Autism Spectrum Disorders 0-5

By Linda Goodman, Director, CT Birth to Three System and Maria Synodi, Coordinator, Early Childhood Special Education

The Birth to Three System and Early Childhood Special Education have experienced recent increases in the number of young children who receive a diagnosis of autism or a diagnosis of an autism spectrum disorder (ASD). The increases felt here in Connecticut are consistent with a similar trend occurring across the country. A diagnosis of autism or an ASD is being made at younger and younger ages, typically during the toddler and preschool years. Many children seem to receive a diagnosis close to their third birthday and close to the time when they transition from one system to another. A comparison across the two systems is provided to help inform families, birth to three service providers and school district personnel. The hope is that this information will help ensure positive transitions for children and their families.

AUTISM – WHAT IS IT?

Autism is often referred to as a descriptor. The diagnosis is often based upon information gathered by observing a child. The term autism spectrum disorders (ASD) is used to describe the full range of autism disorders. The national agreement is that autism is a complex disability that has a wide range of symptoms and characteristics which vary from mild to severe.

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<tr>
<th>Birth to Three</th>
<th>Special Education</th>
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<tr>
<td>The Birth to Three System uses both the autism classification that is in federal law, the Individuals with Disabilities Education Act (IDEA), Part C that defines autism as a developmental delay which significantly affects a child’s verbal and nonverbal communication and social interaction, generally seen before the age of 3 and also accepts a clinical diagnosis made by a physician or psychologist.</td>
<td>Special education uses the definition in the IDEA, Part B that defines autism as a developmental delay which significantly affects a child’s verbal &amp; nonverbal communication &amp; social interaction, generally seen before age 3 which adversely affects a child’s educational performance. A clinical diagnosis by a physician or psychologist is not necessary but if available is considered to help plan a child’s program.</td>
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SCREENING – WHAT DOES IT TELL ME?

Screening instruments can help to identify children who may need a more detailed and comprehensive assessment. Screening instruments do not make a diagnosis but can lead a professional to identify some next steps.

All Birth to Three programs are including an autism screening using the Modified Checklist for Autism in Toddlers (M-CHAT) or the Brief Infant Toddler Social Emotional Assessment (BITSEA) as part of the initial evaluation for all children 16 months of age or older.

A screening instrument may be used to help advise school professionals to help plan an assessment or next steps. Some screening instruments for preschool-age children include: the Autism Screening Instrument for Educational Planning, the Autism Behavior Checklist, and the Social Communication Questionnaire.

Continued on page 2
### EVALUATION AND ASSESSMENT – WHAT DOES IT INCLUDE?

A comprehensive assessment of a child should include a medical/developmental history, a parent interview, a review of previous evaluations/assessments and other records, a direct observation of a child’s social skills and a standardized assessment of a child’s developmental and functional skills. A child’s evaluation may also include a hearing evaluation if necessary.

The Birth to Three System uses the Autism Diagnostic Observation Scale (ADOS) in their comprehensive assessment to determine if a child meets the educational classification of autism found in the IDEA. A clinical diagnosis of autism or ASD made by a physician or psychologist is not required but if available, is used to identify that the child is eligible for Birth to Three services.

Special education personnel conduct an individually designed comprehensive assessment to determine if a child is eligible for special education due to the child’s disability and because the disability affects the child’s educational performance. School districts can use the ADOS in their comprehensive assessment to determine if a child meets the educational definition of autism found in the IDEA. A clinical diagnosis is not required in order for a child to receive special education. A clinical diagnosis and any recommendations are considered by the child’s team but would not necessarily serve as the sole basis for identification and program development.

### IDENTIFICATION OF AUTISM OR ASD – WHO DOES IT?

Autism or an ASD can be a clinical disorder and/or an educational disability. A clinical diagnosis is made by professionals licensed or certified in a specialty area and must have expertise in the evaluation of children with behavioral and emotional disorders and in the use of autism specific instruments. Professionals that provide a clinical diagnosis include child psychologists, specially trained neurologists and developmental pediatricians. An educational classification of autism is made by education professionals, in Birth to Three and special education, who are licensed and/or certified in their specialty areas and must include at least one team member with experience and training in the evaluation of children with ASD and the use of autism specific instruments.

### PROGRAMS – WHERE ARE THEY?

The Birth to Three System currently has six comprehensive early intervention autism-specific programs. More programs will be added for Fall 2008. For the list of the Birth to Three programs and Birth to Three autism specific programs go to www.birth23.org

Special education & related services are provided by all of Connecticut’s school districts to children with autism or an ASD who qualify for special education & related services. A disability label of autism is not required for a child to qualify for special education.

The Birth to Three System principles include: individualized decisions based upon a child’s needs, intensive engagement (15 to 20 hours per week); family participation, intervention based on developmental sequences and interventions that are planful and systematic; positive behavioral support and a focus on communication and social interaction.

The State Department of Education guidelines outline the consensus of effective programs which include: the earliest intervention; family involvement and cooperative planning; individualized and intensive programming; a comprehensive curriculum; planned systematic instruction and on-going assessment, provision of a structured and predictable learning environment; specially trained personnel and peer relationships.

### GUIDELINES – WHERE CAN I FIND THEM?


Desarreglos del espectro del autismo 0-5

Por Linda Goodman, Directora del Sistema para Infantes a Tres Años de CT y María Synodi, Coordinadora de la Educación especial para la temprana infancia

En Connecticut tanto el Sistema para Infantes a Tres Años como la Educación especial de la temprana infancia han observado aumentos recientes en el número de niños con diagnóstico de autismo o de desarreglos del espectro del autismo (ASD), y se ha reportado una tendencia similar a lo largo del país. El diagnóstico de autismo o de ASD se hace a edades cada vez más cortas, típicamente hacia los dos años de edad y los años preescolares. Muchos niños parecen recibir el diagnóstico cerca de su tercer cumpleaños y de su transición de un sistema al otro. Una comparación de los dos sistemas se ofrece para ayudar a informar a las familias, el nacimiento hasta los tres proveedores de servicios y el personal del distrito escolar. Esperamos que esta información ayude a asegurar transiciones positivas para los niños y sus familias.

EL AUTISMO - ¿QUÉ ES?

Se suele acudir a la voz ‘autismo’ para categorizar. El diagnóstico suele basarse en información que se obtiene mediante observación del niño. El término ‘desarreglos del espectro de autismo’ (ASD) se usa para describir toda la gama de desarreglos de autismo. El consenso general es que el autismo es una incapacidad compleja que tiene una amplia gama de síntomas y características que pueden variar de benignas a graves.

<table>
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<tr>
<th>Sistema para Infantes a Tres Años</th>
<th>Educación Especial</th>
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<tr>
<td>El Sistema para Infantes a Tres Años utiliza tanto la clasificación de autismo de la ley federal (la Ley de educación de individuos con incapacidades IDEA parte C), que define el autismo como un retraso en el desarrollo que afecta significativamente la comunicación verbal y no verbal de un niño así como su interacción social, observado generalmente antes de los tres años y también acepta el diagnóstico clínico de un médico o psicólogo.</td>
<td>La Educación Especial utiliza la definición de la IDEA parte B que define el autismo como un retraso en el desarrollo que afecta notablemente la comunicación verbal y no verbal y la interacción social, observada generalmente antes de los tres años, y que además afecta adversamente el aprovechamiento escolar del niño. No es necesario el diagnóstico clínico de un médico o psicólogo pero si está disponible se considera que ayuda a planificar un programa para el niño.</td>
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EL EXAMEN LIGERO (‘SCREENING’) - ¿QUÉ ME Dice?

Los ‘instrumentos’ de screening pueden ayudar a identificar los niños que pueden necesitar una evaluación más detallada y amplia. Esos instrumentos no determinan un diagnóstico pero pueden llevar al profesional a identificar nuevos pasos a seguir.

Todos los programas de Birth to Three incluyen un screening de autismo haciendo uso de la Lista-cuestionario modificada para el autismo en párvulos (M-CHAT) o la Evaluación socio emocional breve (BITSEEA) como parte de la evaluación inicial de todos los niños de 16 meses o más. | Un ‘instrumento’ de screening puede usarse para ayudar a asesorar a los profesionales docentes ayudándoles a desarrollar un plan de evaluación o pasos subsiguientes. Entre los instrumentos de screening para niños preescolares se cuentan: el Instrumento de autismo para planificación educacional, la Lista-cuestionario sobre la conducta autística, y el Cuestionario de comunicación social. |

LA EVALUACIÓN - ¿QUÉ COMPRENDE?

Una evaluación amplia de un niño debe incluir la historia de su desarrollo desde un punto de vista clínico, una entrevista con los padres, la revisión de evaluaciones anteriores y otros documentos, una observación directa de las aptitudes sociales del niño y una evaluación estándar de las aptitudes de desarrollo y funcionales del niño. La evaluación del niño puede incluir una evaluación de la audición si es necesario.

El sistema Birth to Three utiliza la Escala de observación diagnóstica del autismo (ADOS) en su evaluación amplia para determinar si un niño llena los requisitos de la clasificación educacional de autismo de la IDEA. No se requiere un diagnóstico clínico de autismo o de ASD efectuado por médico o psicólogo, pero si está disponible se utiliza para determinar que el niño es elegible para los servicios de Birth to Three. | El personal de Educación especial realiza una evaluación amplia diseñada para determinar si un niño es elegible para educación especial debido a alguna incapacidad y porque la incapacidad afecta su aprovechamiento escolar. Los distritos escolares pueden utilizar el ADOS en su evaluación amplia para determinar si un niño llena la definición educacional de autismo de la IDEA. No se necesita diagnóstico clínico para que un niño reciba educación especial. Un diagnóstico clínico y cualesquiera recomendaciones se consideran por el equipo del niño, pero no son necesariamente la base única de identificación y desarrollo de un programa.
IDENTIFICACIÓN DE AUTISMO O ASD – ¿QUIÉN LA HACE?

El autismo o un ASD pueden ser un desarrollo clínico, una incapacidad para aprender, o ambos. Un diagnóstico clínico se hace por profesionales licenciados o certificados en un área de especialidad y deben tener pericia tanto en la evaluación de niños con desvíos de conducta o emocionales como en el uso de ‘instrumentos’ específicos de autismo. Entre los profesionales que proveen un diagnóstico clínico se cuentan los psicólogos de niños, los neurólogos con adiestramiento especial y los pediatras de desarrollo. La clasificación educacional de autismo se hace por profesionales docentes en Birth to three y en Educación especial, con licencia o certificación en sus áreas de especialidad, y por lo menos un miembro del equipo debe tener experiencia y adiestramiento en la evaluación de niños con ASD y en el uso de instrumentos específicos de autismo.

LOS PROGRAMAS – ¿DÓNDE ESTÁN?

El sistema Birth to Three tiene actualmente seis programas de intervención de autismo recientemente pro- vistos de fondos. Para la lista de los programas de Birth to Three y los programas específicos de autismo de Birth to Three ir a www.birth23.org. Se agregaran otros programas en el otono del 2008.

Los principios del Sistema Birth to Three incluyen: decisiones individualizadas basadas en las necesidades del niño, dedicación intensiva (15 a 20 horas por semana); participación de la familia, intervención basada en la secuencia del desarrollo e intervenciones que sean planificadas y sistemáticas; el apoyo de conductas positivas y concentración en la comunicación e interacción social.

La educación especial y servicios relacionados se ofrecen en todos los distritos escolares de Connecticut a los niños con autismo o ASD que llenan los requisitos establecidos para recibirlos. No se requiere una etiqueta de incapacidad por autismo para que un niño pueda recibir educación especial.

Las normas del departamento estatal de Educación definen los consensos de programas efectivos que incluyen: intervención lo más temprano posible; participación de la familia y planificación cooperativa; programación individualizada e intensiva; un currículo amplio; instrucción sistemática planificada y evaluación sostenida, provisión de un ambiente de aprendizaje estructurado y previsible; personal especialmente adiestrado y relaciones con compañeros.

PAUTAS – ¿DÓNDE PUEDO ENCONTRARLAS?


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Providers’ Perspective

National Center Promotes Evidence-Based Practice for Children with ASD

The National Professional Development Center on Autism Spectrum Disorders (the Center) funded by the US Department of Education, Office of Special Education Programs, began on July 1, 2007. The mission of the Center is to promote the optimal development and learning of children and youth with autism spectrum disorders (ASD), to increase the number of highly qualified personnel serving children and youth with ASD, and to increase the capacity of states to support the use of evidence-based practices (EBP) for individuals with ASD. This project involves a five-year collaboration among the FPG Child Development Institute and other collaborators at the University of North Carolina (East Regional Center), The Waismann Center at the University of Wisconsin-Madison (Midwest Regional Center), and the MIND Institute at the University of California at Davis Medical School (West Regional Center). Through a competitive state application process, each of the three Regional Centers will collaborate with selected states for a two-year period to:

- promote EBP for early identification, intervention, and education;
- provide sustainable, outcome based professional development and technical assistance (TA) that optimize existing resources, including the establishment of model sites for EBP; and
- measure and evaluate child, family, practitioner, and system level outcomes.

In each selected state, Center staff and state personnel will collaborate to: 1) form a planning group of key stakeholders; 2) identify an ASD training and TA team; 3) complete a review of state capabilities and needs for professional development and TA; and 4) plan, implement, monitor, and evaluate a state plan for addressing those needs. Using web-based professional development resources developed by the Center and its partners, along with hands-on activities, intensive training will be conducted with the state ASD training/TA team and practitioners from model sites. Center staff will then provide TA and onsite consultation, in close collaboration with state personnel, to support implementation of EBP at the demonstration sites. A primary objective will be for state partners to employ this model for training and TA, adapted for each state’s unique needs, with other practitioners in the state, during the second year of the project, with assistance from Center staff. Center staff will continue to assist the state in assessing and monitoring child, practitioner, and systems level outcomes.

An invitation for states to apply is available on the project web site, www.fpg.unc.edu/~autismpdc. Applications are due on June 1, 2008. Three states will be selected for participation from January 1, 2009 through December 31, 2010.

Parents’ Perspective

A Parent’s Story

By Tesha Imperati, Tommy’s Mom

Seven years ago when my son Tommy was diagnosed with autism I never thought we would be where we are today. He is now an active nine year old that is doing well in school, has friends, a great imagination, and a contagious laugh. I also am in a place that I would never have imagined myself. I am my son’s greatest advocate and loudest cheerleader. I am now in the position to help other parents who are going through what I went through seven years ago.

Do not fear the word autism. Educate yourself. Talk to other parents. Reach out for help and advice. Talk with your child’s therapists. They have so much knowledge and can be a great support. Watch the therapists with your child and learn from them. During therapy sessions, get involved. Get on the floor and play with your child and bond with him. As parents and caregivers you know your child better than anyone, and now you have a great opportunity to learn how to help your child reach goals that will help him for the rest of his life.

When Tommy was first diagnosed I was afraid of the label of autism. Now I tell our story to anyone who will listen. When I tell our story there is always a story for me to hear in return. I always learn something new from each parent that I speak with. Talk to other parents, go to support groups. Give support and get support.

Early intervention for our children with Autism is so important. It not only helps our children, but it helps us as parents and care givers. Just by reading this newsletter you are learning something new to help you, your children and your family.

You are going to have good days, great days and bad days, but you are not alone. Other parents are here to help and support.

In addition to being Tommy’s Mom, Tesha is the South Central Coordinator of the Connecticut Family Support Network.

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Early Childhood Special Education Update

Maria Synodi, Coordinator, Early Childhood Special Education

Accountability is a word that people either love or hate depending on the situation and the impact that accountability may have on them or those around them. Accountability in schools means that we want school districts to account for the service they provide, an education to our children. School districts have been confronted with the word ‘accountability’ and its meaning as it applies to educating all students, including preschool-age children with disabilities.

There are both regular education and special education laws that include requirements for holding school districts accountable for the education of all students from the preschool grades through Grade 12. These laws legally obligate states to collect and report information that will hold school districts, as well as the state, accountable for the education of all students.

For early childhood special education, the federal special education law, the Individuals with Disabilities Education Act (IDEA), holds school districts accountable by measuring how school districts perform in three areas: the provision of a least restrictive environment measured by time with non-disabled peers; the measure of developmental and functional progress that children with disabilities make during the preschool years before they enter kindergarten and a measure that identifies that children who come from the Connecticut Birth to Three System get their special education and related services by the time of their third birthday. These early childhood special education measures provide the state and parents a window to the efforts and activities of school districts in providing an education to preschool children with disabilities. It also provides a window for the State to evaluate its own efforts.

Annually the state collects information from school districts and prepares a report that is sent to the U.S. Department of Education. That report, which is a report card of how the state is doing, is called the Annual Performance Plan (APR). From that information, the Connecticut State Department of Education provides a profile of how each individual school district is doing in providing special education to all students with disabilities in 20 measurement areas. Three of the 20 measurement areas are specific to early childhood special education. The latest state profile in the APR can be accessed through the Departments’ website: [www.sde.ct.gov/lib/sde/PDF/DEPS/Special/Perf_Report06.pdf](http://www.sde.ct.gov/lib/sde/PDF/DEPS/Special/Perf_Report06.pdf). Information on individual school districts will soon be on the Department’s website as well. So in this world of accountability, let’s take a look at how we are doing – and use that information to make us even better.

Special thanks to Amber Flint for submitting this logo

Training Calendar

You can register for the following workshops on the SERC website: [www.ctserc.org](http://www.ctserc.org).

**Building the Bridge from the IEP to the Preschool Curriculum Framework**
Tuesday, June 10 and Wednesday, June 11, 2008
9:00 AM to 3:30 PM
SERC Middletown
Anne Marie Davidson and Kim Mearman, SERC
Audience: Preschool and kindergarten general and special educators, administrators, and supervisors
No Registration Fee

**Getting Along with Each Other in the Early Childhood Classroom**
Saturday, June 14, 2008
SERC Middletown
8:30 AM to 1:30 PM
Scott Noyes, Empowering Programs
Audience: Early childhood teachers and administrators from child care agencies
Registration Fee: $25

Resources

**Organizational Resources:**

- Atypical PDD/Asperger Syndrome Support Group
  34 Bullfrog Lane
  Trumbull, CT 06610
  203-261-7872

- Autism Society of Connecticut (ASCONN)
  PO Box 1404
  Guilford, CT 06437
  888-453-4975

- Autism Research Institute (ARI)
  4182 Adams Avenue
  San Diego, CA 92116
  619-281-7165
  Fax: 619-563-6840
  [www.autism.com/ari](http://www.autism.com/ari)

(Continued on back cover)
Birth to Three Update

Linda Goodman, Director, Birth to Three System

Since this newsletter is about autism the following is an update on the changes that the Birth to Three System has made for 2008.

First, the Autism Guideline has been revised. It is posted on the Birth to Three website (www.birth23.org) under “Publications.”

Second, as described in the guideline, all Birth to Three programs will include an autism screening as a routine part of all initial evaluations of children 16 months of age or older.

Third, just as the school districts do, Birth to Three will now determine whether a child meets the educational classification of autism found in the Individuals with Disabilities Education Act, rather than seeking a diagnosis of autism. A variety of individuals can be certified to administer an autism assessment. Only physicians and psychologists diagnose autism.

Fourth, the Birth to Three System now includes six programs that are only serving children on the autism spectrum. Any Birth to Three program that screens a child for autism and is concerned about possible indications of autism, can access an autism assessment by one of these six programs.

Why did we decide to have programs that only serve children on the autism spectrum? Just as with the programs that serve children who are deaf or hard of hearing, we see this as an option for families. It’s not that existing Birth to Three programs don’t provide appropriate services, because they do. But some families may prefer to enroll with a program that specializes in their particular area of concern. Unlike the hearing impairment programs that offer services statewide, the autism programs each offer direct services in a defined set of towns and, at the moment, we do not have service coverage in all towns, especially in eastern Connecticut. We hope that by next year we will have remedied that situation, but in the meantime the autism programs will be making assessment services available statewide.

For anyone who is interested in speaking directly to one or more of the autism-specific programs, you may contact them at the following numbers:

Bilinguals, Inc., Achieve Beyond Autism Program
Mayelin Ravelo: 212-684-0099 X169

Easter Seals of Waterbury, First Partners Autism Program
Maris Faulkner: 203-754-5141

Education Connection, TLC Autism Program
Janae Peluso: 860-567-0863 X170

Greenwich Autism Program, Little Learners
Susan Izeman: 203-629-1880

REM, Kaleidoscope Autism Program
Donna Cimini: 860-571-8602

TheraCare, Academy for Young Minds Autism Program
Deborah Mastronardi: 888-355-3255

Birth to Three State Interagency Coordinating Council Committee Work Update

By Lolli Ross, State ICC Chair

The State Birth to Three Interagency Coordinating Council (ICC) advises and assists the CT Birth to Three System in effectively managing the delivery of early intervention services and supports. The ICC plays a critical role in the provision of general oversight and quality assurance of early intervention services in CT. To accomplish these goals, ICC members work in committees every meeting to address the following priority areas: Quality Assurance, Legislative and Financial Issues, and Communications.

Members of the public are encouraged to work on committees as well.

The Quality Assurance Committee is focusing their attention on services to children with autism, the multi-cultural guidelines, the provision of quality services in natural environments, and on focused monitoring outcomes.

The Legislative and Finance Committee is currently reviewing the workforce needs of the Birth to Three system. Birth to Three program providers report difficulty in recruiting Speech/Language Pathologists and Pediatric Physical and Occupational Therapists. The committee plans to contact graduate training programs in Connecticut and develop proposals as one strategy to address this issue.

The Communications Committee is responsible for internal and external communications as well as family leadership. This group is completing the update of the ICC Member Handbook with a special section for family leaders. They are also developing a brochure for the ICC with a clear mission statement to promote awareness of the ICC with other agencies and programs throughout the state.

To learn more about the committees and their functions, please contact Anna Gorski, ICC staff support, or better yet, join us at a future meeting!

A special welcome to our newest members of the ICC: Patrick Ruddy and Deborah Pagano.
Websites:

- **Autism Society of America**
  7910 Woodmont Avenue, Suite 300
  Bethesda, MD  20814-3067
  800-3autism (800-328-8476)
  www.autism-society.org

- **Autism Speaks**
  2 Park Ave.
  11th floor
  New York, New York 10016
  212-252-8584
  www.autismspeaks.org

- **Connecticut Autism Spectrum Resource Center (ASRC)**
  101 North Plains Industrial Road
  Harvest Park, Bldg. 1A
  Wallingford, CT  06492
  203-265-7717
  www.ct-asrc.org

- **CT FEAT – CT Families for Effective Autism Treatment**
  PO Box 370352
  West Hartford, CT  06137-0352
  860-571-3888
  www.ctfeat.org

- **Indiana Resource Center for Autism (IRCA)**
  Indiana Institute on Disability and Community
  2853 East Tenth Street
  Bloomington, IN  47408-2696
  www.iide.indiana.edu/irca

- **OASIS, the Online Asperger Syndrome Information and Support website**
  lists autism support groups in Connecticut including local meetings and contact names.
  - [http://www.udel.edu/bkirby/asperger](http://www.udel.edu/bkirby/asperger)
  - [http://www.autismsocietyofct.org](http://www.autismsocietyofct.org)

- **TalkAutism**
  - [http://www.talkautism.org](http://www.talkautism.org)

- **CT Autism**
  - [http://www.ct-asm.org](http://www.ct-asm.org)

- **CARe Alliance**
  - [http://www.ctautism.org](http://www.ctautism.org)

- **Autism Information & Support (OASIS webpage)**
  - [http://www.autism-info.com](http://www.autism-info.com)

- **Connecticut Autism Spectrum Resource Center**
  - [http://www.info.med.yale.edu/chldstdy/autism](http://www.info.med.yale.edu/chldstdy/autism)

- **Yale Child Study Center**

- **Birth to Three**
  - [http://www.birth23.org](http://www.birth23.org)

- **CT FEAT**
  - [http://www.udel.edu/bkirby/asperger/suppCT.html](http://www.udel.edu/bkirby/asperger/suppCT.html)

- **Autism Collaboration**

- **National Early Childhood Technical Assistance Center**
  - [http://www.ctautism.org](http://www.ctautism.org)

- **Book**

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