



CONNECTICUT
BIRTH TO THREE SYSTEM
PRESCHOOL SPECIAL
EDUCATION

BIRTH through news

• *Working together for children with disabilities*

• INFORMATION FOR FAMILIES AND PROFESSIONALS

WINTER, VOL.10, NO. 2

Easing the Transition into Preschool for Children with Special Health Care Needs

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Education and Carole Passarelli, M.S.,
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*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



University of
Connecticut

COOPERATIVE EXTENSION SYSTEM
College of Agriculture & Natural Resources

“Increasingly, because of new technologies and treatments in health care as well as advancements in pharmaceuticals, students with chronic health conditions are able to attend school, instead of being educated at home or in special schools” (*NASN, 2006b*)*. Today, more children with special health care needs, including those who are medically fragile, are transitioning at age three into preschool education programs. They transition from home, child care settings, early intervention programs and hospitals into the school setting to access and benefit from an appropriate educational program. Transitions involve change, and despite offering new opportunities, they can be stressful; especially, for parents and families of children with special or complex health care needs. In addition to transitioning to preschool programs, families are navigating multiple systems at the same time and can be interacting with a home care team, hospital team, community service team and school team; all of which may be necessary and relevant. However, this can also be confusing and stressful. Collaboration, planning, and ongoing management and evaluation can ease the transition process for all involved.

Who are these children?

As defined by the federal Maternal and Child Health Bureau, Children with Special Health Care Needs are those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type

or amount beyond that generally required by children. This might include a diagnosis of diabetes, severe food allergy, or seizures and the child may require insulin pump management or administration of specific medication to prevent respiratory arrest or seizures.

Medically Fragile Children are those children who have a serious, ongoing illness or chronic condition for at least a year, require prolonged hospitalization and ongoing medical treatments and require the use of devices to compensate for the loss of bodily function. This might include specific syndromes or severe cardiac disease and the child may require tracheostomy care, continuous oxygen or ventilator care.

Collaboration and Planning

It is well known that health conditions and health-related problems impact a student’s ability to learn and benefit from the educational experience. Meeting the needs of these students can positively influence outcomes for the student, family and school personnel. Collaboration is essential for a smooth transition. Parents, health and educational personnel, and other community providers must work together. Truly effective collaboration, where the family and team members work together in a coordinated way, recognizes the expertise and value of each team member. This collaboration can serve to minimize stress and ensure that the student can receive an appropriate education in a safe environment,

as well as the necessary health care services to maintain his/her health status.

Through this collaboration, an effective planning process can be established. Due to the health needs of these students, the school nurse is one of the key people in this process. In addition to the educational assessments and planning that occur during transition into preschool programs, the planning for the student's health needs should include the following activities:

- Obtaining and reviewing medical records- from primary and specialty health care providers;
- Interviewing the family to obtain health history;
- Meeting and observing the student in the home setting (when possible) or at a school visit;
- Communicating with health care providers to obtain medical orders for medication administration and nursing and medical procedures;
- Compiling a comprehensive health summary;
- Developing an Individual Health Care Plan (IHCP) and Individual

Emergency Care Plan (IECP) relevant for the school setting, based on assessment data and in collaboration with the family, health care providers and school personnel;

- Obtaining consultation and update knowledge and skills; as needed for school nurses and other school staff, as needed
- Obtaining supplies and equipment needed in the school setting;
- Educating school staff and students, as needed;
- Evaluating the need for special transportation, including as health monitoring or health interventions needed during transportation; and
- Serving as a liaison between the school team, the health care providers and family..

Management and Ongoing Evaluation

Once the student enters school an ongoing collaborative interdisciplinary team management process is implemented. For children with special health care needs, this includes

the provision of direct and indirect health care services, which focus on the maintenance of health status and safety, so that the student is able to benefit from the educational program. Ongoing monitoring of the student's health status is essential, as well as, revision of the IHCP and IECP due to changes which may occur at any time with a health problem or condition. Effective communication between the family, health care providers, and the school team is key to a positive educational experience.

Children with special health care needs can be successfully integrated into preschool and public school settings. Collaboration and proper planning assist in a timely, smooth transition from the child's home or other community setting into school. The child, family, educational and health care teams all benefit from this teamwork, making transitions less stressful for all.

**National Association of School Nurses (2006a). School Nursing Management of Students with chronic Health Conditions (Position Paper). Silver Springs, Maryland: Author.*



Cómo facilitar a niños con necesidades sanitarias especiales la transición a la escuela

Por Cheryl Resha, Ed.D., R.N., Connecticut State Department of Educación and Carole Passarelli, M.S., R.N., PNP, New Haven Public Schools and Multidisciplinary Team, ACES

“Cada vez más, en virtud de las nuevas tecnologías y tratamientos en la atención sanitaria y adelantos en los fármacos, los niños con cuadros sanitarios crónicos pueden asistir a

la escuela regular en lugar de tener que educarse en el hogar o en una escuela especial” (NASN, 2006b)*. Hoy en día, más niños con necesidades sanitarias especiales, inclusive los clínicamente frágiles, pasan a los tres años de edad a programas de educación preescolar. Esa transición a la escuela, para acceder y beneficiarse de programas docentes adecuados, puede ocurrir desde el hogar, guardería, programa de intervención temprana u hospital. Toda transición implica cambio, y pese a ofrecer nuevas oportunidades, puede ser estresante; especialmente para los padres y familias de niños con necesidades sanitarias especiales o complejas. Además de

realizar esa transición a programas preescolares, las familias recorren a

(Continued on next page...)

la vez múltiples sistemas y pueden tener interacción con un equipo de atención en el hogar, hospital, servicio de la comunidad y escuela; todo lo cual puede ser necesario y relevante. Sin embargo esto puede ser confuso y estresante. La colaboración, planificación y manejo y evaluación pueden facilitar el proceso de transición para todos los implicados.

¿Quiénes son estos niños?

De acuerdo con la definición del Bureau Federal de Salud de la Madre y el Niño se entiende por niños con necesidades sanitarias especiales los que presentan o se encuentran en riesgo de cuadro clínico de desarrollo, de conducta o emocional y que además requieren servicios de salud y otros relativos de tipo o cantidad que superan los que necesitan los niños en general. Esto pudiera incluir diagnósticos de diabetes, alergia a alimentos severa o convulsiones en que el niño necesitaría un régimen de insulina o la administración de medicación específica para prevenir un paro respiratorio o convulsiones. Niños clínicamente frágiles son los que tienen un trastorno serio permanente o crónico de al menos un año, necesitan hospitalización prolongada y tratamientos constantes, y precisan del uso de aparatos para compensar la deficiencia de función corporal. Esto pudiera incluir síndromes de enfermedad cardíaca severa y el niño pudiera necesitar atención de traqueotomía., oxígeno o ventilador.

Colaboración y planificación

Es bien conocido que los cuadros de salud y problemas relativos a la salud impactan la capacidad de un niño para aprender y beneficiarse de la experiencia docente. Llenar las necesidades de estos niños puede influir positivamente en los resultados para el niño, la familia y el personal escolar. La colaboración es esencial para una transición sin mayores contratiempos. Los padres, el

personal sanitario y docente y otros proveedores de la comunidad deben trabajar de consuno. La elaboración realmente eficaz, donde la familia y los miembros del equipo trabajan juntos de forma coordinada reconoce la pericia y valor de cada miembro del equipo. Esta colaboración puede servir para minimizar el estrés y asegurar que el niño pueda beneficiarse de un programa docente apropiado en un ambiente seguro, así como los servicios sanitarios necesarios para mantener su estado de salud.

Con esta colaboración se puede lograr un proceso eficaz. Debido a las necesidades de salud de estos niños, la enfermera de la escuela es persona clave en el proceso. En añadidura a las evaluaciones y planificación docentes propias de la transición a programas preescolares, la planificación para satisfacer las necesidades sanitarias del niño pueden incluir las actividades siguientes:

- obtener y revisar su historia clínica proporcionada por proveedores primarios y especialistas;
- entrevistar a la familia para recabar su versión del historial sanitario del niño.
- conocer al niño y observarlo en el hogar (siempre que sea posible) o en la escuela;
- comunicarse con proveedores sanitarios para obtener instrucciones para la administración de medicinas y procedimientos de enfermería y médicos;
- compilar un resumen sanitario amplio;
- desarrollar un plan sanitario individual (IHCP) y un plan de emergencia sanitaria individual (IECP) apropiado para el ambiente escolar, basado en la evaluación del niño en colaboración con la familia, proveedores sanitarios y personal escolar;
- obtener consulta y conocimiento y aptitudes actualizados, según necesiten las enfermeras y demás

personal escolar;

- recabar suministros y equipos necesarios en el ambiente escolar;
- instruir el personal escolar y los alumnos, según sea necesario;
- evaluar la necesidad de transporte especial, incluyendo la vigilancia o intervenciones sanitarias necesarias durante el transporte; y
- servir como enlace entre el equipo escolar, los proveedores sanitarios y la familia.

Manejo y evaluación continua

Una vez que el niño ingresa en la escuela se implementa un proceso de manejo por un equipo interdisciplinario. Para los niños con necesidades sanitarias especiales esto incluye el proporcionarles servicios de salud directos e indirectos, concentrados en el mantenimiento del estado de salud y seguridad, de manera que el alumno sea capaz de beneficiarse del programa docente. La vigilancia constante de la salud del alumno es esencial, así como la revisión del HICP y el IECP debido a cambios que puedan ocurrir en cualquier momento con un cuadro de salud o problema. La comunicación eficaz entre la familia, los proveedores sanitarios y el equipo de la escuela es clave para una experiencia docente positiva.

Los niños con necesidades especiales de salud pueden integrarse satisfactoriamente en la preescola y en la escuela pública. La colaboración y la planificación adecuada ayudan a una transición oportuna, sin tropiezos, desde el hogar u otro ambiente de la comunidad a la escuela. El niño, la familia, los equipos docentes y sanitarios se benefician todos de este trabajo en equipo, haciendo las transiciones menos estresantes para todos.

** National Association of School Nurses (2006^a). School Nursing Management of Students with chronic Health Conditions (Position Paper). Silver springs, Maryland: Autor.*



Parenting a Child with Special Health Care Needs

By Karen King, Program Director
St. Vincent's Center Birth to Three
Program, Trumbull

When 7 month old Charlie was referred to Birth to Three, his parents were most concerned about his recent diagnosis of cerebral palsy (which affected every area of his development) and what that would mean for his future. His parents arranged their work schedules so that one of them was always with him because they didn't feel that a daycare could meet his needs.

Charlie's Birth to Three team worked with his family on motor skill development, feeding, and independent play. As time passed, the IFSP was revised to add communication and feeding goals, as well as adaptive equipment and vision services. From the first IFSP, the end of Birth to Three services was discussed.

Just after Charlie's 2nd birthday, discussions about transition (the process of moving from one program to another) became more frequent. His parents became apprehensive as this big step came closer. They weren't sure they would be comfortable sending Charlie to school – he had hardly been away from them at all. The family's service coordinator, Debbie, went slowly. In small steps, she introduced the family to the process of transition. After the Transition meeting, visits were made to several programs so Charlie's parents could see the range of programs available. At the PPT meeting, which was scheduled early, the family requested that the new therapists

and teacher come to Birth to Three visits at home to meet Charlie. Debbie offered the family choices whenever she could so they would have some control over the process. For example, the family chose to transport Charlie themselves and not put him on the school bus. The school system was very supportive of the family as well. They welcomed the family into Charlie's classroom and let them stay as long as they needed to feel comfortable. The last few weeks of Charlie's enrollment in Birth to Three visits were done in his new classroom. Birth to Three joined classroom activities and showed the new team Charlie's equipment, which ranged from adapted seating and standing to an adapted spoon, a neck collar, and a picture schedule. This helped him to adjust to his new surroundings while in the company of familiar people and helped his parents to do the same. In addition, his new team got to know him by working with the family and Birth to Three. In the end, though Charlie took a long time to adjust to school, his parents were positive about the move and began to develop trust in their new team.



BIRTH through 5 news

Information for Families and Professionals

is published periodically by the University of Connecticut Cooperative Extension System in collaboration with the Connecticut Birth to Three System, the Connecticut State Department of Education and the Newsletter Advisory Board. We welcome readers' comments and contributions related to the special needs of infants, toddlers, preschoolers and their families. Please mail correspondence to the editor at 67 Stony Hill Road, Bethel, CT 06801.

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Produced in Communication and Information Technology, College of Agriculture and Natural Resources, University of Connecticut. Graphic Design by Poshen Wang.

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Parenting a Child with Special Health Care Needs

By Jennifer Carroll, parent

Earlier this year I was inspired to create a list of the "Top 10 Things I Have Learned" along the road of parenting. The following is my advice, from a parent who has been there.....

1. There is no crystal ball, and that is a good thing.

You may wish you could know now what things will be like in a month, a year, 10 years. Your child will grow and develop in ways that will amaze you. Enjoy today and do not worry about tomorrow.

2. Trust the coaching model.

I worried about my ability to follow through successfully with all that I was learning from my Birth to Three team and my son's preschool teachers. Looking back, everything my husband and I did within our daily routine helped our son's development.

3. My service coordinator was as much a resource to me as she was

for my son.

She became a trusted advisor, active listener and loyal supporter. She helped connect us to all the resources we needed and understood that all members of our family counted.

4. Transition to preschool special education is not as scary as it seems.

The school system has well-trained partners who will guide you. They will help each step of the way. Communicate with them and be an active member of the team.

5. It is important to involve the whole family in the process.

Siblings, grandparents, and anyone who is part of the child's life is impacted by the early intervention and preschool special education process. For some children, these needs will be life-long. All members of the family have an important role to play.

6. There are times when we just needed to "be".

I was taught to use opportunities throughout the day, such as diaper changes, bath time, playtime and mealtime to apply strategies to help my son's development. There were times when I needed a break from that, too. I learned that it was ok, once in a while, to

enjoy the bath, the game or even the diaper change for what it was and to give us both a break.

7. There are other parents out there who know what this experience is like.

Talk to your service coordinator, your child's teacher or the Connecticut Family Support Network to find out about ways to connect with other families.

8. You have a voice!

You are the expert on your child. Be an active participant in the process and communicate with your team. Share your thoughts, concerns, progress you see and your ideas.

9. Celebrate your child's strengths and interests

Your child has strengths and interests that are important. Though he or she may be receiving services and supports because of a disability or developmental delay, it will always be important to highlight the positives – celebrate their strengths and their successes!

10. You will have your days.....

Keep in mind that as a primary caretaker of your child, you can only do that successfully by taking care of yourself. Take care of your personal needs too.



Together
We
Will

16th Annual Conference

Together We Will: Serve, Support, and Include Children with Special Health Care Needs

Thursday, April 2, 2009 9:00 a.m. to 3:30 p.m.
Holiday Inn, Waterbury

Keynote Presentation:

Coaching: Working Together to Support Families and Their Young Children with Complex Medical Needs

Barbara Hanft, MA, OTR, FAOTA Silver Spring MD

Please note that registration fee waivers and stipends for childcare and transportation are available if needed for family members. Conference brochures will be available in January 2009 and will be mailed to those who have previously attended this annual event. Other interested individuals may request a brochure by contacting Tyrese Bolden, Education Services Specialist, SERC, (860) 632-1485, ext. 210. To learn more about SERC's Early Childhood Education Initiative please visit our website at www.ctserc.org.

Early Childhood Special Education Update

Maria Synodi,
Coordinator, Early Childhood Special Education

The 2009 Together We Will Conference is devoted to ensuring the inclusion of young children who are medically complex and who have special health care needs. The conference topic was identified due to the increasing numbers of young children with complex medical and developmental needs and others who may have frequent illnesses or hospitalizations due to respiratory or pulmonary conditions. These children represent a variety of conditions that require intervention and support.

The State Department of Education has recently released a new guidelines document. The Guidelines for Feeding and Swallowing Programs in Schools was issued in 2008. The document was issued for a variety of reasons including the critical importance of adequate nutrition for children's growth, development and learning. Proper nutrition

helps support children's early educational experiences and opportunities. Meals and snacks are typically an important part of a child's school experience. These opportunities provide for a child's social, language, cognitive and motor development as well as provide nutrition for a child during their day. The Guidelines for Feeding and Swallowing Programs in Schools is intended to help school districts determine when children need feeding and swallowing services and to assist in the provision of quality programs and supports. The new guidelines and related forms and documents can be accessed through the Department's web site at www.sde.ct.gov by clicking on 'special education' and then clicking on 'publications':

Guidelines for Feeding and Swallowing Programs in Schools (2008) [PDF]

Feeding and Swallowing Forms in PDF fill-in format (2008) Consultation Report; Plan; Referral Form Concerns; Referral Swallow Study; Services Questionnaire.

Please know that there are other guidelines documents which have applicability for young children who are medically complex or who have special health care needs. Amongst those guidelines documents are the Guidelines for Assistive Technology; Health Screenings and Speech and Language. Those documents can be accessed through the Department's web site at <http://www.sde.ct.gov/sde/cwp/view.asp?a=2678&Q=320730#publications>.

Looking forward to seeing you at the conference.



Birth to Three Update

Linda Goodman,
Director, Birth to Three System

It seems appropriate in an issue devoted to children with complex medical needs to remind everyone that the New England Assistive Technology (NEAT) Marketplace is a unique and valuable resource in Connecticut that is not available in most states. For parents looking for assistive technology devices or equipment for their children (wheelchairs, seating devices, adapted strollers, communication devices,

adapted toys, environmental controls and other items) it can be a godsend. NEAT's primary facility is in Hartford with a satellite location in Stratford and they will help you try out various pieces of equipment, talk to companies about their products, purchase used equipment, and generally get lots of advice before you commit to purchase these often expensive items. For Birth to Three, the Department of Developmental Services pays annual NEAT membership fees for each Birth to Three program, giving the program staff access to the lending library, workshops, and purchasing advice.

In addition, DDS pays NEAT to pick up any piece of equipment that children who are or were in Birth to Three no longer need. This can be equipment purchased by Birth to Three or equipment that families wish to donate. NEAT will refurbish the equipment and make it available to any Birth to Three program for other families.

Be sure to visit their website (www.NEATmarketplace.org) or call them in Hartford at 866-526-4492 or in Stratford at (203) 378-6977.



ICC Committee Work Update

By Mark A. Greenstein, MD
ICC chairperson

I was listening to a commentator on the occasion of President-Elect Obama's victory, who noted that change is inevitable but true growth and development takes work. I had never thought of this particular distinction and found it appropriate to so many things, not the least of which is the change in the Chairs for the State's Interagency Council for the Birth to Three System. After a number of years, in which she helped lead the Council through the State's last fiscal crisis, Lolli Ross has stepped down as Chair and I have been appointed by Governor Rell as her replacement. It may be trite to say, but I cannot take Lolli's place. Few have her grace and calm; I can only hope to match her dedication and effort. It will require work on my part to grow and develop as the Chair as Birth to Three moves into

what promises to be another time of challenges.

As I begin my work as Chair, I thought I would tell you that I am a pediatrician; one who has trained in both genetics and child development and who has specialized for years in the area of communication in general and autism in particular. I work in several places and teach at the UConn School of Medicine and in its Department of Pediatrics and the Division of Child Psychiatry and have served for many years on the Council. As I thought about the work of growing, I thought about the things that we take for granted. I thought about how many of us learn without being formally taught and how for some, learning can be a real challenge when it doesn't come naturally or easily. Generally many of us learn to walk--no one actually teaches most us how to use our feet and hands and how to balance all the parts that go into getting us from here to there. And while for most of us someone teaches us words, most

of us learn to speak by listening and by what seems to be instinct. However, for many of the children who receive Birth to Three services, these skills do not come either naturally or easily -- and teaching them takes a great deal of effort--on the part of the families and Birth to Three workers. Similarly, I don't know that leadership is always a natural skill. I know I will have to depend on both families and my colleagues both in the Birth to Three System and throughout the State, to help me learn how to best serve the children and families of Connecticut.

As I begin in my new role I would like to invite any of you interested in helping the council do its work to contact me about how you might do so. Please feel free to write me care of the Council or at MGreens@CCMCKids.org. I hope that we can involve many of you, families, providers, teachers, lawmakers, concerned neighbors and friends, as we work together to grow and develop at this time of change.



Calendar

For any of these activities, contact Rebecca Kisluk 860-632-1485 X291 kisluk@ctserc.org or go to the ctserc.org website and look in "Personnel Development". Please note that some events may be full and space availability may be limited or unavailable.

- **Practical Behavior Strategies for Working with Young Children with Autism in Inclusive Learning Environments**
February 27, 2009
9:00 AM – 3:30 PM
Bryan Boyd
Marriott Courtyard, Cromwell
\$40 Registration
- **The Communication and Behavioral Needs of Young Children with Autism: Programming for**

Long-term Change

March 12, 2009
9:00 AM – 3:30 PM
John Burke
Janie Dymant
Crowne Plaza, Cromwell
\$45 Registration

- **Literacy in Action**
Saturday, March 14, 2009
9:00 AM – 2:00 PM
Ida Washington
Paquita Sims
SERC Classroom, Middletown
\$30 Registration
- **Infant Toddler Mental Health: Temperament and Brain Development**
March 20, 2009
9:00 AM – 3:30 PM
JoAnn Robinson
Sheraton Four Points, Meriden
\$40 Registration

- **Replays: Using Play at Home to Enhance Emotional and Behavioral Development of Young Children with Autism Spectrum Disorders**
Audience: family members and caregivers
March 24, 2009
Naomi Angoff Chedd
Karen Levine
Savin Rock School, West Haven
\$15 optional fee to purchase text
- **Replays: Using Play to Enhance Emotional and Behavioral Development of Young Children with Autism Spectrum Disorders**
March 25, 2009
Naomi Angoff Chedd
Karen Levine
SERC Classroom, Middletown
\$50 Registration



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This newsletter is available in English and Spanish. Visit the Birth to Three website at www.birth23.org and click on Publications, or the Department of Education website at www.sde.ct.gov, then click on the Early Childhood link.
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).

National Resources

American Academy of Pediatrics

General information related to child health and more specific guidelines concerning pediatric issues
www.aap.org

Family Village

Information on specific diagnoses, communication connections, adaptive products and more.
www.familyvillage.wisc.edu

Family Voices

A national grassroots network of families and friends that advocates for health care services that are family-centered
www.familyvoices.org

NICHY: National Dissemination Center for Children with Disabilities

Central source of information on disabilities in children, IDEA, No Child Left Behind, research-based information on effective educational practices
www.nichy.org

Parent to Parent USA

A national organization committed to assuring access and quality in parent to parent support across the country.
www.p2pusa.org

Prescription Drug Assistance

Needy Meds is a source of information about assistance programs that help with the cost of medicine and other healthcare expenses
www.needymeds.com

State Resources

State Education Resource Center (SERC)

SERC provides professional development and information dissemination in the latest research and best practices to educators, service providers, and families throughout the state.
www.ctserc.org

Children with Special Health Care Needs

Striving to enhance the quality of care and services provided through the medical home model
www.dph.state.ct.gov Click on

programs and services at the top and then click on children and youth with special health care needs. Or call Child Development Infoline at 1-800-505-7000

Connecticut Family Support Network

Assisting families with resource information on health care and direct advocacy and support in accessing health care and health financing resources
www.ctfsc.org 1-877-FFN2day (376-2329)

Connecticut Parent Advocacy Center, Inc

A statewide organization that offers information and support to families of children with any disability or chronic illness ages birth through 26. They specialize in the area of public education
www.cpacinc.org 1-800-455-CPAC

Connecticut Lifespan Respite Coalition

Assistance in locating respite resources
www.CTRESPITE.org

