after the new year.

- SERC will continue to serve as the agent of Department of Education and the Birth to Three System in sponsoring a series of workshops on the topic of serving children within the autism spectrum. SERC will also be working with the two agencies in again helping to sponsor the annual Together We Will Conference. This year’s Together We Will Conference will be held on April 26, 2001 at the Sheraton Waterbury Hotel. A “Call for Proposals” to present at the conference has been disseminated.

- The Department of Education is continuing to disseminate the Preschool Curricular Goals and Benchmarks document and the Emerging Literacy paper to professionals in early childhood and early childhood special education. The document is intended to outline the expectations for young children receiving a quality preschool experience. Department staff is continuing to provide training throughout the state.

As we look to the future and the new year ahead, celebrate the past and continue to look ahead to the future.

Happy Holidays!

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State ICC Update

By Ann Gionet, Parent, Chair of SICC

**Family participation comes in many sizes!**

Opportunities abound for family input into services and supports for the Birth to Three System. People can play any part that fits their families’ needs; being a member of a Local Interagency Coordinating Council (LICC), a member of the State Interagency Coordinating Council (SICC), provide comment at the SICC meeting, or provide a family perspective for the Birth through Five News. Families are critical stakeholders and the information they possess regarding supports and services must be shared in order to assure a quality product is being delivered to all users in the system.

The State Interagency Coordinating Council would like to extend a warm welcome to all families to come and share in our effort to assure quality services and supports for families with young children in Connecticut. I would like to take a moment and describe the variety of efforts going on in Connecticut where families’ input is vital. Presently members of the State Interagency Coordinating Council are working on the Infant and Toddler Mental Health Task Force as well as on the Therapy Services Task Force. Throughout the year, members participate on the Collaboration Committee and the Fiscal Committee. A few members of the SICC are taking part in the self-assessment for the Federal Office of Special Education Programs. The self-assessment steering committee is made up of a group of stakeholders, including families, who are looking intensely at
traveling with young children, whether they do or do not have a disability, can be challenging. When traveling long distances, planning ahead will help prevent frustration for all riders in the car. Consider the following tips as you plan your travels:

Consider the length of time your child tolerates being in the same position. Children in car seats, especially if they are molded to a particular child, can become uncomfortable. If a child typically gets frustrated after being in the seat for an hour, don’t expect their tolerance to suddenly increase for the trip.

Remember your child expects you to anticipate his or her every need and respond accordingly.

Consider the time of day your child will be most likely to travel well. If you need to drive two hours, and your child normally takes a two-hour nap from 1 p.m. to 3 p.m., planning to travel during that time may make sense if your child will sleep in the car. Think about your child’s dietary needs: Can she or he snack while riding or will you need to pull over regularly? (You may have better luck always pulling over for meals. Use these stops as an opportunity to stretch, change diapers, and use the bathroom to freshen up.)

Identify your child’s favorite toys or activities. At the beginning of the trip, try to let your child entertain him or herself and always save the best toys for last. If your child becomes bored with their options too soon, you may be in for some rough riding. Sometimes borrowing different toys from a friend may help also. The “new” toys may help ease the tedium of the trip.

Determine locations to stop along the route. Plan your itinerary and stick with it. Look at a map and choose stop points for snacks, meals, bathroom breaks and stretching. You may need to pull off the road sooner, but try not to skip scheduled stops when things are going well. Once a child is frustrated things can quickly go from bad to worse. If more than one child is along for the ride, one’s problem will often escalate the frustration of another.

Identify who will sit closest to the child. If your child needs a lot of interaction to remain entertained, plan on having an adult in the back seat, next to the child. An older sibling may be able to help out as well.

Regardless of who sits by the child, if the helper begins to become frustrated or irritable, the younger child will surely sense it and be more likely to become upset as well. If possible, avoid having two small children sit right next to each other. Listening to “I want that” or “He’s touching me or my things” can become very upsetting very quickly.

Preparation is the key. Plan to double your driving time: If it would take three hours without children, plan on six. If you arrive in four, you will be very happy.

Remember, the trip home may be difficult. Everyone will be tired and the anticipation of going home is not always as motivating as a vacation or seeing friends and relatives.

Planning a trip or an outing may require extra effort from parents, but it may be worth it. Someday your child is likely to remember the event with fondness and nostalgia.
I’VE LEARNED TO JUST BE "MOMMY!"

By Jacqueline A. Cantoni

My husband and I have two beautiful boys. Jimmy is five and Nathan is three. At three months, Nathan was diagnosed with epilepsy, at six months legally blind, and at nine months cerebral palsy. He has yet to crawl, walk, talk, see or feed himself. The first 18 months were a difficult time for our family. We were overwhelmed and challenged. Being inundated with medical information, research and doctor visits, I felt more like a nurse and case manager than a mommy – which is all I expected to be!

When Nathan was 18 months old, my entire perspective changed. He was hospitalized for seven weeks during which he spent time in the pediatric intensive care and his life was at risk. It was at that point I realized how much I loved this little boy. The medical diagnoses consumed me, and I forgot he was just a little boy and I was his Mom. This is when I made the connection with his special needs and my life. I began to accept the reality of our situation and became very comfortable with it. Part of the reality was the different abilities. Part also was that Nathan was a very happy and contented boy who lived in a family that loved him very much.

I learned a hard lesson. I learned to give myself permission to be just a Mom. As soon as I allowed this, Nathan helped me treasure every day. I started to feel special that God entrusted him to me as a gift to take care of during my lifetime. I changed my perspective on how I viewed our situation and that is what made a difference. I dug myself out from the volumes of medical reports and began to focus on the needs of a little boy – hugs, kisses, wagon rides, playing games, reading books together with his brother Jimmy, dancing with the family and the all-important cuddle time. The different abilities became secondary.

It was then that I once again began to live my life with the laughter and love that I once knew. I have been given the complete acceptance of my circumstances that I finally moved past them and on to a greater understanding. I learned that it was not as important for my little boy to sit up or crawl as to have the opportunity to smile, laugh, love and be loved.

My perspective changed with this transition. I realized and accepted there will be times while raising a child with special needs that:

We have limited privacy in our home.

In the early stages we had people in our home almost every day. I have since learned to schedule days off for Nathan allowing time just for our family. Also, I have learned to be truly thankful for the support and care my son received from the therapists and nurses visiting our home.

We may feel out of balance.

I have learned to make choices to keep our family in balance. There are times when I feel like I should always be doing physical therapy exercises. Instead I choose other options. I now make sure I take Nathan for wagon rides – because that’s what little boys do.

Some people may not understand our situation.

Some people may look at Nathan and be uncomfortable seeing or holding a special needs child. I now believe that most people have good intentions and mean well. In an effort to make them feel comfortable I focus on the beautiful little boy he is. Some will be blessed and
see his beauty and others may take longer to notice.

**Our family may not be perceived as typical.**
I have come to an understanding that every family is unique and one is not necessarily better or worse than another. I feel very blessed with my given family.

**Special needs children are perceived as different.**
Nathan has challenges that make him different from other children. But, he is a precious little boy first and all children are unique and special in their own way.

I have learned my eyes may fill with tears as I try to describe the radiant colors of a sunset to my child whose sight has not yet developed. I am quite thankful to share it with him through my eyes.

I have learned it is important to take one day at a time. When I begin to think about a lifetime of care for a special needs child, I remind myself that I know I have the love and strength to care for him just one day at a time.

The most important lesson time has taught me is that Nathan is just a beautiful little boy and I am his Mommy. And that’s what makes everything else okay.

**FAMILY DILEMMAS**
*By Susan Grimaldi*

I have a six-year-old son named Christian who has been diagnosed with cerebral palsy, autism and cortical vision impairment. He has a gastrostomy tube and is currently learning to eat pureed food. He walks with the aid of a walker. He cannot speak, but understands what we say when he is spoken to and is learning some sign language.

They don’t understand.
Some people believe that Christian has no feelings because he does not speak or relate to them in a normal way. For a long time, this bothered me because I knew Christian’s emotions were the same as any other boy his age. As time went by, I realized that I could not change the way other people chose to think about him. I decided not to let other people’s attitudes towards Christian bother me. They will never have the privilege of being close to him or feeling the great love that he is capable of giving to others.

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As a parent, creating balance in my life has been difficult to achieve. It felt hard just to hire that babysitter, to get away on a Saturday night for some fun and relaxation. Just to find someone who is willing to stay with Christian and his two brothers is always a difficult task. Once I find a good, responsible babysitter, I have learned to pay them well and treat them with great respect. As time goes by, I have learned that I need to go out and have fun and that this is as important as going to work!

**We’re not normal.**
I feel as though my family is typical. My three boys go to the public school. We attend school functions, play at the playground and do every activity that other families do. Most people in my town are accustomed to seeing Christian at different activities, fairs and school functions. Christian participates in his own way and fits in to community life.

**We have no privacy.**
I have learned to take control over my family schedule when I feel overwhelmed with home visits. The visits are always fun and informative, but they take their toll in loss of private time. I have learned to use certain days of the week for home visits and the therapists, nurses and other professionals would have to schedule us on those days. The rest of the week, I used for whatever private time I needed. I really had to make this commitment to myself for those days. Eventually, I felt that I had control over my schedule and that helped me look forward to these home visits.

**He is not like other children.**
I learned to stop comparing Christian with other children. I realized that he had his own timetable and was not going to grow and develop like other children. I learned to appreciate the small steps of progress he has made and look forward to his future progress.

**UNDERSTANDING COMMON DILEMMAS: CONTRIBUTIONS TO MY WORK WITH CHILDREN AND FAMILIES**
*By Peg Palmer, Board of Education and Services for the Blind, Windsor, Connecticut*

Though I am a teacher of young children with vision impairment, much of my work revolves around their parents. One of my biggest challenges is to provide information to help each family understand and overcome
the obstacles they face. The following is information that may help others in working with families:

In my experience, families with a child with a disability face most of the same dilemmas that other families face. Like all families, balancing the needs of all family members is a difficult task.

While families who have a child with disabilities have much in common with other families, they also face unique challenges that are particular to each individual household. To address these specific and individual challenges, I work to listen with greater empathy and acceptance.

I have promoted parent groups and parent get-togethers as a vehicle for families to communicate and share their experiences. Participation in these groups eases the sense of isolation and alienation that many families feel. Out of these dialogues, strengths are shared.

At times, parents may find it easier to talk to visiting professionals instead of other family members or friends. Though I try to bring an acceptance and understanding to this situation, at the same time, I also try to help parents bridge the communication gaps with their own loved ones.

While the medical community may focus on what is wrong with their child, my focus as an educator is on the child’s strengths. From these strengths, parents and I can fashion plans to promote further development. In this way, I can bring a very positive outlook to a family.

I try to be more sensitive in scheduling my appointments, knowing that my presence may be disruptive to a family’s normal routines.

Overall, my underlying awareness of these common dilemmas has helped me view each child within the wider context of the family. Hopefully, this has helped me to serve families better.