Connecticut Birth to Three System

FY 2015 Annual Data Report

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This report, past data reports, and other publications are available at:
www.birth23.org/aboutb23/AnnualData

Our Mission

The mission of the Connecticut Birth to Three System is to strengthen the capacity of Connecticut's families to meet the developmental and health-related needs of their infants and toddlers who have delays or disabilities. The System will ensure that all families have equal access to a coordinated program of comprehensive services and supports that:

- foster collaborative partnerships
- are family-centered
- occur in natural settings
- recognize current best practices in early intervention
- are built upon mutual respect and choice

Early Signs

"We are so grateful that we caught this early enough to make a difference in our son's life."

– Parent in Birth to Three

"Birth to Three has become part of the standard of practice and an integral part of the 'screen then refer when needed' protocol. It is embedded in most electronic medical records, and clinic notes often include 'Call Birth to Three' in the patient instructions."

–Dr. Ann Milanese, CT Birth to Three System Medical Advisor

Parents are often the first to wonder if they need help for their little ones. Talking with friends, family members and their trusted medical providers often leads them to Birth to Three. The Connecticut Birth to Three System wants all parents to understand and be able to describe their child's abilities and challenges. We work to ensure that a developmental delay or disability is identified as soon as possible, and that families of eligible infants are offered appropriate supports at the earliest opportunity.

There are multiple screening activities used throughout the community to identify infants and toddlers who may need early intervention.

Developmental or behavioral delays are often identified by primary care physicians and advanced practice registered nurses who use validated screening tools at regular intervals as a vital component of well-child care. Child care providers, Family Resource Centers, Early Head Start staff, and others frequently include developmental and behavioral screening as a vital aspect of their services and supports. Families enrolled in Ages and Stages fill out developmental questionnaires at home to learn about their children's development. The results of these screenings lead to discussions with parents on the importance of early development and support referral to Birth to Three at the earliest sign of a developmental or behavioral delay.

Screenings for autism have become part of the standard of care for pediatric providers. Birth to Three collaborates with the "Learn the Signs, Act Early" initiative to promote education and training for early care providers. All toddlers referred to Birth to Three at age 16 months or older are screened for possible autism spectrum disorders. When screening indicates a concern, a Birth to Three autism-specific program can complete the diagnostic evaluation.

Three statewide screening initiatives managed by the Connecticut Department of Public Health also provide early identification of children needing supports:

- **Newborn Hearing:** All babies are screened at birth and those with a possible hearing loss are quickly referred for diagnosis. Infants who are deaf or hard of hearing are eligible for specialized Birth to Three services.
- **Metabolic or Genetic Disorders:** All babies are screened at birth for a number of congenital disorders, many of which have associated developmental delays that prompt a referral to Birth to Three.
- **Lead Poisoning:** Universal lead screening is completed annually for each child from 9 months to 3 years and parents of children with lead poisoning are strongly encouraged to refer their child for Birth to Three supports.

Making the Connection: Referrals

We receive referrals by phone, fax and online to connect families with our supports through the Child Development Infoline a specialty unit within 2-1-1 Infoline.

- **1-800-505-7000** toll-free, TDD, multilingual
- **www.birth23.org/referrals** *on-line and print & fax forms*

In FY15 we made referrals even easier by adding a "Refer a Child Here" button on our website home page. We also polled referral sources and redesigned our online referral form, creating unique versions for Parents/ Guardians/Foster Parents, Department of Children and Families case workers, and All Others, especially medical providers. Anyone with concerns about a young child's development may refer a child to the Connecticut Birth to Three System. Only the parent or guardian can accept their child's referral and schedule a developmental evaluation. There were 426 intake "contacts" submitted by others that were declined by the child's parent, so did not proceed to referral. **A total of 8,874 referrals were received by the Birth to Three System in Fiscal Year 2015** (July 1, 2014 – June 30, 2015).

"Making a referral by fax is easy and gives me documentation for the child's chart. When I refer a child to Birth to Three, I receive a letter telling me who will complete the developmental evaluation."

-Dr. Cliff O'Callahan, Pediatric Faculty and Director of Nurseries, Middlesex Hospital

"The website referral form is easy. I can complete it in-between my visits to families or whenever I have time."

-DCF Case Manager

"One of the things I love about Birth to Three is that it starts as early as possible. The Academy of Pediatrics has a schedule of recommended developmental checkpoints which creates a good opportunity for earlier identification. When you put resources in early, there are fewer costs further down the line for families and their communities. This is especially important for families with low economic or educational resources and high social stressors. Birth to Three is crucial to keeping educational, medical, psychiatric and social costs down."

-Dr. Peg O'Neill
community Pediatrician

Children were referred from all across Connecticut, from birth until close to their third birthday. Since this report covers FY15 (July 1, 2014 through June 30, 2015), children referred during FY15 were born in 2012, 2013, 2014 or 2015. Here are the statewide birth counts for those calendar years and the 12-month referral counts for the corresponding fiscal years:

Calendar year births *(CT DPH data)*		Fiscal Year referrals *(CT B23 data)*	
2012	36,103	FY12	8,419
2013	35,467	FY13	8,333
2014	35,523	FY14	8,720

Sixty-five percent (5,665) of children referred were boys. The median age at referral was 20 months.

Age at referral	number of children	percentage
Birth – 11 months	1,888	21%
12 – 23 months	3,514	40%
24 – 35 months	3,472	39%

Most families spoke English (78.3 %) or Spanish (15.1 %). There were 40 additional household languages spoken by families of children referred.

Measuring Developmental Differences

Every infant and toddler develops new skills at a slightly different pace than others his or her age. Birth to Three evaluations help families know as much as possible about their children's development in every area:

- problem solving skills (cognitive),
- understanding and expressing ideas (communication),
- self-help skills such as eating (adaptive),
- ability to move well, see and hear (motor and physical), and the
- ability to express feelings and understand other people (social-emotional).

"Many families worry about their children's development. Birth to Three offers a way of helping families find a balance point, to go back to their family and friends for advice and support, but also expand into the new territory that their child has led them to."

-Dr. Mark A. Greenstein, Developmental Pediatrician, and geneticist
CT Children's Medical Center and St. Francis Hospital

Two professionals with different types of training based on the areas of developmental concerns reported come to the family's home or the child care setting to interview the parents about their child's needs and skills, and assess the child's ability to complete a variety of activities (see page 13 for a listing of different types of early intervention providers). Parents and professionals work together to get a complete picture of the child's abilities as compared with what is typically expected at that age. Together they complete a multidisciplinary evaluation and compile information about the child's daily routine. The developmental evaluation involves using one or more standardized evaluation tools, and the results are discussed with the parent and provided in a written report. When all of the developmental, health and daily routines information has been considered, eligibility is determined.

For a listing and description of assessment tools commonly used for measuring infant development, visit **www.birth23.org/referrals/evaluation-and-assessment/.**

Children Who Were Eligible

Families are told that their children are eligible for Birth to Three supports due to either a:

- significant developmental delay, or
- diagnosed medical condition with a high likelihood of resulting in developmental delay.

In FY15, there were 8,259 evaluations completed and 5,319 (64.4%) children were eligible.
Families from 168 Connecticut towns received Birth to Three supports in FY15.

4,788 children (90%) were eligible for early intervention supports due to significant delays in their development

- 3,934 (74%) tested 2 standard deviations below average in at least one area of development
- 788 (15%) tested 1.5 standard deviations below average in two or more areas of development
- 66 (<1%) could not be tested, but had a significant developmental delay according to informed clinical opinion

531 children (10%) were eligible because they had a diagnosed medical condition with a high likelihood of resulting in developmental delay, including:

- 128 children: premature birth (28 weeks gestation or less) or extremely low birth weight (<1000 grams)
- 110 children: autism spectrum disorders (known at the time of referral)
- 65 children: brain/spinal anomalies or infections
- 59 children: deaf or hard of hearing
- 44 children: Down syndrome
- 30 children: cleft palate
- 26 children: known chromosomal or metabolic disorders (other than Down syndrome)
- 24 children: neuromuscular disorder
- 6 children: blind or visually impaired

Eligible Children's Race and Ethnicity as described by their parents - total of 5,319 eligible children

Ethnicity	*White*	*Black*	*Asian*	*Native American*	*Pacific Islander*	*Multi-Racial*
Hispanic	1,506	86	3	12	14	55
Non-Hispanic	2,688	559	233	11	30	122

462 families of eligible children did not accept Birth to Three supports.
537 families enrolled in Birth to Three but chose to receive only those supports that are available at no cost for at least one month during the year. These supports include:

- evaluation and assessment
- IFSP development
- service coordination
- transition supports
- procedural safeguards.

Family Options When a Child is Not Eligible

Families of children who were not eligible for Birth to Three or whose children left the Birth to Three System before age three may still be concerned about their child's development. Child Development Infoline made 2,789 follow-up calls to families whose children were not eligible for Birth to Three supports:

- 1,743 messages were not returned
- 710 indicated no need for resources
- 225 unable to be reached or left a message
- 111 requested community resource information

Birth to Three teams always provide information about other community resources to match families' concerns.

Families can enroll in **Ages and Stages Questionnaires,** which allow them to track their children's ongoing development. If a parent's responses on the standardized questionnaire show that their child's development may be delayed, a trained professional calls them to review the results and the family may seek another evaluation. When a child is learning new developmental skills at the same pace as his peers, the family is sent a developmental status report with suggested activities to continue to enrich their child's daily activities and help their child learn new skills.

If a child is not eligible and their family or medical provider still has concerns after three months or more, they may re-refer the child for a new developmental evaluation. In FY15, there were 446 children who were initially not eligible, then re-referred and found eligible at a later point in the year.

Families Partnering with Professionals

"Our job as parents, pediatricians and educators is to help Finn be "the best Finn" he can be. That is true for every child. My office visits give a little window into the child's life. Birth to Three meets families right where they are so they get a much bigger view of how things are going. Birth to Three is right in the home and treats the whole family by taking a holistic approach. Working with a good provider can make it a great experience for the whole family."

-Dr. Peg O'Neill, community Pediatrician and Finn's primary health care provider

Families team with their Birth to Three home visitor to develop activity-based developmental learning opportunities right in their home during regular routines. Parents are coached to identify the daily activities that involve their children and look for opportunities within those activities for learning and practicing new skills. Having Birth to Three come to their home is tremendously helpful. Worries about traffic, bundling up the baby, exposure to inclement weather and germs, getting child care for an older child and arriving home in time for a meal or nap are alleviated by bringing early intervention supports right to the family.

Home-based supports can involve everyone in the home – brothers and sisters, grandparents and pets. Supports provided in the child's early care setting can involve the child's friends and caring adults.

Most families develop an Individualized Family Service Plan (IFSP) with their Birth to Three team and receive supports that meet their child's unique needs and match their priorities for their child. Parents who have regular visits with a Birth to Three professional pay a monthly fee on a sliding scale based on their family size and income, which can be adjusted if there are documented extraordinary expenses, or when there is a change in income or family size unless they choose to only receive the supports that are available at no cost.

Providing effective supports in a family's home requires updated professional knowledge, sensitivity, the ability to shape new learning strategies suggested by families as part of the activities being worked on and to know what truly matters to the family. To see what an early intervention visit looks like, watch the "Early Intervention Home Visits" video at: **https://www.youtube.com/watch?v=8fOJGmIdj0c.**

Family choice is important. Each family may choose their program from among those available that serve their hometown. Parents sometimes transfer their child from one program to another due to a relocation, choice of a different program, or seeking a specialty to fit their child's diagnosis of hearing impairment or autism spectrum disorder. There were 768 transfers completed in FY15.

In FY15, there were :

- 39 Birth to Three agencies, who employed
- almost 1,200 service providers, who completed
- 96,868 home visits and a total of 109,718 early intervention visits

Deaf/Hard of Hearing programs	*children served*
American School for the Deaf	92
CREC Soundbridge	79
NE Center for Hearing Rehabiltation	25

Autism-specific programs	*children served*
ABC Intervention Program	218
Beacon Services of CT	160
Creative Interventions	206
Education Connection Autism Program	84
Little Learners	39
South Bay Early Childhood	150

General Programs	*children served*
Abilis	278
Benchmark (AWS)	159
Building Bridges, LLC	367
CES - Beginnings	127
Cheshire Public Schools - Darcy School	84
Child and Family Network	8
Children's Therapy Services	248
Cornell Scott Hill Health Center	143
CREC Birth to Three	544
East Hartford Birth To Three	121
EASTCONN Birth To Three	150
Easter Seal Birth to Three	328
Family Junction	10
HARC - Steppingstones	476
Jane Bisantz & Associates, LLC	414
Kennedy Center, Inc.	89
Kennedy-Donovan Center	114
Key Human Services, Inc.	149
LEARN: Partners for Birth to Three	267
McLaughlin & Associates, LLC	388
Oak Hill Birth to Three Program	85
Project Interact, Inc.	260
Reachout, Inc.	484
Rehabilitation Associates of Connecticut, Inc.	1,218
S.E.E.D.	451
SARAH, Inc. - KIDSTEPS	645
St. Vincents Special Needs Services	80
STAR Rubino Center	118
TheraCare	1,050
Wheeler Clinic Birth to Three	245

Meet the Daly Family

Based on an interview with and approved by Brooke Daly

"Who do you have in your support network?" asked the woman sitting next to me. It was our first meeting with Birth to Three, and I was feeling isolated and still very new to my identity as the stay-at-home Mom of a 2-month-old born with special needs. Finn was born 5 weeks early in late December, and two months before, my husband Kevin and I learned that he has Down syndrome, or Trisomy 21. Finn's medical provider thought that he might need surgery, so we had to keep him at home during flu and virus season. Having Birth to Three come to our home was really a lifeline.

I had done some research online when we learned of Finn's diagnosis, but didn't really grasp it. One of our pediatricians, Dr. O'Neill, was wonderful – talking with us about Down syndrome, the importance of a strong support network and the key role the parents play when a child has special needs. Our neonatal intensive care unit social worker reinforced those messages and made the referral for us. She said that Finn's diagnosis made him automatically eligible for supports and that Birth to Three would be a big help to us. I had heard about Birth to Three before, but when you are not a part of that world, and so much information is thrown at you, it takes time to absorb and sort through it all.

Marcie and Kim from Birth to Three were there from the beginning, reassuring me that "everything will be okay", really listening to any fears or concerns, and celebrating many successes. I have learned to describe the things that Finn is doing well in between visits, and the areas where he is lagging. We work together to keep our plan of supports fluid and changes are made as needed. Most of the time we meet at our home, but Finn also enjoys his Music Together class and Marcie has joined us there. We thought this would be a great way for Finn to increase his social interactions, and the teacher has welcomed all of us and solicited feedback.

Finn's big sister, Rosie, loves playing with him at the water table, rolling balls back and forth and playing dolls and cars and trucks. She also has the usual sibling complaint of, "He's touching my stuff!" Finn has made some buddies and I have found friends through the CT Down Syndrome Congress meetings and events. On World Down Syndrome Day, I read a story to Rosie's kindergarten class about Down syndrome, and Finn is the most popular kid when we visit.

My husband, Kevin, participates in early intervention visits when he can and I always give him updates when he gets home. Even my mother has joined us a few times and is very impressed by the coaching style of our work together. Things have changed a lot in the world of special needs since she was young. Dr. O'Neill, Finn's primary care physician, is in the loop all the time. We continuously keep her updated, and she appreciates knowing what we are doing.

I am a "Parents First Call" support line volunteer, helping parents who just learned about their baby having Down syndrome to know that it can be difficult at times, but for the most part they are just like any other baby and letting them know what a blessing Finn has been to our family. I also let them know that it's really important to use the resources we have. Birth to Three has been just wonderful. It will be hard not seeing them anymore when Finn turns three. We are getting ready for his transition to preschool special education and have heard great things about the school Finn will attend. Yes, there is business to be done when our Birth to Three team comes to our home, but our relationship is not just business. I can tell that they adore Finn and that means a lot to me as his Mom.

Parents First Call phone number is 888-486-8537

Planning for Supports

" I love getting Birth to Three reports and the Birth to Three plan of services to sign. They keep me informed and offer good information for follow-up with the parent at the child's next health care visit."

-Dr. Cliff O'Callahan, Pediatric Faculty and Director of Nurseries, Middlesex Hospital

"In my specialty practice I see families with a high level of distress who are accompanied by their Birth to Three provider. They come to dialogue and bear witness, and they can help interpret for the families both at the visit and afterward."

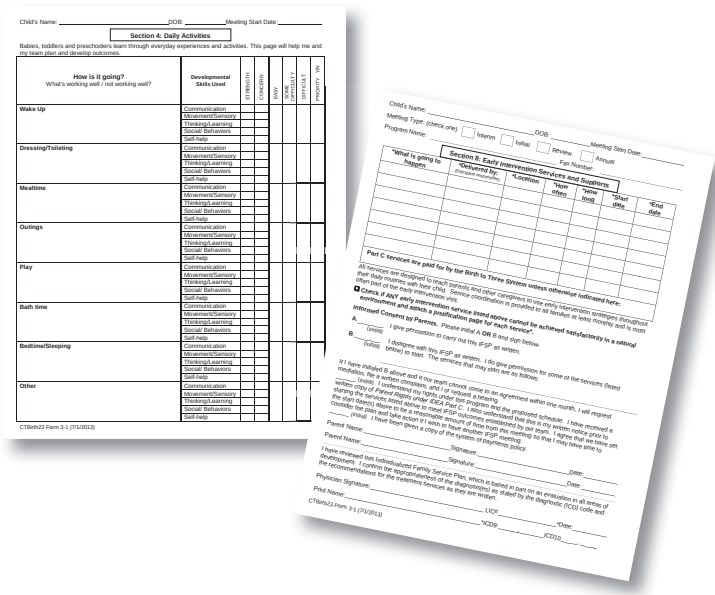
-Dr. Ann Milanese, CT Birth to Three System Medical Advisor

"I always read the Birth to Three reports and the team includes me. I am not a speech therapist, so I rely on the Birth to Three provider and parent to keep me informed about each child's developmental progress."

-Dr. Peg O'Neill, community Pediatrician

Families describe their daily routines to their early intervention team, discuss activities during the day when supports are needed, and identify the skills that they want to improve. Focusing on the developmental skills needed to make regular activities successful supports families in practicing new skills throughout their daily life. It also gives providers better information on how to meet the family's and child's needs. Combining knowledge gained from research on best practices with the realities of daily life, the parents and Birth to Three team decide together which services are likely to support their goals, which types of professionals will coach the parent, and how often the family will work with each person on their team. The child's primary health care provider participates in launching the plan of services.

The IFSP is reviewed at least every six months and revised at least annually. Here is an excerpt from the IFSP, Form 3-1. You may view the complete document in English, Spanish, Portuguese or Polish at: **www.birth23.org/providers/procedures/forms/.**



Every family has a primary service provider who is the service coordinator. Every member of the team meets with the parent and child and the full team regularly shares information. Other members of the child and family's early intervention team may make joint visits or provide consultation when more than one type of service is provided. The primary provider supports the family in making good use of all the information from team members and community learning partners. This "primary provider approach" has been shown to increase family reports of helpfulness and improved family well-being when compared with scheduling frequent, multiple provider home visits. It also leads to equal or better child learning.

Families and providers can include assistive technology to increase, maintain, or improve their child's ability to function in daily life. Examples may include high-tech devices such as hearing aids or an electric wheelchair, or low-tech devices such as a modified spoon handle and curved, high-sided bowl to promote independent feeding. During FY15, IFSPs for 386 children listed an assistive technology service and 457 listed assistive technology devices.

Some families receive intensive services, which means more than 13 hours of service per month. During FY15, 1,166 children had intensive services included on their latest IFSP.

"Love the Birth to Three program! Hopefully, my son will be able to attend school with the rest of the kids his age."

-Parent in Birth to Three

"I feel the past year has been so amazing for both me and my child. Our Birth to Three teachers are fantastic."

-Parent in Birth to Three

"J. is our service coordinator and has gone above and beyond her job description for our family, Many, many thanks."

-Parent in Birth to Three

Here are the types of Birth to Three providers and the numbers of children whose IFSPs included them for some portion of FY15:

Type of professional	*# of children*
Speech/Language Pathologist	6,093
Special Educator	4,151
Early Intervention Associate or Assistant	3,146
Occupational Therapist	2,603
Physical Therapist	2,416
Board Certified Behavior Analyst or Associate Analyst	1,051
Early Intervention Specialist	887
Social Worker or Intern	661
Audiologist	458
Psychologist	341
Occupational Therapy Assistant (COTA)	201
Speech/Language Clinical Fellow	86
Nutritionist/Dietician	54
Nurse	28
Family Therapist/Professional Counselor	22
Physical Therapy Assistant	17
Orientation & Mobility Specialist	8
Other	28

"I love and trust my Birth to Three provider. This is the second time I am using Birth to Three and know that my child will be successful in meeting his goals."

-Parent in Birth to Three

Birth to Three Personnel

"D. and S. have been my family's primary therapists for over 1 1/2 years. Their impact on our lives is immeasurable. They are very professional, knowledgeable & understanding especially with the dynamics of our big family. Never have I felt judged by them, only supported & encouraged. God has blessed us with them in our lives!"

-Parent in Birth to Three

Meeting families' needs requires that Birth to Three professionals continually hone their skills and utilize updated approaches that are research-based. The Birth to Three System supports professional development of early intervention staff by offering training and technical assistance on many topics. During FY15, the Birth to Three System offered intensive training to nine program teams comprised of 60 providers on the three core tenets of early intervention:

- natural learning environment practices
- coaching as a style of interaction
- primary service provider approach to learning

In addition, 104 professionals successfully completed an intensive course on Birth to Three Service Coordination. This four-day training included an overview of current federal and state early intervention laws and regulations, the policies and procedures necessary to provide effective service coordination to families, how to best engage families, build healthy relationships and value and respect each family's unique culture and lifestyle and adapt professional knowledge and techniques for use by parents and other caregivers.

Historically, providers of early intervention supports are well-trained to address developmental delay and disability, but often are less well-trained to address the impact of trauma on a child's development (Gilkerson, et al., 2013). To enhance providers' skills in working with families who have experienced traumatic life events, the Connecticut Birth to Three System convened a Learning Community that addressed six challenging situations and behaviors that impact the social-emotional and cognitive development of children:

- Poverty and severe socio-economic stress
- Domestic abuse
- Substance abuse
- Mental health challenges
- Parents with intellectual disabilities
- Children who are medically fragile or chronically or terminally ill

Learning Community members read and discussed research articles and learned evidence-based practices from experts in each area, focusing on the impact of each adverse condition and appropriate interventions to consider. Boosting awareness, identification, understanding and knowledge of resources helps facilitate protective factors for children and families, which can lead to better socio-emotional outcomes. This is intended to help reduce the number of vulnerable children entering school with an accumulation of difficulties and behavioral problems.

All Birth to Three programs participated in trainings on the
"Key Principles for Providing Early Intervention Services in Natural Environments"

- Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts.
- All families, with the necessary supports and resources, can enhance their children's learning and development.
- The primary role of a service provider in early intervention is to work with and support family members and caregivers in children's lives.
- The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child's and family members' preferences, learning styles and cultural beliefs.
- IFSP outcomes must be functional and based on children's and families' needs and family-identified priorities.
- The family's priorities, needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support.
- Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations.

- www.ectacenter.org

Families are the Best Teachers

Babies and toddlers learn best when they have many opportunities to practice new skills during their regular daily activities. Parents and their primary provider develop new ways to teach each child in the places where they live, learn and play including families' homes, child care, and other community settings. Family members and caregivers consistently use these techniques during regular activities throughout the day, so that bath time, dinner and getting dressed for bed are successful and promote development.

"Finn's dad, Kevin, loves to read stories to the kids at bedtime, and folds in pointing to pictures and offering choices as activity-based learning. Finn is learning some American Sign Language (ASL) to express himself, and everyone in the family knows the signs too. His sister, Rosie, loves to report that, "He used 'more' when we were playing ball," Grandma cares for Finn one day a week and always comments on things he's doing. She finds out what we are working on, gives us suggestions on how to include it during his day and considers ways to reinforce that learning when she chooses the toys she buys for her grandson."

-Marcie Percival, SLP,
Service coordinator

"Brooke is a wonderful mom - she's Finn's 24 hour a day teacher. She knows him better than anyone and we share ideas and feedback at every visit. Brooke takes ideas and comes up with many examples of how to use them in between my visits – that makes all the difference!!"

-Marcie Percival, SLP,
Service coordinator

Making a Positive Difference

Birth to Three early intervention provides infants and toddlers with an opportunity to reach their best potential. Children who exited in FY15 and had received at least six months of services improved across three outcomes that are measured for every child in Birth to Three for at least six months:

Birth to Three is effective in helping families improve their children's development.

Developmental Learning Measured	Caught up to their Peers or Maintained		Reduced the Gap relative to their Peers	
Positive social relationships	1,556	60%	1,408	73%
Acquisition of knowledge and skills	1,346	52%	1,923	74%
Take appropriate actions to meet their needs	1,843	71%	1,637	63%

Families reported feeling more confident and competent as a result of receiving Birth to Three services and supports. Families enrolled for more than six months said Birth to Three helped them to:

- Help their children develop and learn (99%)
- Communicate their child's needs effectively (98%)
- Know their rights under IDEA, Part C (99%)

"We are very thankful and appreciative of all of the help our Birth to Three team provided. We were sad to see them transition out, but feel good about the skills they taught us."

-Parent in Birth to Three

"This program has helped us out so much when it comes to how and what to teach my child. It also became therapy for me as a parent because it brought in hope when I thought my child wouldn't learn much with her disability and delay."

-Parent in Birth to Three

"Children's medical needs are addressed by their pediatricians and subspecialists. We provide medical follow-up in our center-based program, but ongoing continuity in the home by Birth to Three provides very important supports and also addresses parents' feelings of isolation and anxiety about how their infants are doing."

-Dr. Victor A. Herson
Former Medical Director of Neonatal Intensive Care Unit, Connecticut Children's Medical Center

Seeking To Be Even Better: State Systemic Improvement Planning, Phase One

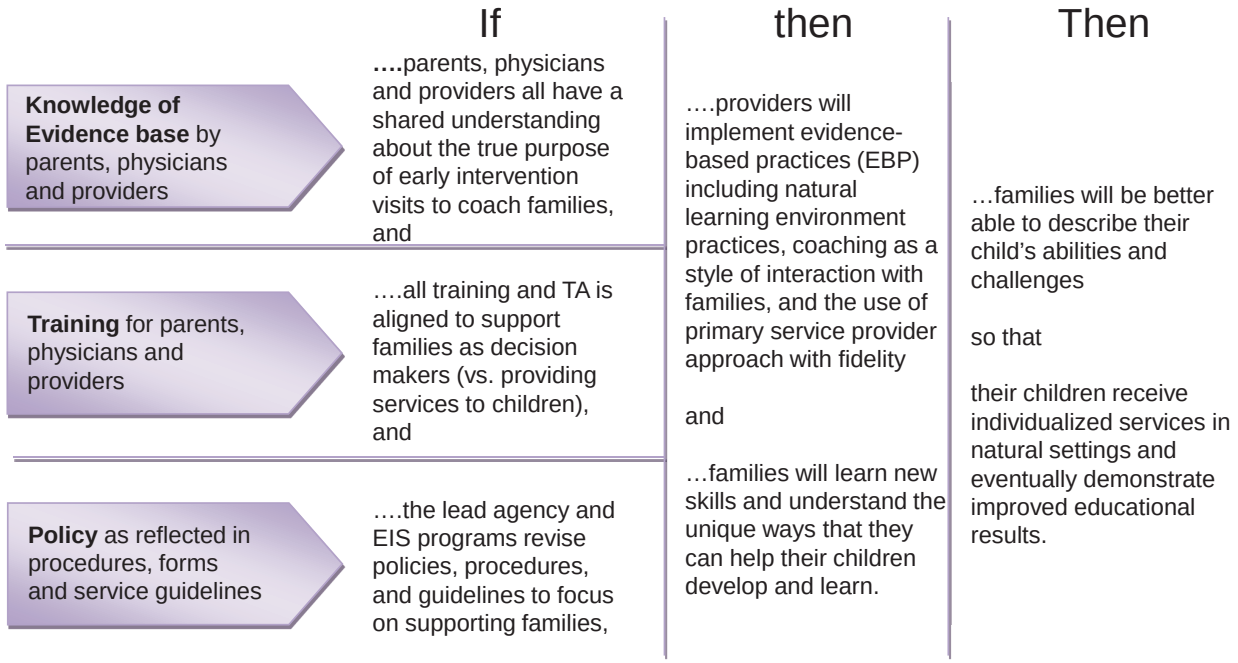
For the ninth year in a row, Connecticut was reviewed by the federal Office of Special Education Programs and designated as "meeting requirements" – the highest rating possible!

Even so, the Birth to Three System administration and stakeholders engaged in intensive data review and discussions of priorities, searching for areas that could be improved. Ultimately, Connecticut chose to focus resources on families in this way:

> "Parents of children who have a diagnosed condition will be able to describe their child's abilities and challenges more effectively as a result of their participation in Early Intervention."
> – CT State identified Measurable Result (CT SiMR)

Stakeholder meetings were held to begin identification of improvement strategies to support families with this goal. In Phase Two, the improvement strategies will be developed into implementation plans for the next five years.

Here is the Theory of Action:



"My son learns best by watching, parallel play, and hand over hand when he doesn't know how to move his body."

"My son's language is great, but he often needs reminders to take a breath before he speaks so he can be heard."

When It's Time to Say Goodbye

Most families continue with Birth to Three until their children turn three years old or no longer need our services and supports. Birth to Three prepares families for this transition as early as possible by helping them connect with their local school district and other resources in their community that match their interests and needs.

"N. has been a true partner in my journey to help my child"

-Parent in Birth to Three

"We'll miss our team as my son is transitioning out of Birth to Three and into the public school system. We had a great three years."

-Parent in Birth to Three

Families left Birth to Three in FY15 because:

	# of children	% of all exits
Child turned three years old	3,141	60%
Parent withdrew their child	918	17%
Attempts to contact were unsuccessful	548	10%
No further services needed by child	402	8%
Moved out of state	259	5%
Deceased	10	<1%

Of the 3,141 children who left at age three and were referred to their local school district for preschool special education:

	# of children	% of all exits
Eligible prior to exit	2,258	72%
Eligibility not determined prior to exit	345	11%
Not eligible, but referred to another program	307	10%
Not eligible, and not referred to another program	231	7%

Birth to Three prepares families for this transition as early as possible by helping them connect with their local school district and other resources in their local community.

Early Intervention Funding Sources

The Birth to Three expenditures for Fiscal Year 2015 were $52,888,751 from all sources, including state funds, federal funds, parent payments and commercial health insurance reimbursements. Birth to Three is the payer of last resort and successfully maximized other revenue. This included billing Medicaid, which resulted in $7.6 million in federal revenue into the State General Fund, thereby decreasing the net State contribution to Birth to Three by that amount.

ACTUAL FY 2015 EXPENDITURES	
All Funding Sources	
State Funds	$42,715,178
Total Federal IDEA funds	$5,288,085
Commercial Insurance Receipts	$4,194,914
Parent Fees	$1,317,542
TOTAL EXPENDITURES	**$53,515,719**

FEDERAL FUNDS ONLY	
Salaries & fringe benefits	$1,376,095
Other Expenses	$44,664
State & Local ICCs	$12,766
Public Awareness & Child Find	$286,945
Personnel development	$115,257
Supervision and monitoring	$11,407
Procedural safeguards	$67,461
Total System Components	$1,914,605
Direct Services	$3,373,480
TOTAL FEDERAL	**$5,288,085**

Note: $1 million in federal funds was IDEA Part B Child Find funding transferred from the CT Department of Education.

"The Connecticut Birth to Three System has survived by reinventing and adapting itself, for example, by creating specialty autism programs. These programs could function in a vacuum, but collaborate in very productive ways so that families have a choice around how services are provided."

-Dr. Ann Milanese
CT Birth to Three System
Medical Advisor

The average annual cost per child for 12 months of service provided by contracted programs was:

	Gross	Net (after insurance reimbursements)
General program	$9,367	$8,708
Deaf/Hard of Hearing program	$12,040	$11,582
Autism-specific program	$27,642	$23,749

Children and families served by deaf/hard of hearing programs are often fitted with hearing aids to enhance the child's available hearing for communication and social-emotional development, which contributes to those higher costs per child. Families whose children and families are served by autism-specific programs often receive intensive services averaging 46 hours per month, which contributes to the higher costs per child in these programs.

We Can't Do It Alone: Our Village

Many people, committees and agencies work with the Birth to Three System in supporting Connecticut's families with young children.

The Governor-appointed State Interagency Coordinating Council is comprised of stakeholders from throughout the state who advise and assist the Connecticut Birth to Three System. Their three standing committees are focused on Quality Services, Communications, and Legislative and Fiscal issues. Meetings are open to the public and agendas and minutes are posted on the Birth to Three website here: **www.birth23.org/aboutb23/sicc/.**

State Interagency Coordinating Council Members, as of June 30, 2015, included:

Mark A. Greenstein, M.D.
Developmental Pediatrician and Clinical Geneticist, Chair

Sharri Lungarini
Parent, Vice Chair

Elaine Balsley
Provider, REACHOUT Inc.

Ann Gionet
Dept. of Public Health

Anne Giordano
Provider, Education Connection

Corinne Griffin
Birth to Three Parent

Gerri Hanna
(alternate for Mary Beth Bruder)
University Center for Excellence

Ginny Mahoney
Dept. of Social Services

Jennifer Miner
Insurance Department

Kim Nilson
Dept. of Children and Families

Carol Peltier
Provider,
American School for the Deaf

Lorna Quiros-Dilán
Office of Protection and Advocacy

John Reilly
DORS - Board of Education and Services for the Blind

Lynn Skene Johnson
Dept. of Developmental Services

Maria Synodi
State Dept. of Education

Louis Tallarita
State Dept. of Education, Children who are Homeless

Elisabeth Teller
Provider, SARAH, Inc., KIDSTEPS

Alice Torres
Early Head Start

Myra Watnick
Provider, Rehabilitation Associates

Carol Weitzman, M. D.
CT Chapter, American Academy of Pediatrics

Community Connections

Connecticut's **Local Interagency Coordinating Councils (LICCs)** are independent regional partnerships that work to:

- Ensure that infants and toddlers with developmental delays are included as valued members of the early childhood community at planning and policy levels, and throughout everyday community activities
- Promote communication and collaboration among early childhood providers
- Share ideas and solutions in their communities

LICC priority areas include:

- Transitions from Birth to Three to preschool special education and other early childhood programs
- Coordination of information and resources across public and private agencies

LICC Chairs

- Danbury – **Trish Butler**
- Torrington –**Anne Giordano**
- Lower Fairfield –**Karen Feder**

Special thanks to the many families, health care providers, community and State agencies who support our efforts, including:

- Child Development Infoline, Kareena DuPlessis, Director, http://cdi.211ct.org
- United Way of CT, Richard Porth, President and Chief Executive Officer www.211ct.org
- Medical Advisor, Dr. Ann Milanese of Connecticut Children's Medical Center
- The CT Association for Infant Mental Health, Heidi Maderia, President
- The CT Down Syndrome Congress www.ctdownsyndrome.org
  Parents' First Call 888-486-8537
- Connecticut Children's Medical Center Neonatal Intensive Care Unit, Dr. Victor Herson, Director
- Yale New Haven Hospital www.ynhh.org
- The Connecticut Office of Early Childhood, Myra Jones-Taylor, Commissioner, www.ct.gov/oec
- Child Health and Development Institute, Judith Myers, President and Chief Executive Officer
- CT Chapter, American Academy of Pediatrics, Jillian Wood, Executive Director www.ct-aap.org
- CT Department of Public Health, Dr. Jewel Mullen, Commissioner www.ct.gov/dph
  - Early Hearing Detection and Intervention Program, Amy Mirizzi and John Lamb
  - CT Immunization Registry and Tracking System, Nancy Sharova and Ramona Anderson
  - Healthy Homes Lead Prevention Initiative, Francesca Provenzano, Krista Veneziano and Jimmy Davila
- CT Department of Social Services, Roderick Bremby, Commissioner www.ct.gov/dss
  - Medical and Behavioral Health, Dr. Rob Zavoski

Town -By- Town Snapshot of referrals and children served

Here are the numbers of referrals from each Connecticut town from July 1, 2014 through June 30, 2015 and the number of children in each town who were eligible at any point during the year. Provisional birth data from the CT Department of Public Health for calendar year 2014 are also provided as a context for consideration of the Birth to Three numbers.

NOTE: An infant can be referred within days of being born and can continue to be eligible until their third birthday – almost three full years. Since this table is only a one-year snapshot, many towns will have more children served than were referred because they were referred in a previous fiscal year. Data are not provided for any town with five or fewer children referred or served to protect confidentiality.

Town	Referred	Served	2014 Births
ANDOVER	≤5	7	14
ANSONIA	57	65	219
ASHFORD	13	15	38
AVON	29	37	142
BARKHAMSTED	7	≤5	19
BEACON FALLS	16	14	37
BERLIN	42	49	137
BETHANY	≤5	7	32
BETHEL	41	51	173
BETHLEHEM	≤5	≤5	25
BLOOMFIELD	29	33	196
BOLTON	≤5	10	37
BOZRAH	≤5	8	23
BRANFORD	45	47	188
BRIDGEPORT	493	556	2,108
BRIDGEWATER	≤5	≤5	10
BRISTOL	165	203	668
BROOKFIELD	41	43	110
BROOKLYN	18	31	69
BURLINGTON	18	13	72
CANAAN	8	10	24
CANTERBURY	9	11	48
CANTON	15	19	69
CHAPLIN	6	7	15
CHESHIRE	43	52	190
CHESTER	≤5	≤5	20
CLINTON	35	24	85
COLCHESTER	37	44	134

Town	Referred	Served	2014 Births
COLEBROOK	≤5	≤5	5
COLUMBIA	12	11	44
CORNWALL	≤5	≤5	2
COVENTRY	36	39	109
CROMWELL	39	42	137
DANBURY	275	330	1,000
DARIEN	55	46	198
DEEP RIVER	≤5	7	25
DERBY	23	30	124
DURHAM	11	13	47
EAST GRANBY	8	19	42
EAST HADDAM	8	11	79
EAST HAMPTON	29	40	102
EAST HARTFORD	183	252	668
EAST HAVEN	49	66	252
EAST LYME	26	31	141
EAST WINDSOR	38	47	107
EASTFORD	≤5	≤5	8
EASTON	≤5	8	38
ELLINGTON	29	33	138
ENFIELD	95	119	317
ESSEX	≤5	7	27
FAIRFIELD	110	113	546
FARMINGTON	45	48	217
FRANKLIN	≤5	≤5	18
GLASTONBURY	67	73	243
GOSHEN	7	≤5	12
GRANBY	25	30	67

Town	Referred	Served	2014 Births
GREENWICH	157	142	542
GRISWOLD	22	38	103
GROTON	144	174	582
GUILFORD	41	32	124
HADDAM	14	18	67
HAMDEN	114	122	545
HAMPTON	≤5	≤5	16
HARTFORD	606	658	1,874
HARTLAND	≤5	≤5	16
HARWINTON	≤5	11	25
HEBRON	17	19	65
KENT	≤5	≤5	18
KILLINGLY	64	84	174
KILLINGWORTH	20	13	31
LEBANON	14	19	57
LEDYARD	35	33	166
LISBON	9	11	27
LITCHFIELD	10	11	53
LYME	≤5	6	14
MADISON	29	25	97
MANCHESTER	168	220	783
MANSFIELD	16	24	70
MARLBOROUGH	12	11	49
MERIDEN	193	228	740
MIDDLEBURY	16	15	61
MIDDLEFIELD	≤5	≤5	28
MIDDLETOWN	97	122	523
MILFORD	88	107	477
MONROE	37	34	149
MONTVILLE	35	43	158
MORRIS	≤5	≤5	15
NAUGATUCK	90	88	345
NEW BRITAIN	300	388	987
NEW CANAAN	40	34	131
NEW FAIRFIELD	12	25	75
NEW HARTFORD	6	9	47
NEW HAVEN	428	463	1,815
NEW LONDON	88	114	344

Town	Referred	Served	2014 Births
NEW MILFORD	73	79	234
NEWINGTON	43	69	287
NEWTOWN	48	54	171
NORFOLK	≤5	≤5	12
NORTH BRANFORD	28	24	106
NORTH CANAAN	≤5	≤5	≤5
NORTH HAVEN	33	37	183
NORTH STONINGTON	15	8	49
NORWALK	260	277	1,122
NORWICH	114	152	502
OLD LYME	≤5	7	26
OLD SAYBROOK	≤5	9	65
ORANGE	14	9	103
OXFORD	20	28	85
PLAINFIELD	39	54	141
PLAINVILLE	34	60	143
PLYMOUTH	23	28	78
POMFRET	8	6	27
PORTLAND	20	35	99
PRESTON	7	≤5	35
PROSPECT	20	17	77
PUTNAM	40	51	85
REDDING	17	18	55
RIDGEFIELD	47	43	124
ROCKY HILL	32	34	216
ROXBURY	≤5	≤5	8
SALEM	11	6	46
SALISBURY	≤5	≤5	18
SCOTLAND	≤5	≤5	8
SEYMOUR	29	44	147
SHARON	≤5	≤5	13
SHELTON	67	70	318
SHERMAN	≤5	≤5	15
SIMSBURY	59	59	177
SOMERS	18	23	55
SOUTH WINDSOR	49	59	198
SOUTHBURY	24	25	88
SOUTHINGTON	87	106	362

Town	Referred	Served	2014 Births
SPRAGUE	≤5	11	34
STAFFORD	25	30	99
STAMFORD	381	431	1,806
STERLING	9	11	32
STONINGTON	18	26	132
STRATFORD	133	115	488
SUFFIELD	30	37	80
THOMASTON	19	14	62
THOMPSON	22	29	49
TOLLAND	27	32	100
TORRINGTON	95	118	362
TRUMBULL	81	79	319
UNION	≤5	≤5	≤5
VERNON	59	85	356
VOLUNTOWN	6	7	14
WALLINGFORD	98	101	358
WARREN	≤5	≤5	8
WASHINGTON	≤5	≤5	18
WATERBURY	433	484	1,531
WATERFORD	26	32	117
WATERTOWN	36	39	186
WEST HARTFORD	119	152	602
WEST HAVEN	154	177	613
WESTBROOK	10	12	39
WESTON	26	21	66
WESTPORT	63	59	165
WETHERSFIELD	52	60	212
WILLINGTON	6	11	48
WILTON	41	34	118
WINCHESTER	12	13	96
WINDHAM	101	105	261
WINDSOR	75	81	272
WINDSOR LOCKS	15	23	119
WOLCOTT	20	20	112
WOODBRIDGE	11	13	59
WOODBURY	15	12	49
WOODSTOCK	21	15	59
TOTALS	**8,874**	**10,153**	**35,523**

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The Honorable Dannel P. Malloy, Governor - Nancy Wyman, Lieutenant Governor

FY15 administered by the Connecticut Department of Developmental Services
Morna A. Murray, JD, Commissioner - Jordan A. Sheff, Deputy Commissioner
Now administered by the Connecticut Office of Early Childhood
Myra Jones-Taylor, PhD, Commissioner - Linda Goodman, Deputy Director

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Lynn Skene Johnson, Ed.D., Connecticut Birth to Three System, Director

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