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BIRTH TO THREE SYSTEM
PRESCHOOL SPECIAL
EDUCATION

BIRTH through news

- *Working together for children with disabilities*
- INFORMATION FOR FAMILIES AND PROFESSIONALS

Changing Expectations – Be a Voice!

*Nancy Prescott, Executive Director
Connecticut Parent Advocacy Center*



*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
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Parent advocacy does not come naturally or easily to most parents. I had been working at the Connecticut Parent Advocacy Center (CPAC) preparing parents to become effective advocates for their children with disabilities when my own skills were put to the test. My then three year old daughter was diagnosed with cancer and suddenly, it seemed as though everything I knew I should do and had been telling others to do had vanished in an instant.

Today, when I talk with parents about the steps they can take to get appropriate services for their child, I think that I, and the other parent staff at CPAC, do a better job of offering support and guidance because we have all tried, and sometimes faltered, as we worked at being the best advocates for our children. We understand how challenging it can be and we want other parents to know that they shouldn't waste what little energy they may have, worrying about what they did or didn't do. Parents and professionals can learn from their mistakes so things will go more smoothly next time and so others can benefit from their efforts and discoveries. Surely, there is no foolproof recipe for successful parent advocacy but here are a few suggestions we believe are essential to keeping on the right track.

Be informed. Read, ask questions, learn what the jargon means, gather information from a variety of sources and remain open to incorporating new information into plans for your child.

Keep track of information. Request copies of all reports, organize information in a way that makes sense to you, put your concerns in writing and keep a copy for your files.

Explore options. Investigate services and programs, talk with other parents and professionals about what works for children with similar needs, and recognize that there may be more than one right approach, therapy or time frame for helping your child reach their potential.

Find a balance. Establish priorities and focus on what is most important and doable for you, your child and your family at any given time.

Believe in yourself. Have confidence in the knowledge and experience you bring to decisions that are made about your child. Acknowledge when you do not have all the answers and ask for help in figuring out how to work towards a better outcome.

Communicate, communicate, communicate. Keep in touch with everyone on your child's team. Respect other's opinions, share new information and concerns and focus on finding solutions to current needs rather than constantly revisiting old problems. Connect with other parents. Parenting a child with special needs can



be a lonely job. Sharing information, finding out about local resources and networking with other parents who understand how you feel can be as essential to preparing you to advocate for your child as knowing all of the special education laws and rights.

Effective parent advocacy is critical to ensuring that our children receive services that will prepare them to grow up and become independent and contributing members of their communities. With time and practice we can and do improve our skills so that we become a voice that is heard at the decision-making table.

Cambie sus expectativas cambiantes - ¡Tenga voz!

*Nancy Prescott, Directora Ejecutiva
Centro de Connecticut de Intercesión de los Padres*

Interceder, abogar, no resulta fácil, natural, para la mayoría de los padres. Estando en el Centro de Connecticut de Intercesión de los Padres (el 'CPAC'), donde enseñaba a otros padres a abogar por sus hijos con incapacidades, se puso a prueba mi propia capacidad al enterarme del diagnóstico de cáncer de mi hija de tres años: súbitamente pereció desvanecerse todo lo que sabía que debía hacer y había estado aconsejando a otros que hicieran. Hoy, cuando hablo con otros padres de los pasos que pueden dar para lograr servicios adecuados para sus hijos, creo que yo, y los demás miembros del staff del CPAC que son padres o madres, hacemos mejor el trabajo de ofrecer apoyo y guía porque todos hemos tratado, algunas veces titubeando, de ser los mejores abogados de nuestros niños. Bien comprendemos cuan desafiante puede ser, y queremos que

And just as we learn from each other, our children will learn from us how to speak up for themselves. Now, more than twenty years later, I see my daughter assuming that role and I think that, just maybe, I did not do such a bad job after all.

For more information or a copy of a fact sheet entitled Five Steps to Becoming Your Child's Best Advocate (English/Spanish) please contact CPAC at 1-800-445-2722 or cpac@cpacinc.org.

otros padres sepan, que no deben gastar la poca energía que puedan tener preocupándose por lo que hicieron o dejaron de hacer. Padres y profesionales pueden aprender de sus errores para que las cosas salgan mejor la próxima vez y así otros puedan beneficiarse de sus esfuerzos y descubrimientos. Seguro, no hay receta infalible para la intercesión de los padres, pero aquí van algunas sugerencias que creemos esenciales para mantenernos en buen camino.

Infórmese. Lea, pregunte, aprenda lo que significa la jerga, recopile información de varias fuentes y mantenga la mente lista a incorporar información nueva concerniente a los planes para su hijo.

Siga de cerca la información. Solicite copias de todos los informes, organice la información de manera que tenga sentido para usted, ponga por escrito sus inquietudes y mantenga una copia para su archivo. Explore alternativas. Investigue servicios y programas, hable con otros padres y profesionales de lo que funciona en niños con necesidades similares, y reconozca que puede haber más de un enfoque, terapia o momento correcto, para ayudar a su



hijo a alcanzar su potencial. Sopesese, encuentre un equilibrio. Establezca prioridades y concéntrese en lo parezca más importante y hacedero para usted, su hijo y su familia en determinado momento. Tenga fe en si mismo. Tenga confianza en el conocimiento y experiencia que usted lleva a sus decisiones. Exprésese cuando no tiene todas las respuestas y pida ayuda para averiguar qué hacer para lograr un resultado mejor.

Comuníquese, comuníquese, comuníquese. Manténgase en comunicación con todos los que integran el equipo de su hijo. Respete las opiniones de los demás, comparta toda nueva información e inquietud, y concéntrese en encontrar soluciones a las necesidades actuales más bien que en repasar constantemente problemas viejos.

Comuníquese con otros padres. La crianza de un niño con necesidades especiales puede ser un trabajo solitario. Compartir información, investigar recursos locales y mantener una red de comunicación con otros padres que comprenden cómo usted se siente puede ser tan esencial para

(Continued on next page...)

Trainings and Conferences

These workshops are from the State Education Resource Center (SERC). The registration information can be found on their website at www.ctserc.org. The registration fee may be waived for parents of children with disabilities upon request to SERC. Please note that some advertised events may be full and space availability may be limited or unavailable.

- **October 22, 2008**
Autism Diagnosis and Observation System
Christine Peck, CES
Time 9:00 AM – 12:00
Location: Sheraton Four Points, Meriden
Fee: \$20
- **November 6 & 7, 2008**
Autism Diagnosis and Observation System
Jennifer Olson, J. Olson Consulting
Time 8:30 – 4:30
Location Rensselaer at Hartford
Contact Rebecca Kisluk 860-632-1485 x 291 or kisluk@ctserc.org
Fee: \$125
- **November 12, 2008**
Transdisciplinary Teamwork with Birth to Three Early Intervention Settings: An Overview
Carol Trivette, Orlena Hawks
Puckett Institute
Time: 9:00 am – 3:30 pm
Location Sheraton Four Points, Meriden Fee: \$40
- **November 15, 2008**
Block and Mathematical Thinking
Karen Hewitt, Learning Materials Workshop
Time 9:00 am – 2:00 pm
Location SERC Classroom, Middletown
Fee: \$30
- **November 18, 2008**
Thoughtful Response to Agitation, Escalation, and Meltdowns with Children with Autism Spectrum Disorders
Rebecca Klaw, Autism Services by Klaw
Time: 9:00 am – 12:00 pm
Location: Sheraton Four Points, Meriden
Fee: \$25
- **November 18, 2008, Evening**
Thoughtful Response to Agitation, Escalation, and Meltdowns with Children with Autism Spectrum Disorders
Rebecca Klaw
Time: 4:30 – 7:30 pm
Location: Sheraton Four Points, Meriden
Fee: \$25
- **November 19, 2008**
Building Relationships with Young Children with Autism Spectrum Disorders
Rebecca Klaw
Time: 9:00 am – 3:30
Location: Marriott Courtyard, Cromwell
Fee: \$45
- **November 22, 2008**
Introduction to Autism for Early Childhood Community-based Teachers and Administrators
Susan Izeman, Greenwich Autism Program
Time: 8:30 am – 12:00 noon
Location: SERC Library Community Room, Middletown
Fee: \$20
- **December 4 & 5, 2008**
Social Communication, Emotional Regulation and Transactional Support (SCERTS)
Amy Laurent, Communication Crossroads
Time: 9:00 – 3:30
Location: SERC Classroom, Middletown
Fee: \$200 (includes 2-volume manual)
- **December 10, 11, & 12, 2008**
It Takes Two to Talk
The Hanen Centre (For Birth to Three speech pathologists only)
Time: 8:30 – 5:00 (day one) and 4:30 (days two and three)
Location Marriott Courtyard, Cromwell
Fee: \$100
- **December 17, 2008**
Assessing Infants and Toddlers with the BITSEA and the M-CHAT
Marianne Barton, UConn Dept. of Psychology
Time: BITSEA 9:00 – 12:00 M-CHAT: 1:00 – 4:00
Location Crowne Plaza, Cromwell
Fee: \$20 per session, \$40 full day

prepararlo a abogar por su hijo como conocer todas las leyes y derechos relativos a la educación especial.

La intercesión eficaz de los padres es crítica para que nuestros niños aprovechen servicios que los preparen para crecer y ser independientes y útiles para su comunidad. Con

tiempo y práctica podemos mejorar nuestra habilidad para ser una voz que se oiga en la mesa de las decisiones. Y según aprendemos unos de otros nuestros niños aprenderán de nosotros cómo hablar por sí mismos. Ahora, más que dentro de veinte años, veo a mi hija asumiendo ese papel, y creo que tal vez no lo habré

hecho tan mal después de todo.

Para más información o una copia de la hoja titulada Cinco pasos para ser el mejor abogado de su hijo (inglés/español) comuníquese con el CPAC llamando al 1-800-445-2722 o visitando cpac@cpacinc.org.

Advocating for My Child

By Laura Knapp, Dylan's Mom

Having a child with a disability can be challenging and rewarding. As a parent of a child with a disability I can say the rewards outweigh all of the challenges.

My child Dylan received services through the Birth to Three System. I had an excellent relationship with his Birth to Three providers. I was a part of the team and was included in all therapy sessions. I knew that once he turned three he would transition to the school system. As one can imagine, the transition to the school system was intimidating. I was supposed to let my three year old son enter school. I was being asked to just let him go and trust the staff members. I was not going to be a part of the therapy sessions or be in class. Would my input even count? They were, after all, the "experts." Fortunately, my experience was not what I fearfully anticipated.

For my son's first Planning and Placement Team (PPT) meeting I put together an outline. I wrote what I wanted for him and why. I also jotted down what I was willing to compromise on and what I was not. I familiarized myself with special education rights and the manual, Educating Special Needs Children.

At the PPT I respectfully listened to school district staff. I believe that effective communication involves listening. I then spoke about my son, as I am the expert about him. I presented my list of priorities and explained why they are important to me. I gave the team reasonable examples that relate to the issues he would face at school, including his use of sign language as a primary communication tool and his need for a nurse to monitor his tracheotomy. I asked the district how they could make these accommodations. Would hiring a teacher of the deaf and training paraprofessionals be enough? Would his classmates be able to communicate with him? I was not willing to compromise his only method of communication. Would the school nurse be able to

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BIRTH through 5 NEWS

Information for Families and Professionals

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Seven Tips for Effective Advocacy

By Molly Cole

University of Connecticut Center for Excellence on Developmental Disabilities

Advocacy can be a challenging role for many parents. Whether you are advocating on behalf of your own child and family or to change a program or policy for many others, here are some basic tips:

- Effective advocacy is not about personal attacks but about system level or programmatic issues. Focus on assertive communication, but exercise diplomacy and tact. It is easy to earn the label of “angry parent” and hard to lose it.
- Advocates are not victims. Think about the way in which you share your story and don't present yourself or your child as a victim.

Use your struggles to teach others. A victim's mentality makes you dependent on someone else for the solutions and makes you and your child objects of pity.

- Be persistent and organized, don't assume anything, and have all the facts. It is important to do your homework, know the laws and your rights, and the evidence supporting your position.
- Learn the art of negotiation. Identify areas in which you can compromise, and those that are non-negotiable. Program and policy change take time, and you may not get everything you want right away.
- Build trusting relationships. Trust develops over time and is developed through participation between families and professionals on various committees so that parents can have a direct impact on decision making for plans,

policies and programs.

- Trust does not require agreement on all issues, nor does trust require perfect solutions.
- You may need to reach individuals at higher levels of authority to resolve issues or change policies. You should never take “no” from someone who does not have the authority to say “yes.”
- If you were able to move forward in improving a program, service or policy, celebrate—even if it isn't everything you wanted.



devote undivided attention to my son's medical needs? As a team, we discussed what would be appropriate and found the best placement for him in a private placement, with all the appropriate supports, outside our school district.

As I embarked on this journey with my son I quickly learned that I needed to know more about special education. I attended trainings such as Connecticut Parent Advocacy Center's (CPAC) Next Steps Advocacy Training and I took classes at the Learning Disability Association. Through classes I gained knowledge about who needs to be at a PPT and where to document any requests I make of the district that are not written on the Individual Education Plan (IEP). I learned about State Regulations as well as the Federal Law.

My son's needs have changed over the years and he now attends school in our town. He attends the same school as his brother and sister. Everyone is pleased about that. I continue to advocate for him. I continually ask the PPT to put themselves in his shoes. For example, he needs certain medication during the day. How will he get his medicine if there is a lockdown? His 1:1 nurse at school now carries a locked fanny pack.

The best part is that he now interacts with his non-disabled peers. He is able to choose activities, answer questions, and participate in sharing time with his assistive technology devices. He actually has a few “girlfriends!” They are quick to inform his nurse if he needs something. The kids “fight” over who will wheel him back to

class. He meets up with his siblings and buddies in the hall, at recess, lunch and fire drills. Most of all, he loves school.

We may not always agree at the PPT meeting. We do collaborate, mutually respect each other, listen and keep communication open. When one of the team members misunderstands or is unclear on something, it causes confusion and blame. My team opted for monthly meetings to keep communication open and effective. We usually have questions to address. I also periodically spend time in his special and regular education classes to collaborate and understand what strategies the staff is using. It is a successful, rewarding process when you become an active and supportive member of your child's team.

Early Childhood Special Education Update

Maria Synodi,
Coordinator, Early Childhood Special Education

When parents start seeking an advocate, it is a big clue to the school district that parents need information and support to deal with one or more special education issues. While issues can surface at any time, they most often occur at transition points. That's any kind of transition. Transition from a Birth to Three program to preschool special education or transition from the preschool grade to kindergarten are two big transition points. These two major transition points are also major stress points for families. Transition can be easier—and less adversarial—when parents have the information, resources, and support to guide them through the process of change.

Some considerations for school districts in working with families:

Make sure that parents have needed and critical information prior to any meeting or decision-making. Parents want to contribute to the discussion about their child and want to be an active member of the decision-making process. Be sure that parents have information such as the basic tenets of special education law and the planning and placement team process. Help parents understand the purpose of any meeting in advance including what will be discussed and what decisions will be made.

Give parents plenty of time to ask questions. Encourage parents to ask questions before, during, and after any meeting held to make any decisions about a child's eligibility or to plan a child's program. The discussions between parents and school district personnel can help to clarify

confusion and give meaning to the decisions that will be or have been made.

Communicate in a manner that parents can clearly understand and make sure that parents do understand. Conflicts often arise because one person misunderstands the other. Make sure that what you mean and what you say is clearly understood by families. This can include the rationale, guidelines, or policies for some decisions. Take ongoing opportunities to ensure that parents truly understand. Touch base with them frequently. Many parents were an active participant in their child's early intervention program and want to continue to be an active and support in their child's education.

Assign a district point person. It is helpful when parents know that they have someone to go to in a district. Give parents a primary point person or case manager they can call upon. Oftentimes parents seek the input of multiple people from inside and outside of the district which often creates confusion and mixed messages. Having a consistent person to answer questions, provide information and support is critical.

Help parents understand their child's educational strengths and needs. Special education decisions are intended to support a child in acquiring an equitable educational opportunity and benefit. Resources that help parents understand what children need to know and do at each age and stage of development is key. The state early learning standards, the Preschool Curriculum Benchmarks, is one resource to help parents understand what children need to learn in preschool in preparation for kindergarten.

Help parents get connected. Having parents connect to other parents

can be beneficial. It can provide opportunities for families of children to get together outside of the school day and also provides a forum for parent conversations and support. Some schools may want to consider using veteran parents to support new parents whose children are entering special education.

Develop a resource library of materials and resources. Written information is often quite helpful. The development of parent packets full of information on special education, the specific school system and classroom, school and community resources can be informative and can provide parents a window to other services, programs and opportunities for them and their child.

The State Department of Education's Bureau of Special Education web site has a number of publications that include resources and information for families, including their due process rights. The web site is: www.sde.ct.gov/sdelcwp/view.asp?a=2678&Q=320730. The Connecticut Parent Advocacy Center (CPAC) is another great resource for getting information. Their web site is www.cpacinc.org/.



Birth to Three Update

Linda Goodman, Director, Birth to Three System

Even though this isn't an issue about autism, I want to announce that we have added four more autism programs that started September 1, 2008. We now have at least one autism-specific early intervention program covering every town in Connecticut. The new programs are:

ABC Intervention Program

Myra Watnick; 203-255-8872
Serving the Naugatuck Valley and greater New Haven

BEACON of Connecticut

Steve Woolf; 866-935-8872
Serving all of eastern Connecticut and towns in the south central part of the state

Creative Interventions

Christine Levine; 860-413-9538
Serving the greater Hartford area and towns south of Hartford

LEARN Partners for Autism

Catherine O'Brien; 860-434-4800
Serving the towns in Southeast Connecticut

Please consult the provider list or the Autism Guideline insert on the Birth to Three website (www.birth23.org), under "Publications" for the exact town listing.

Since this issue is about advocacy, I'd like to quote from an article called *Assertiveness and Effective Parent Advocacy* posted on the Wrightslaw website (www.wrightslaw.com) by Marie Sherrett a parent from Maryland.

Ms. Sherrett says that assertive parents:

- Express themselves clearly, directly and without guilt
- Are not intimidated
- Prepare for meeting
- Stay together
- Are informed
- Keep records
- Collaborate
- Effectively communicate
- Demonstrate self-confidence

If you are the parent of a child in Birth to Three you may think that you need some assistance from another parent to work on your assertiveness skills. If that describes you, please feel free to contact the Family Support Network at their toll-free number 877-FSN2DAY (877-376-2329). They will be more than happy to help.

ICC Committee Work Update

By Lolli Ross, State ICC Chair

As my term as Chairperson of the Connecticut Birth to Three Inter-agency Coordinating Council (ICC) nears its end, I thought this would be an opportune time to reflect on what the ICC has accomplished in the past five years and where we are headed.

I stepped into the role of Chairperson in January 2003, shortly after Governor Rowland recommended that Connecticut's Birth to Three system no longer be under Part C of the IDEA federal mandate. This recommendation would have greatly diminished the quality of the system and would not have allowed equal access for all families who needed services. What followed in the months ahead was a true testa-

ment to the power of people working together towards a goal. Outstanding parent and professional leaders on the ICC and throughout the state rallied and saved the Birth to Three system.

There were sacrifices made in this process, however, as eligibility criteria were narrowed, family cost participation was implemented, and payment policies for providers were altered. As a committee whose primary role is to advise and assist the lead agency, the ICC had to take an active role in ensuring that appropriate cost saving measures were being implemented that had the least impact on Connecticut's families who receive Birth to Three services. ICC members advocated and successfully worked with the lead agency to amend the family cost participation to account for family size and to reduce family participation fees for many Connecticut families.

The ICC has also continually monitored the impact that those 2004 changes have had on families and the programs that provide Birth to Three services to ensure the provision of quality services to children and their families. This continued advocacy lead to the restoration of broadened eligibility that was implemented last year. The ICC continues to monitor the impact of family cost participation and will continue to advocate for solutions that best serve Connecticut's families. Infants and toddlers cannot wait for services and the ICC is working with the lead agency to make sure that families who are referred for services do not have to wait for an assignment to a Birth to Three provider.

Connecticut has an outstanding quality assurance system to make sure that children and their families receive the very best services, supports, and outcomes. As the key

(Continued on last page...)

Resources

Books/Publications

Assuring the Family's Role on the Early Intervention Team: Explaining Rights and Safeguards, Joicey Hurth and Paul Goff, Frank Porter Graham Center, June 2002. Available on-line at: www.nectac.org/pubs/titlelist.asp#assuring.

You Are an Advocate for Your Child with Special Health Care Needs, available on-line from www.familyvoices.org.

Special Education: A Parent's Guide for Children's Success, Michael Bailey, PublishAmerica, April 2007, paperback, cost \$22-\$24.

WrightsLaw: From Emotions to Advocacy – The Special Education Survival Guide, 2nd Edition, Pam Wright and Pete Wright, January 2006, cost \$20.

Websites

www.sde.ct.gov/sdelcwp/view.asp?a=2678&Q=320730 – the Connecticut State Department of Education, Bureau of Special Education, has some publications specifically for parents and families. Information includes: Helpful Connecticut Resources for Families (2008); Parent's Guide to Special Education in Connecticut (2007), including Due Process Forms from Parent's Guide; and Students with Disabilities and Parental Choice in Connecticut (2003).

www.cpacinc.org – the Connecticut Parent Advocacy Center, Inc. is the statewide nonprofit organization that offers information and support to families of children with any disability or chronic illness, birth - 21.

www.ctserc.org – the State Education Resource Center, funded primarily by the Dept. of Education to provide training and information to families

and education professionals.

www.familyvoices.org – Family Voices is a national grassroots network of families and friends which advocates for health care services and provides information for families who have children with special health care needs.

www.nectac.org – the National Early Childhood Technical Assistance Center, providing support and information to families and professionals in early intervention and preschool special education.

www.pacer.org – Pacer Center, the parent training and information center in Minnesota that also provides technical assistance around the country to other centers.

www.wrightsLaw.com – WrightsLaw is the leading website about special education law and advocacy.

stakeholder group, the ICC has played an integral role in the development of this system making sure the standards are high and that programs are held accountable and take ownership in their

ongoing quality improvement process.

This year, I will pass the gavel on to Dr. Mark Greenstein, a true champion for Connecticut's youngest citizens and

their families. I look forward to my continued participation on the council with his leadership as we face these challenges and new opportunities.

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