

# Responsible Decision Making for Our Connecticut Children with Disabilities and Special Needs

## 2016 Update



### Report to the Governor and the General Assembly



# Connecticut Family Support Council Membership

## Appointed Members

## Statutory Members

April Dipollina - Waterford	State Interagency Birth-to-3 Coordinating Council Chairperson: Mark Greenstein, MD
Karen Hlavac - Wallingford	Commission on Children Designee: Stephen Hernandez Executive Director: Elaine Zimmerman
Lisa Sheppard – Fairfield Co-Chair	Department of Children and Families Designee: Sara Lourie Commissioner: Joette Katz
Renee Toper – Central Village	Department of Developmental Services Designee: Robin Wood Commissioner: Morna A. Murray, JD
Mona Tremblay – Putnam	Department of Education Designee: Marcus Rivera Commissioner: Dianna R. Wentzell, Ed.D.
Allison Quirion – Hebron	Department of Public Health Designee: Ann Gionet Commissioner: Raul Pino, MD, MPH
Jody Santoro – Cromwell	Department of Social Services Designee: Sylvia Gafford-Alexander Commissioner: Roderick L. Bremby
Laurie Cantwell – Cromwell	Office of the Child Advocate Designee: Open Child Advocate: Sarah Eagan, JD
Office of Healthcare Advocate Designee: Annika Burney, RN Healthcare Advocate: Victoria Veltri Non voting member	Office of Protection and Advocacy for Persons with Disabilities Designee: Linda Mizzi Executive Director: Craig B. Henrici

\*\*Current at time of publication: March 2016

Council Membership Vacancies by Appointing Authority

Governor (3), Senate Pro Tempore (1), Speaker of the House (1), House Majority Leader (2),  
Senate Majority Leader (1)

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**Thank you to the Office of the Healthcare Advocate for their generosity and printing of this Annual Report.**



**CONNECTICUT STATE STATUTE – TITLE 17a SOCIAL AND HUMAN SERVICES AND RESOURCES CHAPTER 319b DEPARTMENT OF DEVELOPMENTAL SERVICES Sec. 17a-219c**

**Sec. 17a-219c. Family Support Council.** (a) There is established a Family Support Council to assist the Department of Developmental Services and other state agencies that administer or fund family support services to act in concert and, within available appropriations, to (1) establish a comprehensive, coordinated system of family support services, (2) use existing state and other resources efficiently and effectively as appropriate for such services, (3) identify and address services that are needed for families of children with disabilities, and (4) promote state-wide availability of such services. The council shall consist of twenty-seven voting members including the Commissioners of Public Health, Developmental Services, Children and Families, Education and Social Services, or their designees, the Child Advocate or the Child Advocate's designee, the executive director of the Office of Protection and Advocacy for Persons with Disabilities or the executive director's designee, the chairperson of the State Interagency Birth-to-Three Coordinating Council, established pursuant to section 17a-248b, or the chairperson's designee, the executive director of the Commission on Children or the executive director's designee, and family members of, or individuals who advocate for, children with disabilities. The family members or individuals who advocate for children with disabilities shall comprise two-thirds of the council and shall be appointed as follows: Six by the Governor, three by the president pro tempore of the Senate, two by the majority leader of the Senate, one by the minority leader of the Senate, three by the speaker of the House of Representatives, two by the majority leader of the House of Representatives and one by the minority leader of the House of Representatives. All appointed members serving on or after October 5, 2009, including members appointed prior to October 5, 2009, shall serve in accordance with the provisions of section 4-1a. Members serving on or after October 5, 2009, including members appointed prior to October 5, 2009, shall serve no more than eight consecutive years on the council. The council shall meet at least quarterly and shall select its own chairperson. Council members shall serve without compensation but shall be reimbursed for necessary expenses incurred. The costs of administering the council shall be within available appropriations in accordance with this section and sections 17a-219a and 17a-219b. (b) The council shall: (1) Gather input and develop a vision and guidelines for family support services in Connecticut; (2) review existing program policies, procedures and funding mechanisms for conformity to the guidelines and make appropriate recommendations; (3) monitor the implementation of the guidelines and recommendations; (4) report to the Governor and the General Assembly on an annual basis regarding the status of family support services, including the implementation of the guidelines and recommendations; (5) advocate for family support services in accordance with the guidelines; (6) compile and distribute information on family support services within public and private agencies; and (7) perform such other duties as are related to the advancement of family centered supports, policies and services.

(P.A. 94-228, S. 3, 4; P.A. 95-257, S. 12, 21, 58; P.A. 96-185, S. 13, 16; P.A. 98-100; P.A. 01-195, S. 127, 181; P.A. 07-73, S. 2(a),(b); Sept. Sp. Sess. P.A. 09-7, S. 137; P.A. 10-93, S. 9.)

History: P.A. 94-228 effective June 8, 1994; P.A. 95-257 replaced Commissioner and Department of Public Health and Addiction Services with Commissioner and Department of Public Health, effective July 1, 1995 (Revisor's note: The phrase "Commissioners of the Departments of Public Health ..." in Subsec. (a) was changed editorially by the Revisors to "Commissioners of Public Health ..." for consistency with customary statutory usage); P.A. 96-185 made a technical change in Subsec. (a) reflecting transfer of birth-tothree program to Department of Mental Retardation, effective July 1, 1996; P.A. 98-100 amended Subsec. (a) by increasing members from 24 to 27, adding the Child Advocate, individuals who advocate for children with disabilities and increased from 2 to 3 the appointments by the president pro tempore of the Senate and the speaker of the House of Representatives; P.A. 01-195 amended Subsec. (a) by making technical changes, effective July 11, 2001; pursuant to P.A. 07-73 "Commissioner of Mental Retardation" and "Department of Mental Retardation" were changed editorially by the Revisors to "Commissioner of Developmental Services" and "Department of Developmental Services", effective October 1, 2007; Sept. Sp. Sess. P.A. 09-7 amended Subsec. (a) to replace provision re 4-year term and limit of 2 consecutive terms with provision re service in accordance with Sec. 4-1a and requirement that members serve no more than 8 consecutive years, and to make a technical change, effective October 5, 2009; P.A. 10-93 amended Subsec. (a) to permit designees of Child Advocate, executive director of Office of Protection and Advocacy for Persons with Disabilities, chairperson of State Interagency Birth-to-Three Coordinating Council and executive director of Commission on Children to be members of council and by making a technical change.

# The Connecticut Family Support Council Annual Report Responsible Decision-Making for Connecticut's Children with Disabilities

## Overview:

Our Connecticut Families, supporting children with disabilities and special health care needs, have been - for a number of years - navigating a landscape of service and support reductions, which have had direct effect on both their stability and ability to plan appropriately for the future of their children and families. It can be no surprise that previous budget cuts and those anticipated in the future do have a drastic impact. Wait Lists for services are becoming greater than anticipated. The question becomes -- What are We Doing to Help and Support Each Family Within our State and Local Communities?

Connecticut faces big decisions and as we come into a much anticipated presidential election Year. As a follow up to our last year's report and the 2016 priorities for Connecticut's families who care for and struggle with children with disabilities and special health care needs we need to review the cumulative effects of the budgetary cuts that have taken place over the past 5 years.

Program cuts hit hard those working tax-paying families who have children with disabilities. The costs of care and support often are 2 to 3 times more than for a typically developing child and this burden falls on the parents; if various support and relief mechanisms are removed, there is real concern that families could fail.

## We Need To Protect & Re-distribute:

As Connecticut Legislators face the decisions needed to balance a budget and make whole the financial instability of our state we need to remind each other of the core family priorities that our Connecticut families need in order to be successful.

***The CTFSC priorities this year are to protect eligibility and improve access to support services. This includes BOTH high quality behavioral and medical health care and restoration and assurance of continued benefit levels with access to support services inclusive of educational services and related community based supports.***

If we do not work together, investigate and find solutions for our families then we have failed as a state. Families with children with disabilities need support in order to survive in this economic climate. It is not enough to Wait List families who need support services.

This year CTFSC wanted to highlight several areas of concern via family stories and share solutions that are viable, doable and could assist families navigating Connecticut's systems of care for the disability community.

This year we have teamed up with additional partners to work together on what you will come to know as the 2020 Campaign. The 2020 Campaign began back in 2014 at the CT Council

on Developmental Disabilities where they initiated a plan to close Southbury Training School (STS) and the five remaining regional institutions by the year 2020. That Council sought support from a number of agencies and to date including the following:

The CT Council on Developmental Disabilities (DD Council)

The Arc Connecticut (ARC)

The CT Office of Protection and Advocacy for Persons with Disabilities (OP&A)

The University of Connecticut Center for Excellence in Developmental Disabilities (UCCEDD)

The State Independent Living Council (SILC)

The CT Cross Disability Lifespan Alliance (CCDLA)

The CT Family Support Council (CTFSC)

### **The 2020 Campaign – Background – Current – Solution**

Thirty years ago, the consent decree leading to the closure of the Mansfield Training School was signed. Fifteen years ago, the United States Supreme Court decided the Olmstead case, which affirmed the constitutional right of people with disabilities to live in the community in the most integrated setting appropriate to their needs. In 2015, Connecticut continues to maintain 6 segregated, state-run institutions, where over 400 individuals with intellectual disabilities reside.

In 2015, Connecticut inexplicably still continues to isolate these citizens, knowing that this model of institutional care is morally, legally and fiscally irresponsible...there is another way...

The CT Family Support Council joined up with the 2020 Campaign because Connecticut can no longer afford to operate a dual system – a system that attempts to support simultaneously both institutional and community services, but which, in reality, is producing incoherent policy and gross inequities that do not align with the DDS Mission, Vision and Core Values. Here are the issues that must be addressed through its closure and the solutions it can pass on to our Connecticut families:

- 1. Equity:** Southbury Training School exists as an antiquated, expensive, facility that supports under 300 people, while thousands of individuals with intellectual disabilities are being denied services - told they must wait until their families are in the throes of extreme personal crises before receiving critically needed support. The waiting list of families who need support and assistance from DDS is troubling. Last year over 14,000 families signed a petition to address the waiting list issue. As long as the state of Connecticut maintains segregated institutions, taxpayer resources are wasted, and the public receives confusing messages about the needs of the people and the fundamental direction of State policy.
- 2. People can be served well and live a good life in the community.** In Connecticut today, there are individuals with the same types and severity of disability as those living in STS and the Regional Centers who live in the community--in group homes, in apartments, in their family homes, with services and supports tailored to their needs.

When Mansfield Training School closed over 20 years ago, every resident moved to a community setting--none to an institution. Moreover, there are 15 states and the District of Columbia that have no state institutions; individuals with intellectual and developmental disabilities live safely in community based settings. No individual with a disability needs to live in an institution. Although all individuals who have moved to community living improve in their adaptive behavior skills, the largest gains are among individuals with "severe and profound" disabilities. All of the longitudinal research that has been done tracking individuals who have left state institutions is consistent across the country on this point, including the study of individuals leaving Mansfield Training School in Connecticut. And there is a large waiting list from which the Department of Developmental Disabilities (DDS) was only able to move eleven non-emergency families last year.

- 3. Cost.** At over \$335,000 per person per year, Southbury Training School is among the most expensive residential care offered by the DDS, surpassed only by state-operated regional centers. Costs at Southbury Training School are more than 2 times the cost of private group homes, which provide high quality services for individuals with similar levels of service needs. Therefore, moving residents to community-based options operated by private providers will inevitably lead to savings. This service array can include a full range of options from group homes to apartments and must include well-managed, appropriate unlicensed residential options which many states have used as part of their deinstitutionalization process.
- 4. Solution.** Closing STS will result in savings through the cessation of excessive overtime, the disbanding of an unnecessary fire department, and the elimination of the costs of running a power plant, maintenance shop and numerous kitchens. These are costly, inefficient anachronisms of an institutional system that have unnecessarily burdened taxpayers for years. The costs of serving the current residents of STS and the Regional Centers in private community settings would be approximately \$98 million. This is based on the DDS FY16 Funding Guidelines and on the amounts specified in the DDS FY 2016 RFP for Public to Private Conversion Homes. These are annual recurring costs only. There would also likely be non-recurring costs (capital expenditures). These would come from the General Fund. This does not include potential income from the sale of STS or Regional Center property. The State has already given away for \$0 over 900 acres of the STS campus: approximately 900 acres to the State Department of Agriculture to preserve as farmland and 45 acres to the Town of Southbury for senior housing. Located in Fairfield County, sale of the remaining 600 acres for fair market value could be expected to raise significant funds that could be dedicated to the needs of individuals with intellectual disabilities.

The closure of STS and the five regional centers could net approximately \$87 million annually to fund additional residential services in private community settings, while also serving all of the current residents of these facilities. This annual savings could provide funding for nearly one thousand individuals who currently languish on residential waiting lists. This would constitute a desperately needed increase in services without any increase in the overall budget for DDS.

Fortunately, Connecticut can build on the lessons learned from other states that have completed the institutional closure process during the past twenty-four years. Today there are fifteen states and the District of Columbia (see list below) that operate NO state institutions, the most recent being Oklahoma, which closed its last facility in August 2015. The evidence is clear from those states that with appropriate services and supports, no person with a developmental disability, regardless of complexity of disabilities, needs to reside in a state operated institution.

### **States with NO State Institutions**

Alabama	West Virginia	New Hampshire
Alaska	New Mexico	Minnesota
Hawaii	Oklahoma	Vermont
Indiana	Oregon	Tennessee
Maine	Rhode Island	
Michigan		

For all of these reasons, the CT Family Support Council recommends:

1. The closure of Southbury Training School and the Five Regional Centers on or before December 31, 2020.
2. And the legislative mandate by the general assembly of the re-allocation of any savings, including funds from the sale of the STS property to go directly back to DDS for ongoing support of the families on the waiting list.

### **CTFSC and the Annual Report**

Within this context, the Connecticut Family Support Council (CTFSC), along with its State Agency Partners, continues to address these difficult times by informing our governing leadership decision makers how this effects the children and families with disabilities and special health care needs of Connecticut.

Within this year's Annual Report the CTFSC shares a number of family stories, in hopes that the reader will get a glimpse of what families endure day to day. As indicated above, for families, this landscape is riddled with challenges: yet despite limited resources and ever-changing demands, our Connecticut families work hard to survive and deal with the changing conditions - and continue to put one foot in front of the other and make the best and wisest decisions for their families.

Family Support, as defined by the Connecticut Family Support Council, are the supports and services that families require to care for their children with disabilities and special healthcare needs, and those which enable them to fully participate in active life within their communities.

#### ***When we reference "family support", we include:***

- in-home supports
- special healthcare and clinical services

- specialized childcare
- respite care
- parent-to-parent networking, family training and support
- disability related goods and services
- home and vehicle modifications
- inclusive educational programs
- crisis support
- assistive technology and medical equipment
- clinical services including evaluation
- reliable transportation to and from medical and related appointment

The Connecticut Family Support Council's on-going responsibility and charge pursuant to Connecticut General Statute 17a-219c:

(b) The council shall: (1) Gather input and develop a vision and guidelines for family support services in Connecticut; (2) review existing program policies, procedures and funding mechanisms for conformity to the guidelines and make appropriate recommendations; (3) monitor the implementation of the guidelines and recommendations; (4) report to the Governor and the General Assembly on an annual basis regarding the status of family support services, including the implementation of the guidelines and recommendations; (5) advocate for family support services in accordance with the guidelines; (6) compile and distribute information on family support services within public and private agencies; and (7) perform such other duties as are related to the advancement of family centered supports, policies and services.

- Establish a comprehensive, coordinated system of family support services;
- Use existing state and other resources efficiently and effectively as appropriate for such services;
- Identify and address services that are needed for families of children with disabilities; and
- Promote statewide availability of such services.

**Our statutory agency partners include:**

- Department of Developmental Services
- Department of Public Health
- Department of Children and Families
- Office of Protection and Advocacy for Persons with Disabilities
- State Department of education
- Office of the Child Advocate
- Commission on Children
- State Interagency Birth to Three Coordinating Council
- Department of Social Services

These state agency partners along with legislatively appointed family members and advocates work to impact, navigate and collaborate within the broad statewide child serving system in an effort to facilitate change for these children and families. The CTFSC cannot emphasize enough that this group of children and their families are the most vulnerable, cannot speak for themselves and can become overwhelmed with their day-to-day responsibilities which can take a toll over time.

The CTFSC will continue to be a voice for these families and will work toward increasing the awareness of their needs within the Governor's Office and General Assembly. We have seen great efforts on the part of many of our State agency partners who collaborate and work to reduce the functional problems that families are experiencing. Whenever possible and within existing structures, they each collaborate to make meaningful change for individual families that come to their attention. We support and commend these efforts and look forward to continued opportunities for such collaboration and their cooperation to occur.

This year's Annual Report focuses on what families define as major concerns and what they recommend as a foundation on which to build and solidify collaboration between state agencies and families towards the creation of a delivery system that supports our families and children.

The first section includes family stories to provide context for the concerns about elimination and reduction in services and supports in the community. After that, state agencies have included summaries of key state agency services, which support families.

**We devote this annual report to our families and salute their resilience, courage and dedication. Let's make a difference and change the course of events for our families...**

## **Family Stories**

The Family Support Council is very cognizant of its role as the voice for families and children with special health care needs and disabilities. Generally, this Annual Report is a reflection of the Council's review of challenges, successes, and issues of the previous year with recommendations of what needs to happen in the upcoming year. Essentially, readers of the Report receive information mainly from the members of the Council. For the second year, we have asked families to communicate their concerns, experiences, and expectations to you, the reader, directly. In the section below, the Council presents 4 stories from and/or about families with children with special health care needs and disabilities. Stories told by or for these families cover a range of issues including agencies' responses, families' successes and challenges; The Council seeks to offer you glimpses into the lives of the families and children who depend on the Family Support Council and its partnerships to communicate their needs and concerns.

### **ALLISON QUIRION – LITERACY A FUNDAMENTAL HUMAN RIGHT**

I am the Founder of Decoding Dyslexia-CT, a grassroots movement, concerned with the limited identification and appropriate interventions for students with Dyslexia in Connecticut Public Schools. For the past several years parents, educators and supporters have advised policy makers on best practices, which has resulted in Public Acts, 14-39 and 15-97. With the help of our dedicated Connecticut Legislators and our Dyslexia Champion, Senator Catherine Osten, we are starting to see supports for Connecticut students with Dyslexia, but there is so much more to be done.

Decoding Dyslexia-CT has been able to garner the support of constituents statewide, who have in turn advised their legislators about Dyslexia and the issues, surrounding Dyslexia, that currently exist within their districts. Specifically, children are going unidentified and receiving inappropriate interventions due to the lack of knowledge and resources within our Connecticut Schools.

There were hundreds of written and oral testimony submitted to the Education Committee in 2014 and 2015 in support of Dyslexia legislation. Many of the testimonies have common threads and mirror the stories shared below.

*I am a Connecticut parent, of a New Hartford student, who has experienced difficulty with obtaining proper identification and interventions for my child. When my fraternal twin girls entered kindergarten in 2013, one of them had difficulty with learning the alphabet, spelling site words, and eventually learning to read.*

*After a school evaluation she was referred to special education and an Individualized Education Program (IEP) was developed. At that time, I didn't feel that we (parents & teachers) knew exactly what was the root cause of her learning disability? How do you know if you're properly intervening if you don't know the underlying cause?*

*We needed additional answers, as my daughter was not making progress within special education. Now in first grade and struggling, we decided to pay, out of pocket, for an independent education evaluation. The outcome of that evaluation identified my daughter as profoundly Dyslexic. There was difficulty with identifying my daughter as Dyslexic and obtaining appropriate interventions through the school.*

*Through my work with my school district we have found that very few teachers, if any, have formal training related to Dyslexia. By being a part of Decoding Dyslexia-CT, I hope to help change the landscape for students with Dyslexia. No child should be a casualty of inappropriate instruction. In many districts, it is not our students inability to learn how to read, but it is educators who do not have the knowledge to teach them the way they learn.*

*Teachers can't provide appropriate interventions if they are not properly trained. We need to ensure that higher education is providing our teachers with the training they need. – Kelly Howard*

*I am a Connecticut parent, of an East Haddam student, who has experienced difficulty with obtaining proper identification and interventions for my child, despite already having BOTH in place prior to moving to CT.*

*Our family relocated to CT from Texas in 2013. As a new resident in the state of Connecticut my experience with regard to meeting the needs of students with Dyslexia has been less than positive. Inappropriate reading interventions are not the solution for a child with Dyslexia. CT school districts do not understand the multi-sensory teaching approach and Dyslexia. Evidence based interventions and best practices are not found nor taught in many of our CT schools.*

*Along our journey through CT's version of the IEP process we have learned that the system is broken, from Superintendents to Board members to Administrators and teachers. There are many good people that lack the training to teach and identify Dyslexic students.*

*Our reprieve comes during the summer months when our child begs to go to the summer program at Ben Bronze Academy in West Hartford. The skill set of the staff at Ben Bronze is on par with our experiences in public school in Texas. The similarity between the two is training. Training in identification and teaching techniques in an environment that encourages students with Dyslexia to correct weaknesses and develop strong thinking and study skills that make learning enjoyable and build self confidence.*

*Through my experiences in Texas, I witnessed firsthand classroom teachers having the appropriate training. The Texas Dyslexia Teachers had the time and resources to teach at proper ratios to build skills and confidence that would transfer into the classroom. Investing in teachers and the training necessary to provide all students with access to an education is critical. Decoding Dyslexia –CT has been the grassroots movement in the state to bring about awareness and discussion of the challenges in front of us. But more importantly DDCT has started to bring about real change. – Dawn McNary*

Our teachers want to meet the needs of our students. However, Connecticut's institutions of higher education do not provide curriculum to teachers to enable them with the skills, knowledge and resources to teach students with Dyslexia. At a recent State of Connecticut Board of Education meeting Commissioner Dianna Wentzell stated, "If people knew better, they would do better". Well, why don't we give them the tools to do better? It is NOW time to hold higher education accountable so our educators can meet the literacy needs of ALL students.

Allison Quirion, Founder, Decoding Dyslexia-CT

2014 Testimony Link -

[https://www.cga.ct.gov/asp/menu/CommDocTmyBillAllComm.asp?bill=HB-05562&doc\\_year=2014](https://www.cga.ct.gov/asp/menu/CommDocTmyBillAllComm.asp?bill=HB-05562&doc_year=2014)

2015 Testimony Link -

[https://www.cga.ct.gov/asp/menu/CommDocTmyBillAllComm.asp?bill=SB-01054&doc\\_year=2015](https://www.cga.ct.gov/asp/menu/CommDocTmyBillAllComm.asp?bill=SB-01054&doc_year=2015)

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**MONA TREMBLAY, APPROPRIATE SERVICES**  
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As a longstanding parent representative on the CT Family Support Council, I have enormous concern about the current state of affairs, related to the provision of appropriate services for children, adolescents, and adults, with disabilities and/or special health care needs. Having worked in the field of disability advocacy for most of my adult life, and being a single parent who has raised identical twin sons, both diagnosed with Autism and Intellectual Disability, I feel qualified in stating that CT's most vulnerable families have never been more challenged to meet their day-to-day needs; let alone plan for the future. I cannot recall a time which even resembles the present climate. I have lived through decades of Budget cuts, agency reorganization, downsizing, and increased focus on results-based accountability. I have, and continue to participate in, numerous committees, collaboratives, boards, and councils, both locally and at a statewide level; all with a goal of assisting families to meet their children's needs at home, in their schools, and in their communities. In these economic times, we are expected to ask families to do more with less. In fact, in many instances, we can offer no real hope and no solutions. I watch in disbelief, as families languish on impossible "waiting lists". Parents are forced to bring their children to ill-equipped emergency rooms, caregivers are injured, exhausted, and don't know where to turn. There was a time that individuals doing this type of work, could provide clear direction and real answers. The truth of the matter is; we are working harder than ever before, and resolving fewer family dilemmas. The fallout is nothing short of catastrophic.

If my testimony sounds overly grim, that may be because it is. Far too many of my professional as well as personal experiences working with families, reflect a broken, inadequate, service delivery system. In truth, our responses to parents and caregivers pleading with us for help do not convey hope or resolution, to the real challenges they are facing, each and every day.

In the past several months, I have encountered family stories that most people cannot even fathom. Sadly, these stories are not fictional, and they include:

- A desperate mother of a 12-year-old son, repeatedly expelled from school, unsuccessful at his partial hospitalization program, 3-4 inpatient hospitalization stays, and a victim of far too many 911 calls; one resulting in what would be considered “police brutality,” reflective of an uneducated workforce of first responders, on the complexities of children’s mental and behavioral health. Mother is the sole caregiver at home, and recently stated she has become afraid in her own home.
- A single mother of 5 children; all with special health care needs, encompassing a wide range of diagnostic profiles and complexities, has a 7-year-old daughter with an “unknown syndrome.” The child, who has somewhere around 8 different specialists, qualifies for home health care services, to assist the mother with the non-verbal child’s complex feeding needs, morning care (involving dressing and incontinence), and need for constant 1:1 supervision. In spite of many months in search of an agency that will provide this needed, HUSKY-covered service, to this child, not a single request has been filled to date. In desperation, the mother moves a relative-caregiver into their home, because she cannot possibly do everything herself; the father died about one year ago. The relative caregiver is not only a poor fit, but is presenting concerning psychiatric abnormalities, further adding to the responsibilities of the already exhausted mother.
- A toddler is diagnosed with Autism. He is non-verbal, and exhibits a wide range of behavioral challenges, including attempts to jump out of a moving vehicle. With assistance, he qualifies for an IEP, but although he meets the criteria of one of the new Autism Waivers, for medically necessary in-home services, there are no qualified Board Certified Behavior Analysts, willing to service this rural part of the state.
- A young adult with high-functioning Autism has exited the school system. He has failed to get a paying job, even with multiple attempts working with BRS. He no longer qualifies for any real support services. He is on, and has been on, an Autism Waiver Wait List. This waiver has received no additional funding to support new enrollees for many years. He cannot drive, and he lives where public transportation is almost non-existent. For many years, he lived with his father; his only involved parent, but Dad has recently remarried, so he sets his son up in his own apartment, hoping that he can make it on his own. Incapable of making real friends, he latches on to a local Special Olympics team. When he misunderstands the actions of one of his team mates, he lets his anger out by posting inappropriate messages all over their team’s Facebook page. His coach approaches me, worried that this young man’s anger will only get worse, and he has a history of displaying inappropriate behavior to get attention. What should she do?
- An elderly caregiver, well into her eighty’s continues to support her adult son with Intellectual Disability, now in his early 60’s, in her home. He is also legally blind. She has been informed that he cannot secure other living arrangements until his mother dies. Even then, he will be “placed,” in the “first available bed,” in the “first available group home,” regardless of the enormous upheaval to the individual; sure to devastate this significantly challenged, older man.

We cannot continue to know these truths, and fail to acknowledge that the cuts to essential services have gone too far. As a voting parent member of the CTFSC, I am charged with reporting on the status of family support; it is a role I take very seriously. I wish that even some of these individuals could come to you personally, and share their stories and their desperation. They cannot come; especially given the fact that they cannot leave their children; young or old, because they take their parental responsibilities quite seriously, and they continue to care for their children, to the best of their abilities. In all fairness, no legislator can be expected to change what they don't know about or what they do not understand. Can you now know about these families and allow these injustices to continue, or will you take a stand and fight for the restoration of funding, to supply critical supports and services?

Sincerely,

Mona Tremblay, Putnam

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**TOPER FAMILY STORY - IMPACT OF CUTTING FUNDING**  
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My daughter, Abigail, has developmental, physical and medical disabilities. She is a beautiful 7year old that requires 1:1 care daily for safety and all areas of daily living. In addition to DDS, we have a family need to use DSS services, too. Abby is on the Katie Becket Waiver, a program necessary for us to provide adequate care for her. She was put on the wait list at 6 months old and a slot finally opened up when she was 6.5 years old.

DDS has supported my family through grants that are necessary to obtain therapies, services, and supports such as educational liaisons, community behavioral supports, respite and more. It scares me that, as she is aging, so am I and her father. We will not be able to take care of her forever, and I see so many families in my district struggling to obtain housing for their loved ones. One family in particular has been on the wait list for 10 years!!!! Day programs are vital to our population for so many reasons, including the caregiver to be able to work, socialization, vocational skills, community outings and more for clients.

Please remember, the "Disability Club" does not discriminate. You can be born into it, have an accident or illness to become a member. You and your family will be able to share the struggles that we share daily. Please do not wait until you have a "member" to realize that individuals with disabilities should not have to carry one more burdens. Many DDS clients work, and therefore pay taxes too. The struggle for families is real and I am asking you to consider not cutting funding and become more aware of what is needed for basic survival and human rights.

Renee Toper, Central Village, CT

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**LAURIE CANTWELL – NEEDED RESOURCES**  
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As a family member appointed to the CT Family Support Council (CTFSC) and a Board member of the CT Down Syndrome Congress (CDSC), I hear many stories about what is working and what the areas of unmet need are throughout the state. I would like to share my perspective about family support services and share a recent family story.

In October 2015, a family member of a 57 year old gentleman with Down Syndrome reached out to the CDSC desperately seeking guidance and assistance for her uncle, who had been in and out of the hospital for the past several weeks due to several injuries he had obtained from falling many times. He also had pneumonia and a urinary tract infection. It was believed he was having seizures, but nobody was sure. He had been living in a group home, and was now in a nursing home, prior to this latest hospitalization. He no longer works due to the onset of Alzheimers.

The family was extremely disturbed with the condition of the nursing home. They reported arriving one afternoon to visit and nobody knew where her uncle was. After asking several staff members, they eventually found out that he was sent to the ER hours earlier. Nobody in either the family or at his prior assisted living placement was notified. For someone with Down Syndrome and Alzheimers, this was a terrifying experience, and a recipe for disaster. His family felt like this was comparable to sending a child to the ER without notifying family. Her uncle gets easily confused, and panics when he is scared and does not understand where he is or why. The niece was contacting us looking for guidance and assistance to help her family get the best care for her uncle. The family did not know where to turn for help or how to move forward. There was a real sense of urgency because the family did not want him being returned to that same nursing home when he was discharged from the hospital, which would be in a few days.

As the parent of a young child with Down Syndrome, this story had a huge impact on me. I cried as I read through the email, terrified of how many other people are out there in the same situation with nobody advocating for them. I was filled with fear for my own child's future and wondered how this could possibly be happening here in CT in 2015.

I quickly reached out to fellow CTFSC members, and many responded immediately with ideas and resource information. I was able to provide the family with the appropriate contact names of people who could help with their situation. I was updated that he was transferred to a different nursing home and was doing well. I was so very grateful to be a member of the CTFSC and have access to resources which I otherwise would not have known about. It warmed my heart to know I played a small part in helping this family, but this story and so many others like it keep me up at night worrying about the future of our most vulnerable citizens. While this story had a positive outcome, it is being shared because it portrays a very troubling reality of what individuals with disabilities and their families are facing each day. If this gentleman's family were not doing such a good job of advocating for him, he would have continued to live in unacceptable conditions. Our families deserve so much better!

Laurie Cantwell  
Cromwell CT



# STATE OF CONNECTICUT

## OFFICE OF PROTECTION AND ADVOCACY FOR PERSONS WITH DISABILITIES

60B Weston Street, Hartford, CT 06120-1551

1-800-842-7303 (toll-free CT only) (V/TTY)

(860) 297-4300 (V) - (860) 297-4380 (TTY)

(860) 566-8714 (facsimile) [www.ct.gov/opapd](http://www.ct.gov/opapd)

The Office of Protection and Advocacy for Persons with Disabilities (P&A) is an independent state agency providing information, referrals, advocacy assistance and limited legal services across the life span of individuals with disabilities who live in the state of Connecticut. P&A protects the civil and human rights of people with disabilities and responds to assistance from those seeking disability related information, experiencing discrimination due to disability or being denied services. The agency also supports the development of community advocacy groups by providing training and technical assistance. P&A is responsible for investigating abuse and neglect of individuals with an intellectual disability, ages 18-59 and the deaths of all individuals with an intellectual disability over the age of 18 where abuse and /or neglect may have been the cause.

### **Description of Services (across the lifespan):**

- Provide information, referral, advocacy representation and limited legal representation for people with disabilities of all ages;
- Operate advocacy programs that are capable of pursuing legal and administrative remedies on behalf of people with brain injuries, as well as people with psychiatric, developmental and other disabilities;
- Intervene on behalf of children with disabilities who are experiencing difficulty obtaining relevant education supports;
- Conduct investigations into allegations of abuse and neglect involving adults with intellectual disability, ages 18 through 59;
- Provide legal representation and assistance to individuals seeking administrative or judicial remedies in cases involving disability related issues;
- Advocate for individuals who apply for or receive vocational rehabilitation services from agencies funded under the federal Rehabilitation Act;
- Investigate complaints of abuse and neglect of individuals with mental illness, and pursue administrative remedies on behalf of eligible people;
- Advocate for the rights of voters with disabilities through representation, training and technical assistance for people with disabilities and election officials;
- Increase the availabilities of assistive technology devices, information, education and advocacy assistance;
- Conduct full independent investigations into the circumstances surrounding the deaths of Department of Developmental Services clients, especially when abuse or neglect is suspected to have contributed to the death;
- Affirmatively reach out to traditionally underserved populations, conducting community development and public education activities;
- In conformance with Agency priorities, develop and pursue long-term projects to challenge systemic problems within human services and educational structures.

- Receive reports of serious injury or death resulting from restraint or seclusion pursuant to Connecticut General Statutes §46a-150 et seq. and federal regulations - 42 CFR 483.374, Reporting of Serious Occurrences at Psychiatric Residential Treatment Facilities; and
- Receive reports of serious injury or death of a child receiving special education services in Connecticut pursuant to Connecticut General Statutes §46a-150 et seq., §10-76b and § 10-76d.

P&A develops publications based on recurring requests for information from individuals with disabilities, family members and others interested in disability issues. Other publications are developed because of funding mandates and outreach needs. The publications provide information about disability rights and offer strategies for solving individual problems. The following is a link to P&A's publication index:

<http://www.ct.gov/opapd/cwp/view.asp?a=1756&Q=277262&opapdPNavCtr=l#55886>

### **P&A Reports:**

The reports listed below are examples of the types of work handled by P&A staff as part of its federal and state responsibilities to protect the civil and human rights of people with disabilities.

### **P&A Annual Report 2015**

Each year P&A issues an Annual Report summarizing the work that the agency completed during the year. This year's theme is "Celebrating 25 Years of the American with Disabilities Act". The Report contains ADA cases, P&A statistics, abuse investigation information, stories, fiscal data, a listing state and federal statutory obligations, and a section on issues facing people with disabilities in Connecticut. The link to P&A's 2015 Annual Report is:

<http://www.ct.gov/opapd/cwp/view.asp?a=1757&q=574322&opapdPNavCtr=l50816l#57064>

### **Legislative Update 2015**

At the end of each legislative session, P&A issues a report on legislation passed that affects people with disabilities in Connecticut. The link to the 2015 Legislative Update is:

<http://www.ct.gov/opapd/cwp/view.asp?a=1749&q=569150&opapdPNavCtr=l#56978>

**Case Example:** Sean participated in athletics throughout his high school career including football and crew. He lettered in both these sports. Sean maintained this level of accomplishment while also being diagnosed with Type 1 Diabetes. As with many athletes with diabetes, Sean's blood sugar levels fluctuate from low to high numbers. As Sean is insulin dependent, he utilizes an insulin pump in addition to managing his sugar levels through food, drinks, and glucose tablets. He typically utilizes his food and tablets if his blood sugar levels drop too low before the onset of symptoms such as shaking and dizziness. However, Sean's careful preparation was for not as a Coach decided that Sean could not take care of himself.

During a grueling Crew practice, Sean asked for a break in order to consume a sports drink to keep his blood levels in check. Somehow, this question prompted Sean's head coach to stop practice, place him in the coach's chase boat, and state in front of the entire team that Sean's Diabetes was out of control. Sean was and still is stunned at this statement. Sean knows his body, and he is constantly vigilant regarding his diet and exercise. The Coach and Assistant Coach told Sean and his parents that he was a danger to his team as he could pass out. The District, including the principal and the athletic director, took the coaches side without consulting medical professionals. Despite their prognostications of danger, Sean was allowed to continue racing but was relegated to a junior varsity boat. It was not until the prospect of our agency intervening that the district allowed Sean to return to his varsity position.

Unfortunately, the district failed to protect Sean from his fellow teammates. Sean faced a barrage of questioning from his teammates over his Diabetes. This was a sensitive issue that should have been kept between Sean, the coaches, and his doctors. The students parroted their Coaches statements about his Diabetes being out of control. The Principal of the high school told Sean and his family that he had talked to the boys and that it would stop. However, it did not. At the team banquet, in front of Sean's family, Sean's team presented him with a shirt that read "Hello, My Name is Sean and I have a glucose problem". Sean was completely embarrassed. Adding insult to injury, the coaches sat and laughed with the team.

In response to this episode, the Office of Protection and Advocacy has filed a complaint with the Office for Civil Rights. The District discriminated against Sean when it barred and ultimately demoted Sean from his varsity position due to his Diabetes. It also encouraged a hostile environment towards individuals with disabilities by appearing to encourage teasing and name calling. Extra-curricular activities such as sports are crucial to development and participation of individuals with disabilities in their communities. Restricting one's right to participate with non-disabled peers based generalizations and stereotypes cannot stand. This matter is still ongoing, and Sean looks forward to vindication of his rights.

### **Connecticut's 2020 Campaign**

Connecticut currently maintains six state institutions, Southbury Training School and five Regional Centers, where approximately 500 individuals with intellectual disabilities reside. The state of Connecticut through the Department of Developmental Services (DDS) chooses to maintain these six segregated institutions, even though in 1999, the United States Supreme Court, in the Olmstead v. L.C. decision, ruled that segregated institutions violate the Constitutional rights of individuals with disabilities to live in the community as fully participating members of society. State-operated institutions cannot be justified morally or legally. There are 15 states that no longer have institutions and people with the same type and severity of disability as those in Connecticut's institutions, live in community. Until the political will in Connecticut changes to come in line with current societal norms, people with disabilities will be subjected to institutional segregation rather than being valued members of their communities.

In December 2014, P&A, as part of the Developmental Disabilities Network and the ARC Connecticut launched the 2020 campaign focused on closing Southbury Training School and

the Regional Centers by June 30, 2020. The Campaign 2020 organizations looked at the closures as a civil rights issue and a method of producing cost savings that could be used to fund services and supports for people with intellectual disability currently on a waiting list for services. During 2015, the Campaign held many strategy sessions, contracted with a national expert to add the national perspective, met with private providers, and testified before Connecticut's ID/DD Caucus in support of the closure of the institutions on RB 1088, An Act Concerning Services for Individuals with Intellectual Disability. The bill would have required the Department of Developmental Services to submit a plan for the closure of Southbury Training School. The campaign also educated policymakers about the civil rights of people with disabilities, national standards of community placement for people with disabilities, cost savings and improved quality of life when people with disabilities move into the community. Materials addressing myths about the negative effects of community placement were distributed. Information was also distributed to parents and other organizations. The Hartford Courant ran a series of articles and editorials about the issue, exposing the costs of the institution living and the issues with the waiting list.

The 2020 Campaign invested a lot of time and energy during the 2015 fiscal year. The same level of commitment will continue into the 2016 fiscal year as the focus is and should be closing Connecticut's remaining institutions.



## *Department of Children and Families*

*Commissioner's Office*

*505 Hudson Street*

*Hartford, CT 06106*

<http://www.ct.gov/dcf>

Highlighted below are a number of the DCF funded behavioral health and family support services, many of which do not require DCF involvement in order to access. The information or link below each service includes information about how to access the service (contact information which, for some, is based on where a family lives); many of the websites have brochures and/or descriptions and more specific details about that service.

1. Psychiatric Outpatient Clinics for Children - psychiatric and psychosocial assessments, evaluations/medication management and clinical treatment through individual, family and group therapies.

[http://www.dir.ct.gov/dcf/Licensed\\_Facilities/listing\\_OPCC.asp](http://www.dir.ct.gov/dcf/Licensed_Facilities/listing_OPCC.asp)

2. Emergency Mobile Psychiatric Services (EMPS) - 24 hour crisis intervention service for children and families; most children are seen in their home, at school or in the community. EMPS contracts have recently been amended to increase staffing that supports increased volume and additional hours of mobility.

*A family can access this service by calling 211*

<http://www.empsct.org>

3. Adolescent substance use outpatient treatment – screening/evaluation, individual group and family therapeutic interventions in both clinic-based settings and in home depending on the service type. DCF offers multiple evidence based treatment models including: Adolescent Community Reinforcement Approach-Assertive Continuing Care (ACRA-ACC); the link below is for a brochure regarding substance use/abuse services for youth in Connecticut.

[http://www.ct.gov/dcf/lib/dcf/substance\\_abuse/pdf/CTConnection\\_Broch\\_WEB.pdf](http://www.ct.gov/dcf/lib/dcf/substance_abuse/pdf/CTConnection_Broch_WEB.pdf)

4. Intensive In-Home Child and Adolescent Psychiatric Services (IICAPS) - a 6-month home based intervention addressing psychiatric disorders of the child, parenting issues and other family challenges that affect the child and family's ability to function. A team of caregivers provides an average of 4-6 hours per week of intervention with the child and caregivers to prevent hospitalization or to return the child to community-based outpatient care. Look under Intensive Home Based Services at the link below.

[http://www.ct.gov/dcf/cwp/view.asp?a=2558&q=314366#Intensive\\_In-Home\\_Child\\_and\\_Adolescent\\_Psychiatric\\_Services\\_\(IICAPS\)](http://www.ct.gov/dcf/cwp/view.asp?a=2558&q=314366#Intensive_In-Home_Child_and_Adolescent_Psychiatric_Services_(IICAPS))

5. Extended Day Treatment - a multi-disciplinary team of clinicians at 19 program sites deliver behavioral health treatment through individual/family/group therapies, therapeutic recreation and rehabilitative support services; the treatment is provided for a minimum of 3 hours per day and 5 days per week.

<http://www.ct.gov/dcf/cwp/view.asp?a=2558&q=314356>

6. Evidence based in-home models (such as Multi-systemic Therapy [MST] or Multi-dimensional Family Therapy [MDFT] or Functional Family Therapy [FFT], etc.) for a number of special populations.

[http://www.ct.gov/dcf/cwp/view.asp?a=2558&Q=314366#Multisystemic\\_Therapy\\_\(MST\)](http://www.ct.gov/dcf/cwp/view.asp?a=2558&Q=314366#Multisystemic_Therapy_(MST))

7. Trauma Focused Cognitive Behavioral Therapy – specialized treatment for children who have experienced trauma, are having a significant reaction to the event and will benefit from professional intervention; this is provided in community based outpatient settings.  
(See list of TF-CBT Providers)

[http://www.ct.gov/dcf/lib/dcf/behavioral\\_health/pdf/tf-cbt\\_referrals\\_at\\_opccs.pdf](http://www.ct.gov/dcf/lib/dcf/behavioral_health/pdf/tf-cbt_referrals_at_opccs.pdf)

8. Cognitive Behavioral Intervention for Trauma in Schools (CBITS) – DCF is supporting the implementation of CBITS in four school districts; CBITS is an evidenced based treatment model for children suffering from post-traumatic stress symptoms as a result of trauma experiences in their lives. CBITS includes a screening process and treatment to reduce PTSD symptoms including anxiety, depression, low self-esteem, behavioral problems and impulsive behaviors. CBITS builds student resiliency, peer and family support.

<http://www.chdi.org/our-work/mental-health/evidence-based-practices/c-bits/>

9. Care Coordination – uses an evidence-based child and family wrap-around team meeting process to develop a plan of care including the formal and informal network of care to meet the identified needs of the child and family; the first link below provides information about Local System of Care Collaboratives which offer care coordination for families with children who have behavioral health needs.

Care Coordination also provides "wraparound services" defined as an intensive, individualized care planning and case management process for youth with serious or complex needs to help keep these youth in their home, school and community. DCF has a special wraparound project in six New Haven schools for children age 5 through 18 who have complex behavioral health needs, require intensive coordination and multiple services, and who are at risk to be, or have already been, separated from their family and/or community (i.e. residential or hospital level care). The second link describes this initiative.

<http://www.ct.gov/dcf/cwp/view.asp?A=2558&Q=314350>

<http://www.cliffordbeers.org/new-haven-trauma-coalition-2/>

10. Respite Care - a non-clinical intervention that provides stress relief to parents with children ages 4-17 who have serious behavioral health needs and can be provided in the community for up to 4 hours per day for 12 weeks; access to Respite Care is possible through the Local System of Care and information can be found through these links.

<http://www.ct.gov/dcf/cwp/view.asp?a=2558&Q=314372>

<http://www.wrapct.org/Collaboratives.aspx>

11. Voluntary Services Program (VSP) – a voluntary, non-emergency program for children and youth with serious mental illnesses and/or substance dependence; if accepted to the Voluntary

Services the family will have an open Voluntary DCF case; to apply for VSP, a parent/guardian must call **DCF's Careline at 1-800-842-2288; for more information see the link below.**

<http://www.ct.gov/dcf/cwp/view.asp?a=2558&Q=314906>

12. Community Family Advocates – advocates provide support and assistance to the parent/caregiver of a child with serious mental health or behavioral health needs; the family advocate works with the Care Coordinator (above) as part of the team.

<http://favor-ct.org/>

13. Integrated Family Violence Program – DCF has implemented a new service to meet the unique needs of DCF involved families impacted by intimate partner violence (also known as Domestic Violence). The service is called “Intimate Partner Violence – Family Assessment Intervention Response (IPV-FAIR).” It offers a full array of clinical services as well as linkages and referrals to existing community based services.

For more information and referrals to other community resources, contact 211 or follow the link below.

<http://www.ct.gov/dcf/cwp/view.asp?a=4486&Q=572342>

14. ACCESS Mental Health CT – DCF has implemented a program designed to ensure that all youth under 19 years of age have access to psychiatric and behavioral health services through contact with their primary care providers (PCP) regardless of insurance coverage. The program is designed to support primary care physicians by offering telephonic consultation from a psychiatric hub that includes; education on assessment, treatment, and access to community resources for youth with mental health needs.

<http://www.accessmhct.com/>

15. Care Management Entity (CME) – The CME is a model supported by DCF and implemented at the Behavioral Health Partnership (Beacon Health Options - previously Value Options) which is designed to target youth who are in congregate care settings and support their re-integration to home and community settings with appropriate services and supports. The CME also focuses on youth who are frequent utilizers of the emergency room regardless of system involvement or insurance type. This is a team-based model with regional staffing which includes a Network of Care Manager, Intensive Care Coordinator, and Family Peer Support Specialist. The staffing and service delivery model of the CME is influenced strongly by Wraparound philosophy, values, and principles.

<http://www.chdi.org/index.php/publications/issue-briefs/issue-brief-42>

16. Child FIRST (Child and Family Interagency Resource, Support, and Training) – this is an evidence based model designed to decrease social-emotional, behavioral problems, developmental and learning problems, and abuse and neglect among high-risk young children. This service utilizes home-based assessment, family plan development, parent-child therapeutic interventions, education and care coordination/case management for high risk families and children under six years of age (including pregnant women). Services are available across the state from 15 different provider agencies. It does not require involvement with DCF to access this service.

<http://www.childfirst.com/>

17. Modular Approach to Therapy for Children with Anxiety, Depression, Trauma or Conduct problems (MATCH-ADTC) – is an evidence based treatment designed for children ages 7-15. It is different from other outpatient treatment models in that it is designed to treat multiple disorders including anxiety, depression and trauma and conduct disorder. MATCH is composed of different modules which can be organized and sequenced flexibly to tailor treatment to each child's mental health needs and has a data monitoring module which provides feedback to the clinician.

<http://www.chdi.org/our-work/mental-health/evidence-based-practices/match/>

DCF supports and collaborates with various stakeholders around a number of prevention activities. Some of these are specific to DCF-involved families but many are community based initiatives including but not limited to the areas of: health and wellness, safety, early childhood development, education, suicide prevention, positive youth development, parents with cognitive limitations, supportive housing and homelessness, among others. Some helpful websites are included below:

[http://www.ctparenting.com/healthandsafety\\_overview.php](http://www.ctparenting.com/healthandsafety_overview.php)

[http://www.ct.gov/dcf/lib/dcf/prevention/pdf/ysab\\_brochure2010.pdf](http://www.ct.gov/dcf/lib/dcf/prevention/pdf/ysab_brochure2010.pdf)

### Current Initiatives at DCF

Public Act 13-178 directed DCF to produce a children's behavioral health plan for the state of Connecticut. The Act required the plan to be comprehensive and integrated and meet the behavioral and mental health needs of all children in the state and to prevent or reduce the long-term negative impact for children of mental, emotional, and behavioral health issues. The Executive Summary and final plan can be found at the first link below. The second link will take the reader to the PA 13-178 section on the DCF website which has the actual legislation and related materials. The third link is the progress update submitted to the Connecticut General Assembly on October 1, 2015.

[http://www.plan4children.org/wp-content/uploads/2014/10/CBH\\_PLAN\\_FINAL-2.pdf](http://www.plan4children.org/wp-content/uploads/2014/10/CBH_PLAN_FINAL-2.pdf)

<http://www.ct.gov/dcf/cwp/view.asp?a=2534&Q=530638>

<http://www.plan4children.org/wp-content/uploads/2015/04/October-2015-PA-13-178-Progress-Report.pdf>

DCF has prepared a Child and Family Service Plan (CFSP) for the years 2015 -2019 which can be found at the link below. This report is done for the Administration for Children and Families of the United States Department of Health and Human Services. The focus is primarily on DCF's child welfare activities and offers an assessment of DCF performance and outlines future plans and goals to improve performance.

[http://www.ct.gov/dcf/lib/dcf/agency/pdf/connecticut\\_2015-2019\\_cfsp\\_revised\\_oct\\_2014.pdf](http://www.ct.gov/dcf/lib/dcf/agency/pdf/connecticut_2015-2019_cfsp_revised_oct_2014.pdf)

In 2012, DCF implemented a Differential Response System (DRS). This includes the addition of a Family Assessment Response (FAR) track and the development of the Community Support for Families (CSF) program. FAR and CSF are part of an integrated process to DCF's approach to working with and supporting families. The University of Connecticut School of Social Work partners with DCF in evaluating the CSF programs and more recently analyzing

data specific to all family assessment response cases. This link provides additional information on CT's Differential Response System and UCONN's August 2015 report.

<http://www.ct.gov/dcf/cwp/view.asp?a=3741&Q=439746>

The Connecticut Department of Children and Families (DCF) has statutory responsibility for prevention, child welfare, children's mental health and juvenile justice. As such, the state's service array includes a full continuum of programs including child abuse and neglect prevention, behavioral health treatment services, foster care, family preservation services, reunification support services, independent living, services to support other permanent living arrangements and a continuum of congregate care settings. These include:

<b>Prevention</b>	<b>Treatment</b>		<b>Aftercare</b>
Prevention Early Intervention Diversion	Community Based Treatment Foster care Out of home treatment Inpatient Treatment		Transition Aftercare Life Skills Vocational support
Early Childhood Services	Care Coordination	Extended Day Treatment	Community Based Life Skills
High-Risk Infant Program	Care Giver Support Teams	Therapeutic Foster Care	Work/Learn Youth Program
Juvenile Criminal Diversion	Child First Early Childhood Services	Family Based Recovery (FBR)	SWETP
Mental Health Consultation to Childcare	Crisis Stabilization	Multisystemic Therapy (MST)	Supportive Housing for Families
Parent Project	EMPS-Crisis Intervention Service	Multisystemic Therapy for Transition Aged Youth (TAY)	PASS Group Homes
Outpatient Clinics for Children	Family Advocacy	Multisystemic Therapy- Family Integrated Transitions (FIT)	Start Programs (homeless youth)
Cognitive Behavioral Intervention for Trauma in Schools (CBITS)	Family and Community Ties Foster Care	Reentry and Family Treatment (RAFT)	
	Positive Parenting Program (Triple P)	MST- Building Stronger Families (BSF)	
	Reunification and Therapeutic Family	MST- Problem Sexual Behavior	

<b>Prevention</b> Prevention Early Intervention Diversion	<b>Treatment</b> Community Based Treatment Foster care Out of home treatment Inpatient Treatment		<b>Aftercare</b> Transition Aftercare Life Skills Vocational support
	Time	(PSB)	
	Foster Care Clinics	Therapeutic Group Homes	
	Foster Parent Support for Medically Complex	Short Term Assessment and Respite Homes	
	IPV-FAIR	IICAPS	
	Outpatient Clinics for Children	Juvenile Justice Intermediate Evaluations	
	Intensive Family Preservation	Juvenile Sexual Treatment	
	Functional Family Therapy (FFT)	Multi-Dimensional Treatment Foster Care	
	Multidimensional Family Therapy (MDFT)	Solnit Children's Psychiatric Center	
	Permanency Placement Service for Children	Residential Treatment Centers	
	Adolescent Community Reinforcement Approach	Short Term Family Integrated Treatment (SFIT)	
	Care Management Entity	Fostering Responsibility, Education and Employment (FREE)	
	One on One Mentoring		



## *Connecticut Department of Social Services*

*55 Farmington Avenue*

*Hartford, CT 06105*

*<http://www.ct.gov/dss>*

The Department of Social Services' very broad mandate has resulted in the creation and provision of a range of programs and services for residents of Connecticut. The programs and services respond to a broad spectrum of health and human service needs including physical and mental health, food and nutrition, violence prevention and protection, health promotion, financial assistance, family and child support, health insurance, etc.

DSS is the lead agency for persons with disabilities; it administers the TANF, Medicaid, SNAP, Child Support, the Community Services Block grant, and other Federal/State programs.

In the areas of interest and of import to the Family Support Council, DSS is especially responsive. As the Medicaid agency, DSS provides to persons with disabilities and special health care needs: access to personal care assistance/assistants, hospitalization, durable medical equipment, medical supplies, rehabilitation services, orthotics and prosthetics, dental care, radiology, behavioral health services, dialysis, physician services, in home- care/ home care services, personal assistance, transportation, etc.

In general, many families and children with special health care needs and disabilities are aware of Medicaid funded services provided by DSS, including the Medicaid Waivers. Therefore, this year's report to the FSC will present programs and services that support families and children with disabilities and special health care needs that are not usually viewed as linked or connected to disabilities and special health care needs.

### ***I. Supplemental Nutrition Assistance Program (SNAP)***

Children with special health care needs and/or disabilities can have a negative impact on family income and family dynamics. Often, the mother, who tends to be the primary caregiver, must make changes to her employment situation, if she is employed. She will often end her employment or work part-time. Either response can create an economic hardship for many families. SNAP or the Supplemental Nutrition Assistance Program provides families, who are eligible, access to nutrition. In addition, SNAP benefits have been credited with reducing food insecurity for many families.

In Connecticut, as of February 7, 2016, 238,306 households comprised of 422,071 individuals were SNAP program participants. According to the SNAP Division at DSS, 152,905 of these were children under the age of 18.

Income eligibility for SNAP program participation is based on the *Federal Poverty Level (FPL)*. For example, in October, 2014, a family of four could have a monthly income up to \$3678.00 (*185% of FPL*) and qualify for SNAP benefits amounting to a maximum of \$649.00 per month.

Information about this program can be accessed at: [www.ct.gov/dss](http://www.ct.gov/dss) once on the DSS website, scroll down to SNAP, click on SNAP.

## **II. Child Support**

The Bureau of Child Support Enforcement is administered by the Department of Social Services in partnership with the Office of the Attorney General and the CT Judicial Branch. The Program aims to ensure economic security/stability for families, including financial and medical supports, and to establish paternity for children born out of wedlock.

Depending on the type of special need or disability, families with children with special health care needs tend to have higher divorce rates [Marshak, Reichman, et.al, Journal of the New York Bar Ass., etc.] Moreover, in the aftermath of a divorce, issues related to the financial health and well-being of the child or children may surface. The Child Support Division assists with addressing and reconciling these issues. In addition, while establishing paternity for children born to unwed mothers is incepted in hospitals located in the state, those that cannot be completed while the child and mother are in the hospital, can be completed at one of the DSS offices by a Child Support staff person assigned that responsibility. Information about the Bureau of Child Support Enforcement can be found at: [www.ct.gov/dss](http://www.ct.gov/dss); once on the DSS website, scroll down to Bureau of Child Support Enforcement and click on that program.

## **III. Medicaid, HUSKY, and the Affordable Care Act**

Following passage of the Affordable Care Act, the State elected to expand Medicaid coverage. Implementation of the act employed a “no wrong door” policy; applications for health insurance can be made through Access Health CT and/or DSS. As a result of the comprehensive health care reform ushered in by the ACA, insured individuals are assured:

- No co-pay and deductibles for preventive care and immunizations;
- No-pre-existing condition limitations;
- No gender based premiums; and
- No lifetime dollar limits on essential health benefits.

Within the Medicaid service units at DSS, the public health insurance programs impacted by the Medicaid expansion were: HUSKY A, HUSKY B (CHIP), and HUSKY D. Eligibility for these programs is based on Modified Adjusted Gross Income (MAGI) which determines how income is counted and how household size is determined. In addition, the ACA resulted in Presumptive Eligibility being expanded to all categories that are eligible for MAGI eligibility methodology. The Medicaid expansion also resulted in new income limits which increased the number of incomes eligible for participation. However, the following groups were not impacted by the Affordable Care Act: Adult Medicaid (S Track), Long –Term Care, Community Based Waivers, and people eligible for the Medicare Buy-in.

Applications for health insurance can be made: on-line, paper, by telephone, and in-person. Paper, in-person, and telephone applications require data entry into the new AHCT “Integrated Eligibility System.” To apply for Medicaid/HUSKY Health:

- Call 1 -877-CT-HUSKY
- Download an application at: [www.huskyhealth.com](http://www.huskyhealth.com) or [www.connect.ct.gov](http://www.connect.ct.gov)
- Apply in person at one of the 12 DSS offices – [www.ct.gov/dss](http://www.ct.gov/dss)
- Apply through Access Health CT: [www.accesshealth.com](http://www.accesshealth.com)



## *CT Department of Public Health*

*410 Capitol Avenue*

*Hartford, CT 06134*

*<http://www.ct.gov/dph>*

### **1. Connecticut Medical Home Initiative for Children and Youth with Special Health Care Needs (CMHI) 5 centers statewide**

Children and youth age 0 to 21 who have or are at risk for a chronic physical, developmental, behavioral or emotional condition and require health and related services in a type and amount beyond that by children generally. Care coordination, respite and extended service funds, family support. <http://www.ct.gov/dph/site/default.asp>

### **2. Newborn Screening Programs**

The Connecticut Early Hearing Detection and Intervention program strives to ensure that all babies receive the appropriate hearing screenings at birth and babies who are identified as having a hearing loss are enrolled into an Early Intervention program. Connecticut State Law mandates that all newborns delivered in Connecticut be screened for selected genetic and metabolic disorders. <http://www.ct.gov/dph/site/default.asp>

### **3. WIC- Woman, Infants, and children**

Woman Infant and Children Special Supplemental Nutrition Program provide healthcare referrals, nutrition education, breastfeeding promotion and support, and supplemental foods. <http://www.ct.gov/dph/site/default.asp>

### **4. School Based Health Centers**

School Based Health Centers help to provide quality health care for children and adolescents in Connecticut schools. There are more than 84 School Based Health Centers in the state and the centers

have become part of the essential system of care for children and adolescents, providing physical, mental health, and oral health services to over 44,000 students in 23 communities annually. <https://www.ctschoolhealth.org>

### **5. Child Development Infoline**

CDI serves as the single point of entry into CT's early intervention program, Birth to Three, as well as serving as an access point for Early Childhood Special Ed, Children and Youth with Special Health Care Needs (CYSHCN) and Help Me Grow. They provide information, referrals and care coordination for families and connect them to support services which include the Medical Home Initiative sites, Family Support Network and CT Medical Home Initiative at FAVOR. They connect families to specific services, advocacy, diagnostics, trainings, support groups and websites. CDI assesses families' needs and helps them think about additional services they may need. <http://cdi.211ct.org>

## **6. CT Family Support Network**

The CTFSN exists to help families raising children with disabilities and special health care needs, services are free. Family support services include direct 1:1 support, information about the child's disability, a connection to state and local resources, IFSP/PPT guidance, support groups, email distribution lists, training opportunities throughout the year, and an annual conference. Additionally, CTFSN offers a valuable connection to a Parent Mentor who can share experiences, provide emotional support, critical resources and assistance to learning to navigate the state systems, make community connections and network with other families. CTFSN has a diverse staff, including Bi-Lingual family support, and are available in six regions across the state. [www.ctfsn.org](http://www.ctfsn.org)

## **7. CT Hands & Voices & Guide By Your Side (GBYS)™**

Connecticut Hands & Voices is dedicated to supporting families with children who are Deaf or Hard of Hearing without a bias around communication modes or methodology. CT Hands & Voices is a parent-driven, non-profit organization providing families with the resources, networks, and information to improve communication access and educational outcomes for their children. Guide By Your Side (GBYS)™ is a program from Hands & Voices (H&V) that provides emotional support and unbiased information from trained Parent Guides to other families and to the systems that serve them. Outreach activities, parent/professional collaboration, and advocacy are focused on empowering children who are Deaf and Hard of Hearing to reach their highest potential. [www.handsandvoices.org](http://www.handsandvoices.org)

## **8. Parents Available To Help, Parent-to-Parent & Family Voices of CT**

PATH is a network of families providing informational and emotional support to others who have developmental or health related needs. The Family Voices program aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. PATH and Family Voices provide one-to-one parent support with a "veteran parent" who has been through similar experiences and understands what the family is going through. PATH/FV also assists families with information about developmental and health related issues, information about healthcare, provide resources, resources on support groups, specialty doctors, therapy services, hairdressers to name a few. Some calls are associated with providing information on insurance coverage for all children and youth with special healthcare needs. [www.pathct.org](http://www.pathct.org)

## **9. CT Autism Action Coalition**

A coalition of stakeholders who provide a unified voice for all individuals who are affected by Autism Spectrum Disorders and assist in the development and improvement of quality service. Members share relevant information including training, events, conferences, proposals, and financial resources. Active members agree on two to three projects on which to focus. Members agree to widely distribute information as requested by CAAC members, to list serves, websites, or other communication source.

#### **10. CT Medical Home Initiative at FAVOR**

The Connecticut Medical Home Initiative at FAVOR is responsible for processing all requests for Extend Service Funds and Respite Funding. Families are identified at outreach events attended around the state, workshops, phone calls and word of mouth. Bilingual staff is available both on the phone, and for face to face meetings in our office. Staff is available to help families set up Directions Resources for Your child's Care Notebooks. A lending library is available for parents. [http://www.favor-ct.org/ct\\_med\\_home\\_initiative\\_at\\_favor.cfm](http://www.favor-ct.org/ct_med_home_initiative_at_favor.cfm)

#### **11. FAVOR, Inc.**

FAVOR is a non-profit Statewide Family Advocacy Organization serving families, children and youth dealing with a broad spectrum of behavioral and mental health needs, by providing policy and family advocacy. FAVOR is committed to improving the quality of life for children, youth and families in Connecticut by increasing accessibility to effective, culturally competent and high quality family-driven mental and behavioral health services and supports. Through member organizations, FAVOR encourages family participation in policy development and the legislative process. FAVOR offers training, technical assistance and support to parents and caregivers in local communities to assist them in becoming active and equal partners in the System of Care. [www.favor-ct.org/advocacy.cfm](http://www.favor-ct.org/advocacy.cfm)

#### **12. A J. Pappanikou Center for Excellence in Developmental Disabilities**

The Center is one of a national network of University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) authorized by the federal Developmental Disabilities Assistance and Bill of Rights Act and funded through the Administration on Developmental Disabilities. UCEDD Mission is to work collaboratively to promote advocacy, capacity building and systems change to improve the quality of life for persons with disabilities and their families. [www.uconnued.org](http://www.uconnued.org)

#### **13. Autism Services and Resources CT (ASRC)**

ASRC provides information and referral for parents, families, caregivers and professionals working with people with Autism Spectrum Disorders. ASRC offers training and education for families, caregivers and other professionals and the general community along with training and social activities for persons on the spectrum. Resources in the community include support groups, social groups, trained workforce providers, job creation, and community activities. ASRC advocates for persons on the spectrum and their families at the state and local level and the create resources in the community to serve families. [www.ct-asrc.org](http://www.ct-asrc.org)

#### **14. Southern CT State University (SCSU) Center of Excellence in Autism Spectrum Disorders**

The Center of Excellence is a resource center for teachers, school-based personnel, parents and community providers serving individuals with ASD. The Center of Excellence on Autism Spectrum Disorders consists of three divisions: Training, Research, and Outreach. These divisions collaborate to provide professional development training opportunities, facilitate innovative research, assist in establishing effective evidence-based practices, and deliver technical assistance to teachers, other school based personnel, families and community service providers. The goal is to improve student outcomes for individuals with ASD. [www.southernct.edu/asd](http://www.southernct.edu/asd)

### **15. Focus Center for Autism**

The Focus Center for Autism assists children, adolescents and young adults with ASD's reach their full potential by providing clinical programs, community education and family support. The goal is for the children, adolescents and young adults to be able to develop a greater sense of self-awareness, to learn to grow both socially and emotionally and to begin to understand who they are and how they "fit" into their world. Social learning is the backbone of all our programs and we do this through a unique treatment model called Milieu Therapy. [www.focuscenterforautism.org](http://www.focuscenterforautism.org)

### **16. The Connections Program for Children with ASD, Charlotte Hungerford**

The Connections Program provides information and referral for parents, families, caregivers and professionals working with people on the spectrum. They provide training and education for families, caregivers and other professionals and the general community and training and social activities for persons on the spectrum. The Connection's Program creates resources in the community including support groups, social groups, trained workforce providers, job creation, and community activities. The Program advocates for persons on the spectrum and their families at the state and local level and creates resources in the community to serve families. [www.charlottehungerford.org](http://www.charlottehungerford.org)

### **17. CT Parent Advocacy Center**

Connecticut Parent Advocacy Center, Inc. (CPAC) is a statewide organization that offers information and support to families of children with any disability or chronic illness, age birth through 26. The Center is committed to the idea that parents can be the most effective advocates for their children, given the confidence that knowledge and understanding of special education law and its procedures can bring. CPAC is staffed by parents of children with disabilities who have training in, and personal experience with, the law and disability issues. CPAC staff conducts workshops for parents as well as in-service presentations for schools, teachers-in-training and service providers throughout the state so that they may better understand and serve the parents with whom they work. Staff and Board members serve on numerous statewide committees and various organizations, representing issues that are of concern to parents and families in Connecticut. [www.cpacinc.org](http://www.cpacinc.org)

## **Reports**

Healthy Connecticut 2020 – The [Connecticut State Health Assessment](#) helped establish the health status of the state and [Connecticut State Health Improvement Plan](#) a roadmap for improving the state's health and ensuring that all people in Connecticut have the opportunity to attain their highest potential for health. The work behind these two efforts comprise our state health planning initiative, Healthy Connecticut 2020, a blueprint for improving the health of Connecticut residents by the end of 2020.

<http://www.ct.gov/dph/cwp/view.asp?a=3130&q=509550>

Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010

[http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s\\_cid=ss6302a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w)



## *Office of the Healthcare Advocate*

*P.O. Box 1543*

*Hartford, CT 06114*

*<http://www.ct.gov/oha>*

The Office of the Healthcare Advocate (OHA) is an independent state agency that provides advocacy services for Connecticut healthcare consumers, providing assistance for Connecticut consumers enrolled in all types of health coverage, including private and public plans. OHA is not a health plan, but an advocate for you. We hold health plans accountable, and help you successfully resolve your healthcare issues. OHA's mission includes three primary areas - educating consumers about their rights and how to advocate on their own behalf when they have a problem or concern about their healthcare plan, working with or on the behalf of consumers to investigate and appeal denials of service, and providing policy-makers with information about the consumer's experience to better inform needed change.

We have worked with tens of thousands of consumers to explain their rights and the responsibilities of their health plans, and to advocate for patients when they are denied coverage for treatment or denied reimbursement by their health plans. We can answer questions and assist consumers in understanding and exercising their rights to appeal a managed care plan's denial of a benefit or service, and through this work, OHA has saved the consumers of Connecticut over \$60 million since the office opened in 2001.

### ❖ **Have you ever .....**

- Spent hours on the phone with your health insurance company trying to resolve a problem?
- Been denied a service or treatment you thought was covered?
- Felt overwhelmed by medical bills?
- Lost your job and wanted to understand your healthcare options?
- Had trouble finding a provider to take your insurance?

OHA helps you find the answers when you need it most.

### ❖ **Get the Most Out of Your Healthcare Plan: Know your rights.**

Under Connecticut law, you have rights. Coverage must include:

- Emergency treatment
- Preventive screenings
- Mental health coverage
- And more

Under federal law, you may also have rights under HIPAA, Mental Health Parity, Equity and Addiction Act, COBRA and the Affordable Care Act.

We help you understand all aspects of your insurance coverage, referrals, and Explanations of Benefits (EOBs).

### ❖ **Know your options**

Choosing the right health plan for you and your family is an important decision.

Before you buy health insurance or pick a plan, you should understand:

- What the insurance policy covers
- How much it covers and how much you may have to pay out of pocket
- Whether you will have access to your current doctors
- Whether access to other providers you may need is enough

We help you understand what your choices are and help you compare health plans and their services, provider networks (doctors, specialists, Hospitals, pharmacies that the plan works with) and costs.

### ❖ **Get the Most Out of Your Healthcare Dollars: You will Save Time**

We know the healthcare industry, including state and federal laws and regulations. We have the expertise and experience to help resolve your issue.

We will:

- **Listen** to you
- **Research** the issue
- **Determine** what course of action is best
- **Guide** and assist you directly through the process until it is resolved

### ❖ **You May Save Money**

You are entitled to benefits and other services you may not know about or think you are entitled to.

We know:

- What you are entitled to under your plan
- How to identify billing and claim processing errors
- Successful ways to appeal a claim denial based on medical necessity or other reasons
- Ways to resolve an issue before it becomes an expensive problem
- How to recover expenses that you may have paid but did not owe

### **Did you know?**

- To date, OHA has recovered over \$60 million for CT healthcare consumers.
- OHA has an 85% success rate in overturning insurers' denials of health insurance coverage.

### **Our services are free of charge**

Call us with any problem or question related to your health insurance plan or your doctor/healthcare provider. No matter what type of insurance you have, you can use our services.

### **We are on your side**

We do not quit on any case until we have explored every possible solution.

## **Protect Your Rights: You Have The Right To Complain or Appeal**

- When an insurance plan will not pay for a treatment or service, you can ask the plan to change (appeal) its decision
- Your plan must explain how to appeal when it tells you that it will not pay or cover a service
- When you appeal your plan must give its decision within:
  - 72 hours for denials of urgent care (24 hours in some cases).
  - 30 days for denials of non-urgent care you have not yet received.
  - 60 days for denials of service you have already received.
  - If the plan still denies your benefit, it must explain why and tell you how to ask for an outside review (external review).
  - If you do not speak English, you may be able to get appeal information in your native language.
  - We will help you file your complaint and see you through the appeals process, including review from an independent third party.

### **How To Complain or Appeal**

#### **1. Call Member Services—Toll Free Number is on your Health Plan's Card.**

- Ask for a complaint or grievance form or in some cases you may file a complaint over the phone
- Ask your plan to send you a copy of the denial letter
- Check your plan benefits to make sure that you are being denied a service that is covered by your plan. If you don't have this list of benefits, ask your member services to send you one.

#### **2. Get Information**

- Talk with your doctor. Ask for a letter from your doctor stating why you need the service or treatment or why you were given that service or treatment.
- Ask for a copy of any letters that the doctor sent to the health plan for your case.

#### **3. Write Your Complaint or Appeal**

Your letter must have:

- Your plan identification numbers (policy number, group number, claim number)
- The reason for the denial that they explained in the denial letter
- A brief history of the illness and necessary treatment
- Why you believe the decision was wrong
- What you are asking the managed care plan to do

#### **4. What To Do Next**

- You will be told in writing of the health plan's decision, why they made that decision and what to do next.
- If your complaint or appeal has been denied, you need a copy of the second denial letter. This letter will tell you how to appeal on the next level. You may have to send new information with this second appeal that talks about the current reason for the denial.

## 5. External or Outside Appeals

If you have gone through all level of the inside appeals in your health plan, you may be able to file an appeal with the CT Department of Insurance or as arranged by your health plan.

- You must file an external appeal within 120 days of getting written notice from your health plan that you have used all of their internal appeals.

For Help Call the Office of the Healthcare Advocate today: **1-866-466-4446**

- OHA business hours are 8:00am – 5:00pm EST.
- Leave a message after hours and your call will be returned promptly
- Visit [www.ct.gov/oha](http://www.ct.gov/oha) to get information and answers to your questions
- Interpretive services are available

For more information about OHA and our Annual Reports, Fiscal Year Reports, Newsletters, and Brochures in 22 different languages go to:

<http://www.ct.gov/oha/cwp/view.asp?a=4363&q=520922>

For more information about OHA's Legislative Advocacy please go to:

<http://www.ct.gov/oha/cwp/view.asp?a=4363&Q=528798>



## *Department of Developmental Services*

*460 Capitol Avenue*

*Hartford, CT 06106*

<http://www.ct.gov/dds>

### **Background:**

The Department of Developmental Services (DDS) <http://www.ct.gov/dds/site/default.asp?ddssiNav=> has a long history in the State of Connecticut. As early as 1917, services for individuals with an Intellectual Disability were largely provided at the Mansfield Training School until 1940, when the Southbury Training School was opened. Eventually these facilities, along with “Regional Centers” established in the 1960’s, were overseen by what was then called “the Office of Mental Retardation”, a division of the State Department of Health.

In 1975 the Connecticut General Assembly established an independent Department of Mental Retardation (P.A. No. 75-638). The department has been a department in the executive branch, headed by a Commissioner appointed by the Governor, since that time. Although DDS continues to directly operate both congregate and community-based services and supports, the department's focus has largely become community-based relying upon a public/private partnership. The result is a statewide system which provides support and services to persons with intellectual disabilities who reside in family homes, independently, in state-operated facilities, in licensed "community training homes" and in over 870 licensed/certified "community living arrangements." Since 1987, most services and supports provided by DDS have been subject to federal reimbursement under Home and Community Based Waivers (Medicaid) which are approved by the Center for Medicaid and Medicare Services (CMS).

The Division of Autism Spectrum Disorder Services was started as a small pilot program in 2006. Initially the Division served 52 adults and young adults with ASD who did not have Intellectual Disability. At that time the program was limited to Hartford and New Haven counties. Over time the program has grown to its current statewide service of 103 children and adults with ASD without ID. <http://www.ct.gov/dds/cwp/view.asp?a=2730&q=442840>

In 2007, the department changed its name from the Department of Mental Retardation to the Department of Developmental Services. This change reflects the mission and commitment of the department to serve individuals eligible for services with the utmost respect and dignity. Respect and dignity is further promoted through the use of People First Language. <http://www.disabilityisnatural.com/images/PDF/pfl-sh09.pdf>. In 2105, self-advocates also began a “Call Me By My Name Campaign” requesting that the words handicapped, ward, patient, them, and client no longer be used to describe people with IDD.

**Eligibility:**

Individuals must meet DDS or Autism eligibility requirements to receive waiver services. State funded services may be provided to children under age 8, who have not received an IDD or Autism diagnosis through standardized tests, if it appears eligibility criteria will be met when testing is completed. <http://www.ct.gov/dds/cwp/view.asp?a=2039&q=533014>

**Current Numbers (as of 12/31/2014):**

<b>DDS (MIR Report)</b>	<b>Birth to 3 4,955</b>	<b>Age 0-17 2,474</b>	<b>Age 17-21 1, 610</b>	<b>Over age 21 12, 209</b>	<b>Total 21, 248</b>
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<b>Autism (MIR Report)</b>	<b>Children Waiver=30</b>	<b>Adult Waiver=73</b>
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**DDS Individual and Family Support Helpline**

Each region has established a Helpline to provide assistance to individuals and families who do not have an assigned DDS case manager. The Helplines are available to individuals who:

- Are eligible for services from the DDS and
- Do not have a Case Manager because they are not on fee-for-service Medicaid.

They may have Husky, other managed care or private insurance only. Families may request assistance in completing applications and filing for necessary benefits and entitlements, which may include: Guardianship, Social Security Disability Income, Fee-for-service Medicaid, and other requested assistance. They also provide short term case management in emergency situations and facilitate applications to more intensive DDS services.

<http://www.ct.gov/dds/cwp/view.asp?a=2042&Q=462976>

**Family Respite Services**

DDS recognizes that individuals and families often need occasional breaks. These breaks, in the form of out-of home respite care, allow individuals visiting the respite centers to have an enjoyable time, meet new people and participate in a variety of fun activities. Meanwhile, the family is provided relief from their ongoing caregiver responsibilities. Families report that scheduled respite center visits provide them with an opportunity to have their family members stay in a safe, enjoyable and home-like environment through planned respite. At the same time, the caregiver is able to take a few days off from care giving and perhaps go on a short vacation, attend a special event, spend time with other family members, finally finish a project, or simply relax. <http://www.ct.gov/dds/cwp/view.asp?a=2950&q=332730>

**Individual and Family Grants**

Individual and Family Grants are cash subsidies for the purpose of providing individual and family supports or defraying extraordinary disability-related expenses. Supports that may be purchased with these subsidies include, but are not limited to, respite, in-home supports, behavioral supports, nursing, medical or clinical supports, temporary assistance, crisis support, skill training, family training, recreation, transportation, support coordination, and assistance to access community supports. Families can purchase any items or services that support the family to care for their family member who lives with them. These grants may also be available

to individuals who live on their own with no other DDS in-home supports. The amount of the subsidy that is available to families is determined based on the needs of the individual and his or her caregivers. Grant amounts typically range from \$600 to \$5,000 per year. In extraordinary circumstances with additional approval required, individual and family grant payments per year can reach \$10,000. Families are required to keep copies of receipts so they may be available to DDS upon request. Families should provide information to their case manager regarding purchases made with individual and family grant funds.

<http://www.ct.gov/dds/cwp/view.asp?a=2042&q=391108>

### **Family Support Resource Teams:**

Family Support Staff assist families by providing temporary supports to accommodate both individual and family needs. Services are intended to be for a period of less than 90 days unless there are extenuating circumstances. Services may include supports due to changes in the individual's physical, mental or emotional status. Supports may also be requested for assistance needed in direct relation to caregiver age or ability to provide care for the individual while other permanent supports and services can be coordinated. Not intended for ongoing or routine care needs. Examples of supports can include respite, teaching social skills, activities of daily living (ADL) skills, assistance with medical appointments, facilitating initial access to community resources, modeling behavioral techniques, recreation, or assistance in completing forms for access to ongoing supports and community resources.

<http://www.ct.gov/dds/cwp/view.asp?a=2042&q=391120>

### **Case Management**

The DDS case manager is the primary contact for persons who are eligible for DDS supports and services and have fee-for-service Title XIX (Medicaid). The case manager is the individual who the family or individual contacts with questions and for information. The case manager assists family members in 1) identifying needs through a level of need assessment and planning process, 2) gaining access to supports and services to meet those needs and 3) monitoring progress and evaluating the quality of supports and services. The case manager also maintains the master file which contains the important record of information about each individual on their caseload. The frequency of case manager contact is determined by the type and amount of supports and services each individual receives. At a minimum, your case manager should have at least one visit with your family member annually. The frequency of case manager contact will be specified in your family member's individual plan.

<http://www.ct.gov/dds/cwp/view.asp?a=2042&q=390144>

### **Voluntary Services Program**

The DDS Voluntary Services Program (VSP) supports children who have intellectual disabilities and emotional, behavioral, or mental health needs that result in the functional impairment of the child and substantially interfere with or limit the child's functioning in the family or community activities. Many of the children served in VSP have pervasive developmental disorders such as autism spectrum disorder or significant behavioral health or psychiatric disorders and exhibit extremely challenging behaviors. The services are intended to support families to care for their children within the family home.

<http://www.ct.gov/dds/cwp/view.asp?a=2042&q=391150>

## **Money Follows the Person**

DDS has assisted children to apply for Medicaid and return home to the community. These children were under the Katie Beckett waiver and receiving Helpline case management. They were receiving intensive medical services through their Medicaid eligibility. If the child or young adult is eligible for DDS and meets the criteria for MFP, DDS will assist in moving the individual back into the community. [http://www.ct.gov/dds/lib/dds/aging/mfp\\_update\\_012309.pdf](http://www.ct.gov/dds/lib/dds/aging/mfp_update_012309.pdf)

## **Employment and Day Supports Waiver**

The Employment and Day Supports waiver is designed to support individuals who live with family or in their own homes and have a strong natural support system. This includes children under the age of 21 with complex medical needs who would otherwise require institutional placement and individuals over the age of 18 who require career development, supported employment or community based day supports, respite, and/or behavioral supports to remain in their own or their family home. <http://www.ct.gov/dds/cwp/view.asp?a=4189&q=492514>

## **Self-Directed Services**

Since FY 2000, DDS has offered families who receive funds from the department to choose to use their allocated funding to hire and manage their own staff to provide in-home supports. <http://www.ct.gov/dds/cwp/view.asp?a=2050&q=391098>

## **Autism Services**

The DDS Autism Division is designed to serve individuals with ASD who do not have Intellectual Disability. Eligibility for the Division of Autism Spectrum Services does not assure that requests for services can be met immediately or in full. For the individuals receiving services, the services are provided within available appropriations based on the needs of the individual. <http://www.ct.gov/dds/cwp/view.asp?a=2730&q=442840/>

## **More detailed information can be found in the following reports:**

**The Management Information Report (MIR):** provides DDS staff and stakeholders with information about eligibility, consumer services and supports, support needs and new development activities, waiver enrollment and revenue, and personnel management.

<http://www.ct.gov/dds/cwp/view.asp?a=3&Q=455410/>

**Autism Report:** [Reports on the Results of the Pilot Autism Spectrum Disorders Program, Pursuant to Section 37 of Public Act 06-188](#) January 12, 2009

**National Core Indicators:** National Core Indicators (NCI) is a collaborative effort between the National Association of State Directors of Developmental Services (NASDDDS) **National Association of State Directors of Developmental Disabilities Services (NASDDDS)** and the **Human Services Research Institute (HSRI)**. The purpose of the program, which began in 1997, is to support NASDDDS member agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks.

<http://www.nationalcoreindicators.org/states/CT/>



## *Connecticut State Department of Education*

*165 Capitol Avenue  
Hartford, CT 06106*

*<http://www.sde.ct.gov/sde>*

### **Activities to Support Families of Students with Disabilities and Students with Special Health Care Needs**

The Connecticut State Board of Education in its 2009 Position Statement on School-Family-Community Partnerships for Student Success (accessible at <http://www.sde.ct.gov/sde/LIB/sde/pdf/board/SFCP.pdf> and <http://www.sde.ct.gov/sde/LIB/sde/pdf/board/SFCPPolicyGuidance.pdf>) calls for a shared responsibility among three equal partners to support student success in school and through life. To develop effective school-family-community partnership programs, state, district and school leaders, along with parents, community leaders and students, must identify goals for their collaboration. The Connecticut State Department of Education (CSDE) develops and promotes school-family-community partnership programs that contribute to success for all students including students with special health care needs and students with disabilities. The Board endorses a research-based definition of school-family-community partnerships that can be applied to policies and practices across the state that result in student success. School-family-community partnerships are viewed as a shared responsibility with schools and other community organizations committed to engaging families in meaningful, culturally respectful ways, as well as families actively supporting their children's learning and development, beginning in infancy and extending through college and career preparation programs and carried out everywhere that children learn. The CSDE provides resources and technical assistance to school districts to help them implement programs of partnership, in accordance with this policy statement. This includes promoting the six standards of family engagement and the full involvement of all major partners. The six standards of family engagement incorporate parent education, communicating and creating a welcoming climate, volunteering, supporting learning at home, decision-making and advocacy, and collaborating with the community. In addition, the CSDE in collaboration with its partners also promotes trainings, activities and initiatives specific to students with disabilities and students with special health care needs.

### **Initiatives and activities to address the needs of families of students with disabilities and/or special health care needs:**

#### **Connecticut Special Education Parent Survey**

In the spring of 2014, the CSDE, Bureau of Special Education (BSE) conducted the statewide survey of parents of students receiving special education services, ages 3-21. The results of the statewide special education parent survey are used by the CSDE to measure and improve family satisfaction and parent involvement in their child's special education program as part of a protocol for the State Performance Plan (SPP). The objectives of the survey are to identify, from the perspective of parents, areas of strength in Connecticut's special education programs

as well as areas in need of improvement. Each year a report is issued which summarizes statewide findings from the survey. District-level parent survey data is also reported in a supplemental district report. Reports are posted annually on the CSDE Web site at <http://www.sde.ct.gov/sde/cwp/view.asp?a=2626&q=322094#8>. Beginning with the 2014-15 survey administration, each school district will be surveyed every three years instead of every six years, in order to offer school districts the current parent information needed to improve “the percent of parents with a child receiving special education services who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities.” (SPP Indicator 8) For more information, please contact Marcus E. Rivera, Education Consultant, Bureau of Special Education, Connecticut State Department of Education, at 860.713.6932 or [marcus.rivera@ct.gov](mailto:marcus.rivera@ct.gov).

### **Health Services Program Information Survey Report**

The CSDE, as part of its ongoing efforts to support and expand school health services provided to Connecticut students, collects data for school health services. This process is designed to assist the CSDE to understand the status of school health services in Connecticut school districts, the needs of school districts and students in the area of school health services and progress being made in these areas over time. The surveys, beginning in 2004, are available on the CSDE’s Health Promotion Services/School Nurse Web site at <http://www.sde.ct.gov/sde/cwp/view.asp?a=2678&q=320768> . For more information, please contact Stephanie G. Knutson, MSN, R.N., School Health Consultant, Bureau of Health/Nutrition, Family Services and Adult Education, Connecticut State Department of Education at 860.807.2108 or [stephanie.knutson@ct.gov](mailto:stephanie.knutson@ct.gov).

### **Connecticut Parent Work Group**

The CSDE initiated the Connecticut Parent Work Group (PWG) – an advisory stakeholder group of parents of students with disabilities, and state agencies and organizations which serve parents of students with disabilities – in order to advise the BSE on efforts to improve special education parent engagement and satisfaction in local school districts. The PWG advises on the development and administration of the annual special education parent survey, and on the use of survey results, including resources for local school districts to promote parent engagement. For more information, please contact Marcus E. Rivera, Education Consultant, Bureau of Special Education, Connecticut State Department of Education, at 860.713.6932 or [marcus.rivera@ct.gov](mailto:marcus.rivera@ct.gov).

### **Connecticut State Advisory Council on Special Education**

The Connecticut State Advisory Council on Special Education serves as Connecticut’s “State Advisory Panel” per the Individuals with Disabilities Education Improvement Act (IDEA) and its regulations in 34 CFR §§ 300.167 through 300.169. The Council has been authorized since the Act’s inception in 1975, and is also authorized under Chapter 164 Section 10-76i of the Connecticut General Statutes (C.G.S.) with the express purpose to “advise the General Assembly, the State Board of Education and the Commissioner of Education” on special education matters. The Council is specifically mandated to advise the CSDE of the unmet needs in educating children with disabilities and on the administration of the surrogate parent program; to review periodically the laws, regulations, standards, and guidelines pertaining to special education and to recommend to the General Assembly and the State Board of Education any changes which it finds necessary; to comment of any new or revised

regulations, standards and guidelines proposed for issuance; to participate with the State Board of Education in the development of any state eligibility documents for provision of special education; to comment publicly on any procedures necessary for distributing federal IDEA funds; to assist the CSDE in developing and reporting such data and evaluations as may be conducted pursuant to the provisions of the IDEA; to provide a forum for individuals or groups to express their ideas related to statewide special education issues; and to report to the General Assembly concerning recommendations for effecting changes in the special education laws. Council members are appointed in accordance with the IDEA and state law. The CSDE provides administrative assistance to facilitate the activity of the Council. For more information, please contact Marcus E. Rivera, Education Consultant, Bureau of Special Education, Connecticut State Department of Education, at 860.713.6932 or [marcus.rivera@ct.gov](mailto:marcus.rivera@ct.gov).

### **Connecticut Parent Advocacy Center**

The Connecticut Parent Advocacy Center (CPAC) is Connecticut's federally-funded Parent Training and Information center (PTI). CPAC's core funding is a result of U.S. Department of Education grants from the CSDE and from private donations. The CSDE partners with CPAC to offer information and support to families of children with any disability or chronic illness, age birth through 26. CPAC is committed to the idea that parents can be the most effective advocates for their children, given the confidence that knowledge and understanding of special education law and its procedures can bring. Through outreach efforts and referrals from schools, social service agencies and other parents, the number of families that CPAC serves has grown dramatically. CPAC is staffed by parents of children with disabilities who have training in, and personal experience with, the law and disability issues. In addition to assisting parents, CPAC staff conducts in-service presentations for schools, teachers-in-training, and service providers throughout the state so that they may better understand and serve the parents with whom they work. Staff and board members serve on numerous statewide committees and various organizations, representing issues that are of concern to parents and families in Connecticut. For more information, please contact CPAC at 1.800.445.2722.

### **Connecticut Parent Information and Resource Center**

The Connecticut Parent Information and Resource Center (CT PIRC) and its primary partners, the CSDE and the State Education Resource Center (SERC), support school-family-community alliances by building on the strengths of each to provide services and resources for families, teachers and other professionals who work on behalf of the children in Connecticut. For families, CT PIRC provides support, referrals to helpful resources, training sessions, presentations at community events, and special programs that celebrate the cultural and linguistic diversity of families. Professional learning opportunities are also available to school districts. For more information, please contact CT PIRC at 1-800-842-8678.

### **Technical Assistance**

Bureau of Special Education (BSE) consultants provide on-going technical assistance to parents and families across the state. BSE consultants are assigned to specific school districts to field calls from the general public and school personnel, and to provide a personal system of response when individuals have special education questions, concerns, and requests for assistance or due process. Callers may also contact BSE consultants with specific expertise in a special education area, as needed. By fielding calls from school district communities, BSE consultants may refer requests for support to other CSDE bureaus,

agencies, and statewide organizations that provide training, consultation and/or support services. If anyone wishes to file a state complaint, request mediation, or a due process hearing, the BSE consultant may explain the individual's due process rights associated with the IDEA and the mechanism for filing a state complaint, or a request for mediation or a due process hearing. BSE consultants investigate and report on alleged violations of IDEA and state special education requirements via state complaint, mediation, and due process hearing options, in addition to other investigative mechanisms under CSDE authority, including general supervision responsibilities as required by the IDEA. The BSE works to ensure that alleged violations of IDEA and state special education requirements are investigated and resolved. To contact the BSE consultant associated with your child's school district, or to learn more about state due process options, please contact the BSE at 860.713.6910.

### **Coordinated School Health**

The CSDE promotes a Coordinated School Health Program (CSH) and provides a nursing consultant and resources to address concerns and questions of parents and professional related to students with special health care needs. CSH can reduce absenteeism and classroom behavior problems; address risky youth behaviors such as lack of physical activity, poor diet, early sexual activity, and tobacco use; improve classroom performance; better prepare students to be productive members of their communities; make schools more engaging; establish good life-long healthy practices; and address staff wellness needs. The CSDE partners with the State Department of Public Health (DPH), through funding from the Centers for Disease Control and Prevention (CDC) to support CSH activities. [www.ct.gov/sde/healthyconneCTions](http://www.ct.gov/sde/healthyconneCTions)

### **Connecticut Family Resource Centers**

The Connecticut Family Resource Center concept promotes comprehensive, integrated, community-based systems of family support and child development services located in public school buildings. This model is based on the "Schools of the 21st Century" concept developed by Dr. Edward Zigler of Yale University. Family Resource Centers provide access, within a community, to a broad continuum of early childhood and family support services which foster the optimal development of children and families. <http://www.sde.ct.gov/sde/cwp/view.asp?A=2678&Q=320774>

### **Parent Trust Fund**

The Parent Trust Fund is the first family civics initiative focused on training parents in leadership skills to improve the health, safety, and learning outcomes of children. It was established by the Connecticut General Assembly in 2001. The State Department of Education administers the Parent Trust Fund through the State Education and Resource Center (SERC). Qualified public and community agencies/organizations conduct parent leadership training using one or more parent leadership training models such as The Parent Leadership Training Institute (PLTI), Parents Supporting Educational Excellence (Parents SEE), People Empowering People (PEP) and Voices for Families (VFF) . As a result of this initiative, parents, grandparents, foster parents, and others are trained to become skilled advocates and strong voices for children at the local, state, or national level.

[http://ctpirc.org/s/index.php?option=com\\_content&view=article&id=177&Itemid=191](http://ctpirc.org/s/index.php?option=com_content&view=article&id=177&Itemid=191)

[http://www.cga.ct.gov/coc/parent\\_trust.htm](http://www.cga.ct.gov/coc/parent_trust.htm)

### **Guidance Documents**

Special Education guidance documents have been developed to provide disability specific information regarding pre-referral, referral, and eligibility determinations, as well as Individualized Education Program (IEP) guidance. <http://www.sde.ct.gov/sde/cwp/view.asp?a=2678&Q=320730>

## **Building Capacity for School-Family-Community Partnerships**

- ***“How Welcoming is Your School?” Initiative***

The key to engaging parents is to make their schools "feel like family." Schools that extend a genuine welcome and are inviting to families have strong partners in education. The Initiative aims to make parents feel welcomed, to celebrate the diversity of the school community, and set unique goals to improve how inviting the school appears to its community, which ultimately has a positive impact on student achievement. <http://www.crec.org/welcomingschools/>

- ***School-Parent Compacts: Linking Family Engagement to Student Learning***

A school-parent compact is tool for communicating between home and school about student learning goals and strategies. Connecticut has developed an innovative approach that reclaims the original purpose of the compact as an effective action plan for meaningful family engagement in student learning. <http://www.schoolparentcompact.org/>

- ***Partners in Education: A Dual Capacity-Building Framework for Family–School Partnerships***

The U.S. Department of Education’s new framework for designing family engagement initiatives was developed to build the capacity among educators and families to partner with one another around student success. Based in existing research and best practices, this report is designed to act as a scaffold for the development of family engagement strategies, policies, and programs. <http://www.sedl.org/pubs/framework/FE-Cap-Building.pdf>



## **Birth to Three Supports and Services**

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**For Referrals 1-800-505-700**

**[www.birth23.org](http://www.birth23.org)**

The Birth to Three System was created to support Connecticut families whose children under three years of age have significant delays or disabilities. The System is funded by a combination of State and Federal funds, health insurance, and parent contributions. Our goal is to help each family help their child to learn new skills and be active in his or her natural environments during their family's normal routines in places where the family lives, learns and plays. The Birth to Three System uses research-supported practices to coach each family on how to meet their child's unique needs.

Birth to Three ensures that families have equal access to a coordinated set of services and supports that:

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

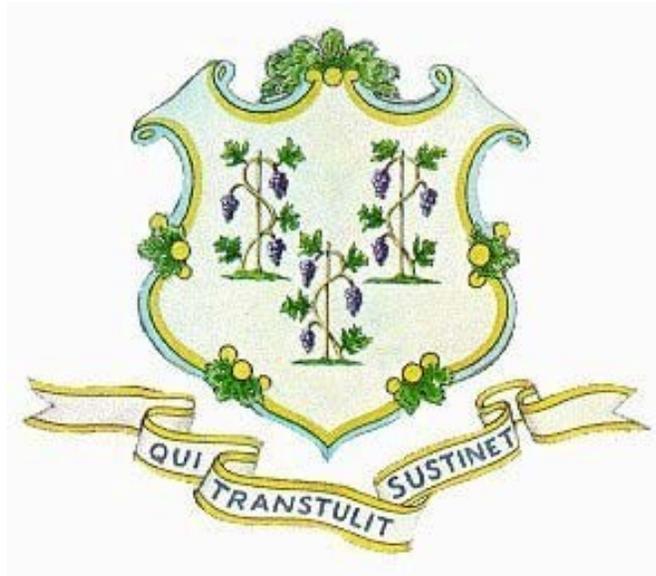
Connecticut's early intervention system offers supports and services at the earliest opportunity through approved Birth to Three programs. Every Birth to Three program offers:

- comprehensive developmental evaluation in the home by trained professionals
- service coordination to help bring together the different people, information and resources needed to support the eligible child and their family
- a variety of trained staff who coach the family on strategies for achieving goals related to their child's needs and their family's priorities. All people working in Birth to Three programs meet personnel standards and are either a licensed or certified professional, or are supervised by a professional.
- Birth to Three staff who work with the family may include an early childhood teacher, physical therapist, speech pathologist, occupational therapist, mental health clinician, or other professionals.
- supports provided during the family's typical activities such as mealtimes, in the child's home, child care setting, or local playgroup
- an Individualized Family Service Plan (IFSP) developed with the parent that reflects the family's culture, values, and priorities

Community partners also participate when invited by the family. The child's primary health care provider is also involved in the coordination of care.

Each Birth to Three program serves a specific set of towns, so parents may choose from among the programs that serve their town and match their needs. Every town has at least one autism-specific program, a choice of programs that specialize in working with families whose children are deaf or hard of hearing, and general programs that support families of children with diverse needs.

For more detailed information go to [birth23.org/aboutb23/annualdata/](https://birth23.org/aboutb23/annualdata/)



Dannel P. Malloy, Governor

Connecticut Family Support Council

460 Capitol Avenue

Hartford, Connecticut 06106

[www.ct.gov/dds](http://www.ct.gov/dds)