

# 2013

Report to the Governor and General Assembly

## Our Families, Our Responsibility



**DDS**



The Connecticut Commission on Children



## Connecticut Family Support Council Membership

### Appointed Members

### Statutory Members

<b>Jennifer Carroll - Glastonbury</b>	<b>State Interagency Birth-to-3 Coordinating Council Chairperson: Mark Greenstein, MD</b>
<b>Terry Cote - Eastford</b>	<b>Commission on Children Designee: Stephen Hernandez Executive Director: Elaine Zimmerman</b>
<b>April Dipolina - Waterford</b>	<b>Department of Children and Families Designee: Sara Lourie Commissioner: Joette Katz</b>
<b>Karen Hlavac - Wallingford</b>	<b>Department of Developmental Services Designee: Marie Bennett (Secretary, CTFSC) Commissioner: Terrance W. Macy, PhD</b>
<b>Tesha Imperati – North Haven</b>	<b>Department of Education Designee: Colleen Hayles Commissioner: Stefan Pryor</b>
<b>Lisa Sheppard – Fairfield Co-Chair, CTFSC</b>	<b>Department of Public Health Designee: Ann Gionet Commissioner: Jewel Mullen, MD, MPH, MPA</b>
<b>Maureen Smith - Middletown</b>	<b>Department of Social Services Designee: Sylvia Gafford-Alexander Commissioner: Roderick L. Bremby</b>
<b>Mona Tremblay - Putnam</b>	<b>Office of the Child Advocate Designee: Sharon Dexler Child Advocate: Jamey Bell</b>
<b>Robyn Trowbridge – Meriden Co-Chair, CTFSC</b>	<b>Office of Protection and Advocacy for Persons with Disabilities Designee: Linda Mizzi Executive Director: James D. McGaughey</b>

**\*\*Current at time of publication: February 2013**

### Council Membership Vacancies by Appointing Authority

Governor (4), Senate Pro Tempore (2), Speaker of the House (1), House Majority Leader (2)

## **Table of Contents**

Connecticut Family Support Council Overview .....	1
What is Family Support? .....	2
State Agency Summaries .....	3
Recommendations .....	6
Focusing of the Future .....	7

## **Appendixes**

A - Department of Developmental Services

B - Department of Public Health

C - Office of Protection and Advocacy for Persons with Disabilities

D - Department of Children and Families

E - State Department of Education

F - Office of the Child Advocate

G - State Interagency Birth to Three Coordinating Council

H - Department of Social Services

## **Family Support Council**

### **Connecticut General Statute §17a-219c**

Sec. 17a-219c. Family Support Council. (a) There is established a Family Support Council to assist the Department of Developmental Disabilities 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, 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; June 12 Sp. Sess. P.A. 12-2, S.123)

# The Connecticut Family Support Council 2013 Report to the Governor & General Assembly

## Overview

Throughout 2012, the Connecticut Family Support Council has remained focused on issues relating to children with disabilities and special health care needs. We at the Council grow increasingly concerned with the fiscal climate in Connecticut and its impact on families, as we watch families struggle and the Governor and General Assembly propose budget reductions that will further challenge the children and families for whom we are charged to advocate.

Our charge, pursuant to Connecticut General Statute §17a-219c is to:

- 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.

In the eighteen years of the Council's existence, numerous advances have been solidified relating to family support services. There is much to be proud of, as we reflect on the current efforts of numerous community providers and our State agency partners that include:

- **Department of Developmental Services**
- **Department of Public Health**
- **Department of Children and Families**
- **Department of Social Services**
- **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**

Systemic accomplishments relating to Family Support include:

- A clear and positive commitment to family support within all child serving State agencies,
- A focus on quality work on behalf of children with disabilities and special health care needs, and
- An existing statewide structure within which family supports can be provided.

We can see that the families who are being reached and served are experiencing increased quality of life, greater opportunities for their children and an expansion of normalcy and integration into the community for their children and families as a whole. Data shows this leads to positive outcomes, including preserved esteem and a sense of belonging, and those factors lead to greater life success and an ability to positively contribute to the communities in which they live.

**Through our routine dialog with those providing family supports in our State, we know that in general, Connecticut families parenting children with disabilities and special health care needs continue to remain passionate and committed to their kids and work hard to be diligent in meeting the often extensive daily and long term needs of their children. However, in the past few years, many have lost services due to program reductions and changes in eligibility standards, and some have lost health insurance due to job loss or other factors. Many have had to seek additional employment options to stay solvent economically in these difficult times, drawing them away from their homes and routines. While this may also be the case for many Connecticut families, factors such as declining opportunity, and any loss in flexibility and stability is of profound impact to children with disabilities and special health care needs due to their very nature and level of fragility as human beings.**

While the issues and challenges of parenting often share common bonds across all children, children with disabilities and special health care needs require additional supports and safeguards in order to reach the same desired outcome as other kids.

To that end, the State of Connecticut has created, continuously funds, monitors and sustains family support programs. While we at the Council acknowledge and celebrate those family supports currently in place, our examination reveals vast numbers of families awaiting services, desperate for supports and experiencing an increasing hopelessness as they try to navigate the demands of their daily life.

We at the Connecticut Family Support Council share a unified vision of positive outcomes for all children in Connecticut and focus our efforts on supporting and enhancing the lives of children and families through advocacy for quality community family support. It is our responsibility to assist the Governor and Legislators to remain aware and informed as to the impact of State funded family support programs, and to illuminate areas of continued unmet need within our State. In an effort to do this, we gathered status reports from our State agency partners on current Family Support Programs being funded and implemented within Connecticut. Some of our larger State agency partners are utilizing Results Based Accountability (RBA) to complete both internal program assessment and to report to external sources. Others have provided a summary of Family Support Program efforts inclusive of a human impact statement. All reports provided to the Council are included in this 2013 Connecticut Family Support Council annual report, in their original format, as appendixes.

We offer this document as our 2013 annual report on the “State of the State” of family support in Connecticut.

## **What is Family Support?**

Family Support, as defined by the Connecticut Family Support Council, are the supports and services families need to care for their children who have disabilities and those which enable them to fully participate in active living within their communities. When we reference “family support”, we include:

- In-home supports
- Special health care 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

~~~~~  
~ *Our Families, Our Responsibility* ~

# Highlights of Current Family Support Programs

## The Department of Developmental Services (DDS)



- Provided Family Support Services to more than 593 individuals statewide in 2012, of which 109 were children. Total number of persons served in FY 2011 was 426.

The total number of persons served in FY2013 is expected to be reduced from the previous fiscal year due to reductions in family support funding.

- Through the Individual Family Support (IFS) Resource Teams, the DDS provided services to approximately 1,729 individuals of which 304 were children.
- The DDS Voluntary Services Program served approximately 436 children statewide in 2012.
- Family Respite Services were provided by DDS to approximately 1,414 individuals statewide in 2012, of which 331 were children.

**DDS Family Respite Service Centers' hours of operation were reduced beginning January 2013 due to funding reductions.**

## Department of Public Health (DPH)



- Partners with several community providers within the Connecticut Medical Home Initiative (CMHI) which provides for five community-based regional medical home care coordination networks. All children served within the CMHI have access to medical homes that deliver comprehensive, coordinated care in a culturally competent manner and link them to basic needs and services essential to reaching their potential and maintaining health throughout the lifespan.
- Through the CMHI, 8,020 children and youth with special health care needs received services in FY 2011.

**\*Based on the U.S. Department of Health and Human Services data, there are approximately 133,000 children with Special Health Care Needs residing in Connecticut.**

- The CYSHCN program exceeds national benchmark standards in all six areas evaluated by the national survey designed to assess impact of programs for Children and Youth with Special Health Care Needs. The survey was conducted by the Maternal Child Health Bureau (2005-2006), and reflect national benchmark standards as including:
  - ~ Families as partners in decision making at all levels and who are satisfied with services they receive.
  - ~ Receive coordinated, on-going, comprehensive care within a medical home.
  - ~ Families have adequate private and/or public insurance to pay for the services they need.
  - ~ Children and youth are screened early and continuously for special health care needs.
  - ~ Services are organized in ways that families can use them easily.
  - ~ Receive the services necessary to make appropriate transitions to adult health care, work, and independence.

~~~~~  
~ *Our Families, Our Responsibility* ~



## The Office of Protection and Advocacy for Persons with Disabilities (OPA)

- Provided intensive advocacy representation to 522 persons with disabilities addressing issues including but not limited to: education, employment, housing, unnecessary institutionalization, rights violations, government benefits, quality assurance, guardianship, parental rights, and childcare in 2012.
- Reviewed 210 deaths of individuals served by the Department of Developmental Services and 4 deaths of individuals served by the Department of Mental Health and Addiction Services.
- Provided information and assistance to 3,609 individuals in 2012, including issues regarding family support and special education.
- Received 1,126 allegations of suspected abuse or neglect which resulted in 1,117 cases investigated by OPA.

## The Department of Children and Families (DCF)



- The DCF Community Support for Families Program, implemented in April 2012, has served 585 children to date.
- Within the “Relative/Kinship Care” priority, DCF child placements with relatives increased from 15.3% (March 2011) to 22.7% (March 2012), reflecting an increase from 731 children placed with relatives to 1,035. As of January 3, 2013, 40% of all children birth to age 11, placed by DCF, are living with relatives (771 children).
- The DCF has reduced out of state placements from 236 in 2009 to 39 in 2012, and congregate (group) placements from 679 in 2009 to 431 in 2012.
- Has implemented the Differential Response System (Family Assessment Response), expanded the agency-wide use of RBA and launched a “Child and Family Teaming” approach.

## Connecticut State Department of Education (CSDE)



- In the spring of 2012, the CSDE, in partnership with the Connecticut Parent Advocacy Center (CPAC), conducted the annual statewide survey of parents of students receiving special education services, ages 3-21, which measures overall family satisfaction and parental involvement in the child’s special education program and identifies areas of strength and areas in need of improvement in Connecticut’s special education programs. The 2012 survey represents the seventh year of a six year survey cycle over which all districts are surveyed. Surveys were sent to all parents of students with disabilities in 19 of 21 districts and to a sample of parents (according to the sampling design) in the two largest participating districts. The survey results are shared with the appropriate districts. Districts are encouraged to use their survey results to inform their school and district improvement plans related to parent participation as well as their staff development agenda. Results are also considered by CSDE and the Bureau of Special Education to inform statewide initiatives. The compiled results of this survey are available on the CSDE website.



- CSDE implements the State Advisory Council (SAC) as authorized by the Individuals with Disabilities Education Act (IDEA), addressing all five goals of the Comprehensive Plan of the State Board of Education.
- Partners with the Connecticut Parent Advocacy Center (CPAC), whose core funding comes through the U.S. Department of Education (USDOE), grants from the CSDE and private donations. CPAC is designed to expand parental knowledge on effective advocacy for children with special education needs.
- Conducts a Health Services Program information survey designed to assist the CSDE in understanding the status of health services in Connecticut school districts and support the longitudinal progression of quality health care for children within public schools.

### Office of the Child Advocate (OCA)



- Documented 353 requests for assistance in FY 2011-2012, in the areas of education, coaching on self advocacy strategies, individualized and professional technical assistance and follow up.
- Opened 57 cases due to concerns regarding safety or unmet need(s) of children. Specific details regarding each individual case remain confidential as required by Connecticut General Statute.
- Conducted/participated in 629 case reviews, had direct contact with 175 individual children living in varied settings throughout the State and assessed their needs and assisted them through self advocacy efforts.
- Case investigation and advocacy included 568 contacts with public agencies and 70 attorneys representing children and families addressing issues relating to child protection, health care access, and special education, access to council and access to child care.



### State Interagency Birth-to-Three Coordinating Council (Birth-to-Three)

- Current data indicates more than 70% of children with disabilities or developmental delays who receive Birth-to-Three services are functioning at grade level in at least three skill areas when they exit the program. Examples of skill areas include: social/emotional development; acquisition and use of knowledge (including early language and literacy); and the use of appropriate behavior to meet their needs.
- Based on RBA data presented in this annual report, 51% of Birth-to-Three service recipients who enrolled in kindergarten in school year 2011-2012 did not require special education services.
- Current data indicates that approximately 10% of the estimated 38,000 children born annually in Connecticut will have received Birth-to-Three services by the time they reach age three.

## Department of Social Services (DSS)



- Administers the implementation of the Katie Beckett Waiver, currently serving up to 200 individuals with special health care needs throughout the State.
- Administers the Children's Trust Fund which provides programs and services to children with special health care needs and their families, including;
  - ~ Family Empowerment Program: In partnership with Child Guidance in Bridgeport, the Trust Fund offers programs and trainings for parents and caregivers.
  - ~Help Me Grow: A program which serves to identify early indicators of developmental delays in children, refers and supports them to connect with necessary services and monitors for their progress developmentally.
  - ~Nurturing Families Network: A program that offers training for staff providing in-home supports for children with special health care needs and their families.

## Recommendations

In times of fiscal constraint, possibilities exist which allow for advancements in quality and efficiency. Those providing family support services in our State remain aware of this and support cooperative and creative approaches to problem solving relating to families of children with disabilities and special health care needs. In order to make such advancements, systemic barriers must be identified and removed, and facilitated dialog must occur with those close to service provision, and result in real time solutions for children and families. To that end we recommend the following be considered:

- Create an interagency work group which is designed to identify and remove service barriers for families of children whose lives interface with multiple State agencies.
- Conduct a comprehensive study of unmet need and identification of service barriers for children with behavioral health needs which include; statewide wait lists for outpatient services, utilization of emergency room intervention, access to inpatient options, denial of services, availability of culturally sensitive interventionists which match the geographic needs of the community in which they work.
- Examine on-going access issues for necessary therapy and services to persons with Autism Spectrum Disorders. (March 2012 survey of the Connecticut Medical Home Initiative Pediatric Primary Care Practitioners indicates 89% continued unmet need).

~~~~~  
~ *Our Families, Our Responsibility* ~

## Focusing on the Future

During the past two years, The Connecticut Family Support Council members from across the State have grown increasingly concerned about the issue of school climate within our State. Council members have heard countless stories, statewide, of young people feeling unsafe, belittled, oppressed, undervalued or victimized within our schools. Many of the children we hear about are children with disabilities and special health care needs, but we know these stories represent vast numbers of school age children every where, and while it may be natural to address these issues from a perspective of “bullying”, the more broad and vital perspective is that of school climate; how does it “feel” to be in a particular educational environment?

We at the Council do not accept that it is enough to be free from harm, albeit an agreed upon minimum standard. As advocates for the children of Connecticut, we believe there are limitless possibilities for excellence within environments which are founded upon respect and cultivate high standards and achievement of personal and systemic commitments to character.

School climate refers to “the quality and character of school and community life.” It is based on patterns of school life experiences and reflects norms, goals, values, interpersonal relationships, teaching, learning and leadership practices, and organizational structures, both State and private, for the well being of our communities.

Today, a number of factors influence the reality of school climate, including the interactions of students and teachers, instructional needs, academic performance, specific laws and regulations and the perceptions of them and those they are designed to protect; all playing a role in how the community works together and how it is understood and experienced by its members.

The Council has made an active decision to focus on school climate, statewide, in the coming year, and will be seeking to develop expertise specific to this issue, as well as a plan to facilitate positive changes in the climate within our schools.

Connecticut Family Support Council members received initial training on this topic in October 2012 and have called upon our own State agency partners from the Commission on Children and the State Department of Education, each of whom possess substantial expertise on this issue, to assist us in developing strategies for positive change. Early discussions are currently underway to secure a series of joint trainings on the issue of school climate for both Council members and school district administrators from across the State.

As we look upon trends in approach and the impact of the variety of existing programs designed to improve school climate currently implemented within our State, fidelity in implementation and evidence of improved results, (specifically students with disabilities and those with special health care needs feeling safer, more supported, and more valued) are difficult to quantify. National findings reveal that the greatest impact upon school climate results from a systematic process of altering the perspectives and actions of adults within school settings.

Each of us has a responsibility and duty to contribute in strengthening this modern day society as it travels forward. Students must understand the moral, ethical and legal conduct that is required of them. Teachers, administrators, support staff and coaches must strive to develop and demonstrate positive character traits which can be emulated by students. Parents and communities need to work together to ensure that we cultivate generations who are focused and prepared to live positive and successful lives.

In the coming year, the Council will seek to develop recommendations through research and practical application, such that advancements can be achieved that are manageable for school settings and which bring about lasting positive impact for our young people.

~~~~~  
~ *Our Families, Our Responsibility* ~



**Serving Individuals through DDS Family Support  
Department of Developmental Services  
Individual and Family Support Resources/Services  
1.10.2013 Update**

The Department of Developmental Services (DDS) provides Family Support Services state-wide to eligible families and individuals. Based upon availability this support includes Family Support Resource Teams, Individual Grants, Respite, the Helpline, Case Management, the Voluntary Services Program and Money Follows the Person. The focus of this report is support we provide primarily to children and young adults (some of the data provided in this report will also include adults).

For more than 20 years, DDS has had **Individual and Family Support (IFS) Resource Teams** to help address the needs of DDS consumers who live at home with families and do not receive services from DDS or its partner agencies and in most cases, are not enrolled in or eligible for services through the Medicaid Home and Community Based Services (HCBS) Waivers. During FY 12, DDS Family Support Workers provided services to more than 593 individuals state-wide, of which 109 were children. The numbers served were lower this year due to the loss of staff and the inability to refill positions.

The IFS Resource Teams, which include nurses, behaviorists, educational liaisons, transition coordinators, recreation staff and direct care staff, provide a variety of critical services that are instrumental in helping to keep individuals healthy and safe, as well as ensuring the overall improvement of the quality of life for individuals with disabilities by reducing family stress that can lead to more costly service needs by:

- Preventing emergency placements for individuals with severe behavioral and mental health needs by performing behavioral assessments and teaching coping strategies to families.
- Assisting those at risk for homelessness through exploration of housing options and community supports.
- Providing transportation to medical/dental/counseling appointments to those with no other means to access these services.
- Providing teaching in areas of daily living to increase an individual's independence by providing in-home personal supports.
- Reduce family stress by offering respite through in-home and community supports.
- Assist individuals in transitioning from school to adult life to a program of their choice including employment by evaluating educational and employment needs and performing a liaison function to ensure their needs are being met.
- Providing supports and services to individuals who are receiving oversight from the Office of Protection and Advocacy by assisting in the implementation of protective service plans.
- Assisting families to access needed community and government agency services.
- Supporting the work of DDS case managers.

Approximately 1729 consumers had access to the supports and services offered by the IFS Resource Teams, 304 of whom were children.

### **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. DDS supported over 1983 individuals or families in 2012, of which close to 40% were children.

### **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. The Department has 11 Respite Centers which served a total of 1414 individuals state-wide in FY 12, including 331 children. As of January 1, 2013, due to cuts in the budget, the department reduced the number of hours the respite centers are open. They were open from Thursday afternoon to Tuesday morning. They are now open from Friday evening to Sunday evening. Due to these cuts, we anticipate we will be able to serve fewer individuals in the upcoming year.

### **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. Each region has approximately 1000 individuals or families who used the Helpline in 2012, the majority being children.

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.

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.

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
- Other requested assistance

### **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.

### **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.

Approximately 436 children were in the DDS VSP program statewide in 2012.

### **DDS/DSS MOU**

The DDS/DSS program (funds received from DSS) benefits DDS consumers who are Medicaid recipients willing to forego home care staff in exchange for funding used to hire dedicated in-home caregivers. DDS did not receive DSS MOU dollars in FY 2012, However, the West Region was able to provide services to six children with recycled 2011 funds.

### **CT Family Support Network**

Provides one-to-one supported services to families through a contract with DDS. This includes advocacy, telephone and individual contact, family/staff trainings -families, and all families, resource and information sharing throughout the State of Connecticut. For more information please visit their website at [www.ctfsn.org](http://www.ctfsn.org).

### **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. DDS anticipates the number of individuals utilizing this opportunity to increase over the next year with dedicated case management funded by MFP.

### **Employment and Day Supports Waiver**

The Employment and Day Supports waiver was approved by CMS to begin April 1, 2012 for a period of five years. This 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. This waiver will serve 200 people the first year and will increase by 100 slots each year.

**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. In FY 12 1,078 families chose to self-direct their services and hire staff to provide respite or in-home supports.

**Autism Services:** The DDS Autism Division currently serves 78 individuals with ASD who do not have Intellectual Disability. Between the calendar years 2009 and 2011, the estimated expenditure, \$836,000 and \$1.09 million respectively increased 30.5%. The majority of funding (over 70%) was spent on Life Skills, job coaching and community mentor services. Both provide social and behavioral supports to the individuals in these programs allowing them to participate in jobs and other community activities. The DDS Autism Division is currently in the process of transferring 25 children with ASD from DCF through their Voluntary Services Program. As of November 1st 2012, four children were receiving services through DDS.

### **DDS Five Year Plan 2012 - 2017**

DDS's Five Year Plan (2012-2017) is a strategic statement of DDS's direction and an outline of priorities which will be used to guide the direction of the current and future service system. The plan contains 25 goals and was submitted to the legislature in February of 2012.

As many of the goals address systemic changes that need to be made to our service delivery systems, many of them will take time and much input from a whole spectrum of stakeholders. Stakeholders, it should be noted, could include anyone who is touched by our services. The people we support, their families, public and private staff, our many partners from other state agencies and the larger community are all potential stakeholders.

Conversations have been initiated with DDS staff to prioritize the order in which goals will be addressed and a new Individual and Family Advocate has become the primary facilitator of the Five Year Plan process. DDS staff will necessarily play key roles with other stakeholders in overseeing the work on specific goals. While there is much interest on the part of DDS and private sector staff in getting to work on the goals, we must use our relatively fragile resources wisely and address goals collectively and systematically. We are very excited with the widespread level of interest in our plan and know that the ultimate results will be both highly regarded and truly responsive to people's needs as they will reflect the input of so many motivated stakeholders



## DDS LEGISLATION

The following bills were proposed by DDS during the 2012 Legislative Session, passed by the legislature, signed by the Governor and have become law:

**S.B. No. 205 (PA 12-44) AN ACT CONCERNING INSURANCE COVERAGE FOR THE BIRTH-TO-THREE PROGRAM** This act amends state statutes concerning health insurance coverage for birth-to-three programs to allow the state to establish a new baseline of state and local expenditures for early intervention services in the next federal fiscal year pursuant to federal regulations. The act changes requirements for individual and group health insurance policies that provide coverage for medically necessary early intervention (birth-to-three) services as part of an individualized family service plan. Existing law prohibits payments for birth-to-three services from applying against any maximum lifetime or annual limit in the policy. The act also prohibits payments from causing: 1. a loss of benefits due to a policy limit, 2. an insured child or family member to be denied health insurance coverage, and 3. a policy rescission or cancellation. The act specifies that payments for birth-to-three services must be treated the same as other claim experience for premium rating purposes. Effective Date: July 1, 2012

**H.B. No. 5105 AN ACT CONCERNING THE JOB EXPANSION TAX CREDIT PROGRAM AND INDIVIDUALS RECEIVING CERTAIN SERVICES FROM THE DEPARTMENTS OF MENTAL HEALTH AND ADDICTION SERVICES AND DEVELOPMENTAL SERVICES** This bill which did not pass would have allowed employers that hire individuals receiving employment services through the Departments of Mental Health and Addiction Services and Developmental Services to qualify for the job expansion tax credit program (an incentive for employers to hire individuals with intellectual and mental health disabilities). The tax credit program runs until January 1, 2014 and would offer a tax credit of \$900 a month for employers who hire a qualified employee. The bill made it through the Commerce and Public Health Committees but died in the Finance Revenue and Bonding Committee. The bill was then passed as part of the June 12, 2012 Special Session in **Section 198** of **H.B. No. 6001 (PA 12-1JSS) AN ACT IMPLEMENTING PROVISIONS OF THE STATE BUDGET FOR THE FISCAL YEAR BEGINNING JULY 1, 2012.**

**H.B. No. 5367 AN ACT CONCERNING COMPETENCY TO STAND TRIAL** This bill which did not pass would have allowed a court to receive notice if a defendant was released from commitment to the Commissioner of Developmental Services prior to the expiration of the statute of limitations for the crime with which the defendant was charged and allows the court to order periodic evaluations of the defendant. The bill also would have allowed the Department of Mental Health and Addiction Services and the Department of Correction to coordinate the custody and treatment of a defendant who presents a significant security, safety or medical risk. The bill passed the House but died in the Senate. The bill was then passed as part of the June 12, 2012 Special Session in **Section 142** of **H.B. No. 6001 (PA 12-1JSS) AN ACT IMPLEMENTING PROVISIONS OF THE STATE BUDGET FOR THE FISCAL YEAR BEGINNING JULY 1, 2012.**

Families can also obtain additional information through the DDS website at [www.ct.gov/dds](http://www.ct.gov/dds).

### Other Important Information:

As of 9/30/2012, there were 57 on the DDS emergency list, 965 individuals on the priority list and 1,394 on the planning list.

**Program Report Card: Voluntary Services Program (VSP) - (Department of Developmental Services-DDS)**

**Quality of Life Result:** All Connecticut children and adolescents thrive in school, at home and in life.

**Contribution to the Result:** The DDS Voluntary Services Program provides in-home supports and training to families to decrease a child's challenging behaviors, allow the family to remain intact, and allow children and adolescents to thrive at home.

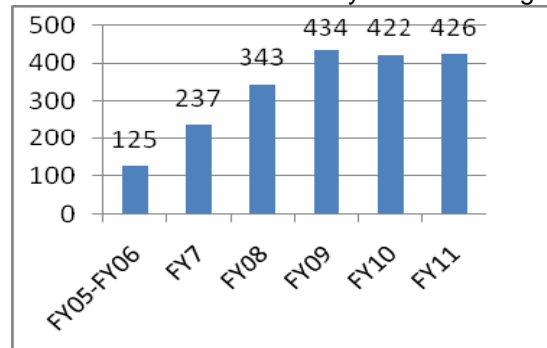
**Total Program Funding:**

Program Expenditures	State Funding	Federal Funding	Other Funding	Total Funding
Actual FY 11	\$27,394,028	0	0	\$27,394,028
Estimated FY 12	\$31,256,734	0	0	\$31,256,734

**Partners:** Department of Children and Families (DCF); Families of children served in VSP; Local Education Agencies (LEAs); Office of the Child Advocate

**How Much Did We Do?**

**Performance Measure 1:** Number of Children enrolled in the DDS Voluntary Services Program.



**Story behind the baseline:**

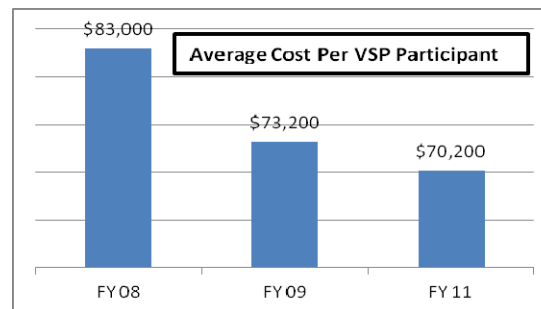
The blue bars represent the number of children and adolescents who were enrolled in the program at the end of the fiscal year (FY). During any fiscal year, adolescents age out of the program when they turn 21, thus the actual number served during the fiscal year includes approximately 15 to 20 additional children.

With no new funding in FY11, there were no new children or adolescents entering the program either through the DDS application process or through the DCF yearly transfer process.

**Trend:** [Flat/No Trend ◀▶]

**How Well Did We Do?**

**Performance Measure 2:** Cost of Service DDS has worked to lower the cost of its Voluntary Service Program. Average cost per child has decreased from approximately \$83,000 in FY 08 to approximately \$70,200 in FY 11. The average cost has gone down as a higher percentage of children are served at home.



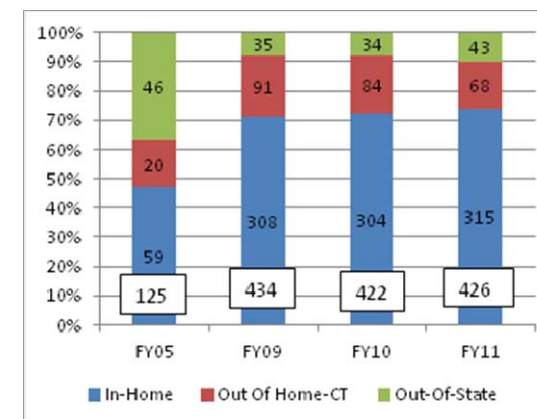
**Story behind the baseline:**

The agency understands the state's fiscal situation and has made every effort to manage its costs. An out-of-home placement typically is at least three times more expensive than supporting a child living with their family. Therefore, DDS's efforts to support families and improve behavioral interventions with in-home supports is both best practice and fiscally responsible. DDS also is working to reduce out-of-state placements, which are not eligible for federal reimbursement under the HCBS waivers.

**Trend:** [▲ Yes]

**Is Anyone Better Off?**

**Performance Measure 3:** Children who remain in-home vs. receiving out-of-home (in CT) and out of CT placement.



This graph represents in home supports vs. out of home supports. Since DDS began this program, this percentage receiving in-home services has increased. In FY11 there were significant numbers of psychiatric emergencies. In-state provider capacity to place these individuals in appropriate settings was strained and thus the percentage of out-of-state placements increased.

**Trend:** [▲ Yes]

### Is Anyone Better Off?

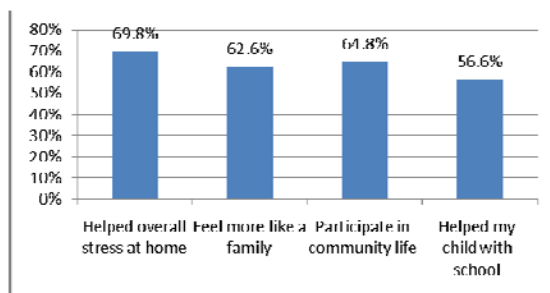
#### Performance Measure 4: Survey of Families with Children in DDS-VSP

During testimony before the Appropriations Committee the Department proposed doing a Survey of families participating in In-Home Behavioral Supports and Services as part of the DDS-VSP Program. The Committee supported this and during September of 2010 the Survey was completed. This is a new Performance Measure.

#### Story behind the baseline: Survey Results:

- 306 Families were sent the survey. There was a 38.2% return rate as 117 surveys were returned.
- For all responses to all questions by all 117 families, the average for all 15 questions was 65% were Strongly Agree or Very Strongly Agree.
- **For the Survey Question #15 - Overall the Voluntary Services Program has been beneficial to our family – 81.6% of the responses were Strongly Agree or Very Strongly Agree.**

The percentages of responses listed to the following questions, reflect the number of responses that were either Strongly Agree or Very Strongly Agree.



Due to the Department receiving no new appropriation for the VSP Program, there were no new children or adolescents entering the Program either through our application process or through the DCF yearly transfer Process. No Survey was completed for FY11 as there were no new children or adolescents added to the VSP Program. We would have been surveying basically the same families. \*\*\* See Data Development Agenda\*\*\*\*

**Trend: [Flat/No Trend ◀▶]**

### Proposed actions to turn the curve:

DDS plans to continue its efforts to expand capacity to support individuals in their own homes. However, services for newly eligible applicants are dependent on new state funding and the ability to reuse existing resources when children age out of the program at twenty-one. In FY10 the number decreased as a result of children aging out and the VSP funding level being reduced. A VSP waiting list was created in FY11 because no new funding was appropriated to expand the program.

In FY 11 DDS expanded by 14 the number of clinical behavioral service providers qualified to provide services under the waiver. Through quality improvements in supports and services to families, DDS hopes to further reduce out-of-home placements.

In FY 11, DDS added four new providers of Individualized Home Supports. DDS plans to continue its efforts to expand capacity to support individuals in their own homes by recruiting additional behavioral consultants.

The agency has increased the number of providers of in-home supports. Behavioral consultation was added as a waiver service in FY10, and the number of behaviorists who are qualified providers increased during FY11. In FY10, 35 new individual behavioral providers were approved as qualified vendors, and an additional 27 were approved in FY11.

### Data Development Agenda:

Although a survey can be helpful in determining the effectiveness of a program, DDS is unable to commit to doing another survey at this time given staff resources to collect and analyze data. Also, families do not always welcome the intrusion of a survey and for this population; it might make more sense to do a survey every few years so as not to badger the program participants' families. That being said, there are other options that could be used to evaluate the effectiveness of this program for families. DDS will discuss the possibility of utilizing the Quality Service Reviews as a tool for quality and effectiveness measurements. Also, DDS has recently agreed to once again participate in the National Core Indicators (NCI) project. DDS will be looking to see if there is a relevant assessment tool as part of the NCI project that could be used to assess the VSP program going forward.



**The Connecticut Department of Public Health**  
**The Connecticut Medical Home Initiative (CMHI) for Children and**  
**Youth with Special Health Care Needs.**

1. What is the quality of life result?

All Connecticut Children and Youth with Special Health Care Needs (CYSHCN) and their families have access to medical homes that deliver comprehensive, coordinated care in a culturally competent manner and link them to basic needs and services essential to reaching their potential and maintaining their health throughout the life course.

2. How does the program contribute to the result?

CHMI provides for five community-based regional medical home care coordination networks; a statewide point of intake, information and referral; provider and family outreach and parent-to-parent support; and access to respite and extended services.

3. Who are the partners?

There are numerous stakeholders and partners who are playing major roles in “doing better”. These include children and youth with special health care needs, their families and Community Based Organizations which represent them including, but not limited to: The Family Support Network, Parents Available to Help/Family Voices CT, CT Kids As Self Advocates, FAVOR, and CPAC. Major roles are also played by organizations represented on the Medical Home Advisory Council including state agencies, AJ Pappanikou Center for Excellence in Developmental Disabilities (the state’s UCEDD), Child Development Infoline, Child Health and Development Institute, the CT AAP, and Community Health Network.

4. How much did we do?

CMHI provided services to 8,020 children and youth with special health care needs in state fiscal 2011.

Children and Youth with Special Health Care Needs are individuals under 21 years of age who have or are at an increased risk for a chronic physical, developmental, behavioral or emotional condition and require health and related services beyond that required for children in general. The program also serves Connecticut residents with Cystic Fibrosis regardless of age. There are approximately 133,000 CYSHCN in CT (U.S. Department of Health & Human Services).

5. How well did we do it?

The Maternal Child Health Bureau conducts a national survey to assess the impact of programs for Children and Youth with Special Health Care Needs in the states. Based on

six core measures, Connecticut is benchmarked against the nation in the 2005/2006 survey as follows:

CYSHCN whose families are partners in decision-making at all levels, and who are satisfied with the services they receive. National: 57.4%, CT 57.8%

CYSHCN who receive coordinated, ongoing, comprehensive care within a medical home.  
National 47.1%, CT 48.5%

CYSHCN whose families have adequate private and/or public insurance to pay for the services they need. National: 62.0%, CT 61.7%

CYSHCN who are screened early and continuously for special health care needs.  
National: 63.8%, CT 70.6%

CYSHCN whose services are organized in ways that families can use them easily.  
National 89.1%, CT 89.4%

Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence.  
National 41.2%, CT 43.3%

Consumers served by the program are surveyed to measure programmatic service delivery and satisfaction. Results from The Medical Home Family Survey conducted from February to June 2010 indicated 87% of the 200 respondents indicated they had access to their child's physician when needed, 91% reported their physician listened to their concerns, 85% reported the office staff were knowledgeable of their child's condition and history. Families reported care plans were in place 44% of the time (note comparison to database analysis below), 96% of those reported they understood their care plans, and 78% reported participation in developing the care plan. Families reported they were satisfied that their child's needs were met by the care plan 91% of the time and 73% reported they were given hard copies of the care plan to share with others. Responses indicated care coordinators always helped to communicate with others involved in the child's care 88% of the time (an additional 8% responded sometimes), and always worked to connect the family to resources 86% of the time (an additional 4% responded sometimes). Respondents with children over 13 years of age indicated 66% always received assistance in addressing health care needs moving towards adult services (5% responded sometimes).

An access database is maintained to measure programmatic progress. Process measures evaluated include the percentage of care plans in place and the number of consumers successfully linked to services. An analysis of the database indicated that in state fiscal 2011 more than 86% of children served by the program were successfully linked to resources outside the medical home and 56% had care plans in place (this was the third year that programmatic expectations included implementation of methodologies to

address linkages and care planning, including standardized documentation of these activities – a baseline in fiscal 2008 indicated approximately 50% received successful linkages outside the medical home and 23% had care plans in place).

5. Is anyone better off?

Analysis of hospital admission data has been done to demonstrate programmatic outcomes. (The following is trend data over time based on available data and is not based on experimental design and does not include comparison to a control group).

Summary of Data from 2006 Cohort of CYSHCN from Stamford catchment area  
Comparison to hospital data from 2006-2009  
(9/23/2010 Nancy L. Barrett)

The cohort of CYSHCN clients selected were children born in 1990 or later from the Stamford catchment area. This data was cleaned then matched with CHIME data for the years 2006-2009.

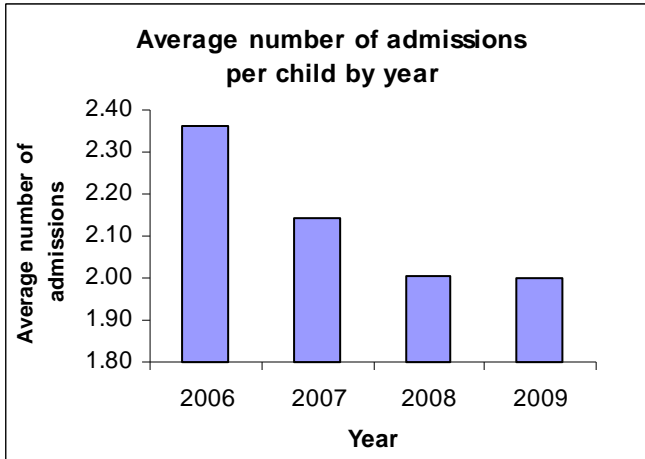
Total in Cohort = 807

Cohort characteristics

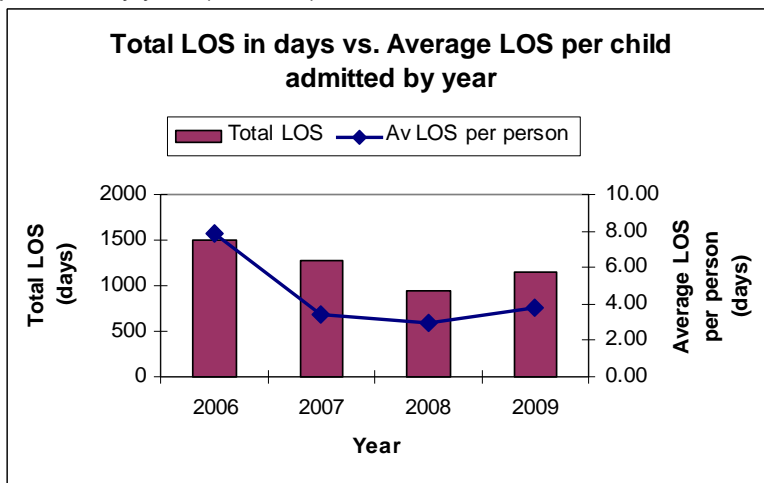
338 (42%) female	48% Hispanic (regardless of race)	44% 0-5 years of age
	24% African American or Black	32% 6-10 years of age
469 (58%) male	(non-Hispanic)	
	18% White (non-Hispanic)	24% 10+ years of age
	4% Other race or races (non-Hispanic)	
	6% Unknown	

The 807 were further split into any client with at least one hospital admission from 2006 through 2009 based on CHIME data. Total admitted = 587 (73%), total not admitted = 220 (27%)

Hospital admissions – the 2006 cohort data was matched to CHIME data from the years 2006-2009 to identify those children with hospital admissions. The graph below shows the average number of admissions per child by year (admitted children only).



The graph below shows the total LOS for all children admitted by year (bars) vs. the average LOS per child by year (blue line).



Conclusions: Trends over time indicate a reduction in the number of hospital admissions; as well as shorter lengths of stay are experienced by consumers served by the program.





## OFFICE OF PROTECTION AND ADVOCACY FOR PERSONS WITH DISABILITIES

The Office of Protection and Advocacy for Persons with Disabilities (P&A) is an independent state agency providing information, referrals, advocacy assistance, investigations and limited legal services to people with disabilities in the state of Connecticut whose civil rights have been violated or who are experiencing difficulty securing relevant support services. P&A 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 deaths of all individuals with an intellectual disability over the age of 18 where abuse and /or neglect may have been the cause. Along with information on the Abuse Investigation Division and Case Advocacy Services, this summary highlights the ten-year report of P&A's Fatality Review Board. For the past ten years, P&A has played a critical role in reviewing and investigating the deaths of people served by human service systems, with particular emphasis on people supported through the Department of Developmental Services. Both P&A's Abuse Investigation Division and the Fatality Review Board for Persons with Disabilities have contributed to this effort.

### STATISTICAL HIGHLIGHTS

- Responded to 3,609 requests for information, referral and short-term assistance.
- Received 1,126 allegations of suspected abuse or neglect resulting in 1,117 cases.
- Provided intensive advocacy representation to 522 persons with disabilities addressing issues including, but not limited to, education, employment, housing, unnecessary institutionalization, rights violations, government benefits, quality assurance, guardianship, parental rights. child care.
- Sponsored or participated in 85 training events reaching more than 2,700 people with disabilities, family members and others.
- Reviewed 210 deaths of individuals served by the Department of Developmental Services and 4 deaths of individuals served by the Department of Mental Health and Addiction Services
- Attended 30 resource fairs or information events reaching more than 3,000 people.
- Distributed more than 14,000 disability related publications.
- Received more than 132,000 hits on the P&A website.
- Provided 3,500 people with disabilities the opportunity to register to vote.

Statistics alone do not tell the full story. The real life experiences of people with disabilities who turned to P&A, as summarized below, provide a glimpse of the impact that P&A's safeguarding activities have had on the lives of people with disabilities in Connecticut. P&A's 2012 Annual Report contains more comprehensive statistical information and more illustrative client stories. It is available on the P&A website at [www.ct.gov/opapd](http://www.ct.gov/opapd).

## **ABUSE INVESTIGATION DIVISION**

Sandra's Story: In late 2011, P&A's Abuse Investigation Division (AID) received a report alleging that "Sandra" (not her real name), a 50 year old woman with intellectual disabilities, was being beaten and "treated like a slave" in her home by her sister, who was also Sandra's guardian and principal caretaker. The reporter stated that the sister was preventing Sandra from attending her day program, and that she had hit Sandra with an extension cord for taking a piece of gum. A review of P&A files indicated that neglect had previously been substantiated in the home due to Sandra not receiving her prescribed medications.

In response to the December referral, P&A investigators made numerous attempts to contact Sandra at the home she shared with her sister. Attempts to schedule appointments proved fruitless as the phone was never answered, and calling card requests to contact P&A were ignored. Investigators made numerous unannounced visits to the home, but no one answered the door, even though sounds from inside the house suggested that someone was home. Meanwhile, Sandra continued to miss her day program. Eventually, the investigators' persistence paid off: as they arrived for another unannounced visit, Sandra's sister opened the door. She insisted that Sandra was not home, but promised that she would be there that next day.

The following day, AID investigators interviewed Sandra. They noted that she looked markedly thinner than she had at the time of their previous investigation. They also noted a large scratch on Sandra's right cheek, and a swollen right elbow. When asked how she had sustained those injuries, Sandra stated she received them from her sister who she also said beat her regularly and hit her with a wire. Although limited verbally, Sandra indicated to investigators that she was fearful on a daily basis that she would be hit by her sister. Sandra was clearly afraid, both of staying with her sister, and, at the same time, of leaving the premises. When interviewed, the sister denied causing any injuries to Sandra, but admitted that she had struck her from time to time.

Because Sandra had apparently been assaulted and sustained injuries, and because she was in fear of further assaults and injuries, P&A investigators contacted the local police and also requested immediate protective services from DDS. Sandra was taken to the hospital for an immediate evaluation and was then relocated to a DDS Community Care Home. Physical abuse was substantiated. Sandra remains living at the Community Care Home at this time and is reportedly doing very well.

**CASE ADVOCACY SERVICES-** For people who are uncertain about their rights, or who are facing daunting barriers, important life decisions, confrontations with powerful systems or even instances of outright discrimination, P&A provides empowering information, straight answers and short-term problem-solving assistance. The following story is one of many that reflect the human impact that P&A has made on lives of people with disabilities living in Connecticut:

Kevin's Story: When advocates met with Kevin and his mother, he had just been suspended from his middle school after having returned from an out-of-district educational placement. Kevin has learning and behavioral disabilities which qualify him for special education and related services under both federal and state law. However, his school had failed to convene educational meetings called Planning and Placement Team (PPT) meetings to evaluate and determine his needs for specialized instruction and support services. Without those supports, Kevin had considerable difficulty navigating the regular classroom program. Rather than providing the Individualized Education Plan (IEP) and resources to allow him to be successful within his school community, the District had responded to Kevin's behaviors with repeated suspensions and other punitive measures, and ultimately, by placing him into a poorly designed, inadequately resourced, segregated program it had hastily developed for students with behavior problems. Following numerous complaints, separate investigations by the State Department of Education and P&A, and a series of embarrassing newspaper articles, that program was adjudged to be a massive failure. The school system promised major changes would be made before the start of the next school year. However, one month prior to the start of that new school year, the school system decided to shut the program down and send its students, including Kevin, to a privately operated out-of-district placement nearly an hour away. At that school, Kevin was routinely physically restrained for misconduct.

Ultimately, Kevin and other students were returned to their home district, but without the individualized assessment and planning processes required by law. Kevin was back where he started – plunked down in a middle school that was ill-prepared to educate him, and without the appropriate evaluations and an individualized plan for teaching him the coping skills and academic information he desperately needed to succeed. In fact, he had lost ground – two academic years had been wasted by his school system as it shuttled Kevin and other students around, ignoring their needs while it made much-publicized efforts to improve test scores and graduation rates for other students.

P&A filed a formal complaint with the U.S. Department of Education's Office of Civil Rights (OCR) requesting an investigation of the school's pattern of unilateral and arbitrary placements and other potentially discriminatory practices affecting students with Emotional Disturbance (ED). OCR agreed to look into Kevin's situation as part of that inquiry. OCR was able to secure a plan of correction from the school system, and a further agreement to comply with it. The agreement ensured system change for Kevin and other students in the district. In Kevin's case, the school district agreed to review his educational placement and convene his PPT so that a placement decision could be made based on evaluations – evaluations that would include information from a variety of resources and a proper discussion of his needs. Kevin's team was also required to determine what and how much educational or other services, such as counseling or other related services he had lost, and to develop a plan to compensate him for those services, giving him the opportunity to catch up with his non-disabled peers. Kevin now attends school in his district with the supports he needs.

Supporting Parents with Cognitive limitations: For many years, P&A has represented parents with Intellectual Disability or borderline intellectual functioning. Through this work,

P&A has learned that it is not unusual for a parent to lose custody of their child - not because of anything they have done wrong, but because of their diagnosis. This occurs despite the fact that a considerable body of research exists demonstrating that parental capacity and intellectual functioning are not closely correlated. In some cases, this occurs because a parent needs some level of ongoing support. This can create difficulty in a child protection system that operates under mandated time lines that require development of a safe, permanent alternative if the birth parent's problem isn't "fixed" within a year or so. Such timeframes for "permanency planning" may be understandable in situations where addiction to substances, lack of skills or criminal acts are involved, but cognitive impairments are not "resolved" by completing a treatment program or making life changes. Even so, parents with intellectual disabilities are sometimes required to attend generic "parenting classes" which may have no bearing on their needs and issues, and may not even be offered in a format that is accessible to them. Even after completing these classes, the parents still need ongoing, individualized instruction and support. This is a situation where fighting discrimination requires both individual case advocacy and systems change work.

The latter has led to P&A's involvement in the State's Parents with Cognitive Limitations Workgroup, and membership in the international not-for-profit organization, The Association for Successful Parenting, (TASP). This year, a P&A staff advocate, was elected to a leadership role within that organization. And, after years of work by many allies, change is coming to Connecticut! The Department of Developmental Services (DDS) has obtained approval for Medicaid reimbursement for parental support and training, beginning early in 2013; and DDS and the Department of Children and Families are working together to meet the needs of families for the first time. These changes have already been making a difference for a number of Connecticut families. For more information visit [www.achancetoparent.net](http://www.achancetoparent.net)!

Partners in Policymaking: P&A also collaborated with its Developmental Disabilities Network partners to sponsor "Partners in Policymaking", (Partners) a nationally recognized comprehensive leadership training for people with disabilities and parents or grandparents of children with disabilities. Participants spent seven overnight sessions at a hotel where they had an opportunity to learn from state and national experts about disability related topics such as History of the Disability Rights Movement, Self Advocacy, Vocational Rehabilitation and Employment Rights, Housing, State and Federal Laws and Regulations, Inclusive Education, Assistive Technology, Communication and Team Building, and the Legislative Process. Monthly hands on activities helped to build oral communication skills culminating in a session where participants practiced expressing legislative ideas with their state senators and representatives. Each participant was responsible for developing a project that would benefit the disability community. Notable projects included training for boards of education about basic disability issues, a brochure on driver training for drivers with disabilities, and a public service announcement encouraging motorists to stay out of accessible parking spaces.

Because of the need to develop leaders in the disability community, P&A staff devoted significant time to Partners. P&A participated on the planning committee and attended sessions of the training, providing extensive support to Latino participants who experienced difficulty with the training. Staff provided training in the areas of cultural diversity, federal disability laws, special education, parliamentary procedure, how the legislature works in Connecticut and assistive technology.

## **FATALITY REVIEW BOARD**

The Fatality Review Board for Persons with Disabilities (FRB) was established to bring greater independence and oversight to the fatality review process for people with Intellectual Disability who receive services from the Department of Developmental Services (DDS). The FRB is supported by P&A and operates independent of the DDS independent mortality review structure. FRB staff tracks all reported DDS client deaths and pursues preliminary inquiries and full, independent investigations into selected deaths. The Executive Director of P&A chairs the FRB. The FRB also has Governor-appointed members who are drawn from medical, law enforcement, human service and forensic investigation professions. Since 2009, the Connecticut Legislature has required the Department of Mental Health and Addiction Services (DMHAS) to report the death of anyone receiving inpatient behavioral health services in a DMHAS-operated facility to P&A within 30 days after the individual's death. The FRB also reviews these deaths and investigates as necessary.

Fatality Review Board Ten Year Summary Report: For the past ten years, P&A has played a critical role in reviewing and investigating the deaths of people served by human service systems, with particular emphasis on people supported through the Department of Developmental Services. Both P&A's Abuse Investigation Division and the State's Fatality Review Board for Persons with Disabilities, which is supported by P&A, have contributed to this effort.

Questions of trust, blame, respect, confidentiality and fear of consequences and/or liability surround all mortality review processes, including those affecting people with intellectual and developmental disabilities. The stakes are high for everyone: for individual human beings who are trying to chart their own courses through life but who may depend, to varying degrees, on the competence and commitment of care givers to help them navigate through the world's complexities; for families seeking answers to agonizing questions; for providers and practitioners whose reputations and ability to continue to practice their professions are on the line; and for leaders in health and human service systems who are trying to implement policies that genuinely respect personal autonomy and individual choices on the one hand, yet establish reasonable safeguards and accountability mechanisms on the other.

Ten years ago, in response to questions about the levels of accountability and trustworthiness with which its developmental services system was monitoring client deaths, Connecticut created a mortality review process which is characterized by independent checks and balances. In contrast to previous practice, the current system

has both internal and external components. It assures that the death of each individual who receives even minimum levels of service through the developmental services system is reviewed, that suspected abuse and neglect are independently investigated, and that trends and systemic problems are identified so they can be addressed. After ten years of operation, a much more complete picture of the mortality experience of people with Intellectual Disability has emerged and a number of important issues have been identified. Many of those issues have been addressed while others still require action. Also emerging is a more sophisticated understanding of what the more persistent “problems” represent. When there has been an error or significant omission which has led to an individual’s death – something that never should have happened and never should be allowed to happen again – it is tempting to respond by imposing new procedural requirements, or by mandating universal training on a particular topic, or by adding additional layers of oversight. Sometimes such responses are warranted and actually helpful. But, sometimes, the ‘problem’ is not so easily isolated and addressed; sometimes it is a symptom of an underlying issue, like the slow starvation of the State’s chronically under-funded network of community service providers over the past fifteen years; or the naïve, yet widespread assumption operating within the culture of the developmental services system that it can do little to affect outcomes once its clients become “patients” in healthcare environments. Sometimes, too, the underlying problem can be best understood as one of misplaced administrative emphasis – too much reliance on regulatory requirements, bureaucratic detail and the myth of organizational perfectibility, and too little investment in cultivating competence and renewing commitment within the “human infrastructure” that is the blood and bones of any human service. Just as Gandhi warned against “systems so perfect that nobody needs to be good”, one of the most significant lessons fatality review teaches involves the critical importance of good values and a sense of shared responsibility on the part of people at all levels of the service system.

The good news is that Connecticut now has a comprehensive mortality review system, and it is clear that most – the vast majority – of deaths reviewed raise no questions about the quality of services or care. In fact, the records reviewed by the Fatality Review Board indicate that many of the individuals who died were genuinely respected, well supported, very much cared about by others, and that a number of those who had terminal conditions were able to pass away in their homes, supported to the end with dignity, respect and affection. At the end of our lives, we should all be so fortunate. Clearly there are many competent and committed caregivers supporting people with Intellectual Disabilities. But, an honest look requires that we acknowledge that too many things still go wrong, and that there are important lessons to learn by vigorously reviewing those cases. We owe it to those whose deaths were untimely to continue to pursue those lessons. In the end, a commitment to continual learning – to relentlessly pursuing an accurate understanding of what happened in each case - what worked and what didn’t, what contributed and what interfered, what needs to change – may be the most important way we can honor those people.

A copy of the full report is available on the P&A website at:  
<http://www.ct.gov/opapd/cwp/view.asp?Q=504040&A=1757>.

## 2013 Program Report Card: Abuse Investigation Division (OPA)

*Quality of Life Result:* All adults with intellectual disability are safe and secure.

*Contribution to the Result:* The Abuse Investigation Division (AID) ensures that allegations of abuse and neglect with respect to adults with intellectual disability are promptly and thoroughly investigated, and that when abuse or neglect is substantiated, Protective Service Plans (PSPs) are initiated through appropriate service agencies in order to remedy conditions and protect victims. If a situation of immediate jeopardy is reported, AID initiates a request for an Immediate Protective Service Plan (IPSP) from the Department of Developmental Services (DDS), pending the results of a full investigation. In addition, AID maintains a central registry of allegations, and monitors the status of PSPs to ensure promised services are, in fact, being delivered, and to determine whether there is a continuing need for a formal protective service plan.

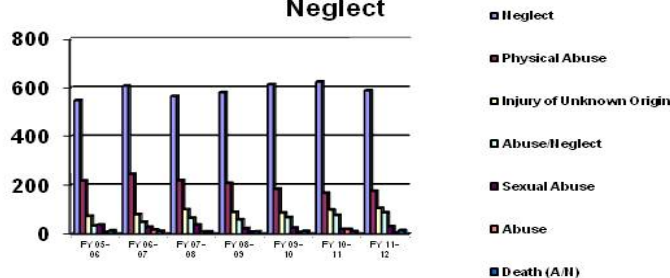
Program Expenditures	State Funding	Federal Funding	Other Funding	Total Funding
Actual FY 12	\$880,355	\$66,280	0	\$946,635
Estimated FY 13	\$847,749	\$63,825	0	\$911,574

*Partners:* Department of Developmental Services (DDS) and private providers licensed or contracted by DDS; State Prosecutors, Statutorily Mandated Reporters; State and local police agencies; probate courts; Departments of Public Health (DPH), Social Services (DSS) and Children and Families (DCF); Fatality Review Board for Persons with Disabilities (FRB); Office of the Chief Medical Examiner (OCME); Connecticut Sexual Assault Crisis Centers; local mental health authorities.

### How Much Did We Do?

Reporting rates of selected, specific categories of abuse and neglect.

**Rates of Selected Categories of Abuse and Neglect**

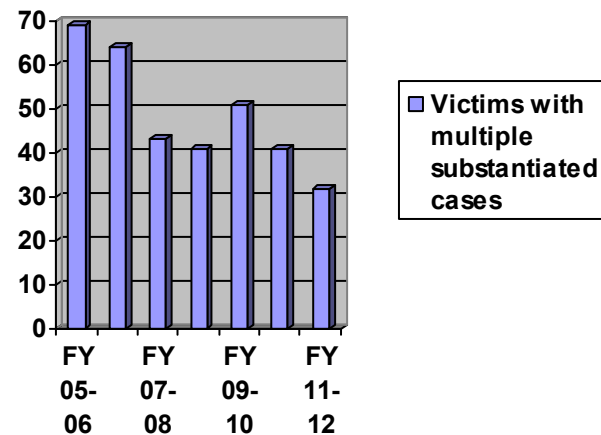


**Story behind the baseline:** Reporting of suspected abuse or neglect is a critical component in statewide efforts to remedy systems issues and protect against abuse and neglect. By tracking overall reporting activity, and focusing on particular categories, significant deviations from historical norms can be identified and further explanations sought. Identifying reporting patterns for particular categories of allegations also assists in developing systemic strategies for preventative efforts.

**Trend:** mixed ◀▶ Pretty stable.

### How Well Did We Do It?

Abuse/neglect victims with multiple substantiated



cases.

## 2013 Program Report Card: Abuse Investigation Division (OPA)

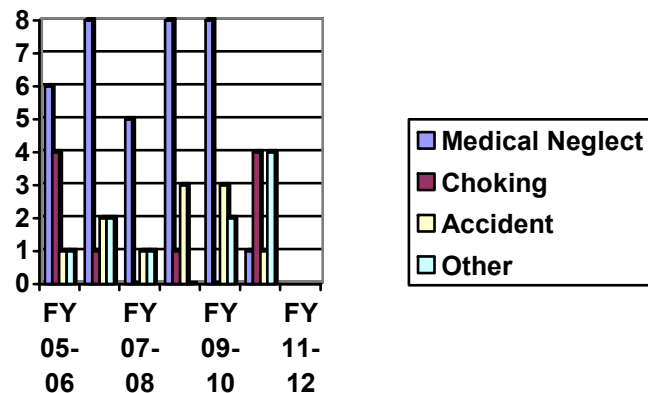
*Quality of Life Result:* All adults with intellectual disability are safe and secure.

**Story behind the baseline:** By focusing on the number of people who repeatedly become victims of abuse or neglect, this is one measure of the effectiveness of protective service interventions (PSPs). The decreasing number of repeat victims shown in this graph correlates to the establishment of a position within AID specifically dedicated to following up on PSPs. The one-year increase does not make a trend but we are aware of it. In addition, we are working to ensure individuals are provided with the appropriate services and supports to minimize the risk of re-victimization.

**Trend:** ▼

### Is Anyone Better Off?

Types of abuse and neglect allegations linked to DDS client deaths.



**Story behind the baseline:** Since 2004, AID has been charged with conducting investigations into all DDS client deaths where abuse or neglect are suspected to have played a role. Although the absolute numbers are relatively small, analysis reflected in this measure has informed efforts to address systems. For instance, in response to several deaths that resulted from choking on food, AID

urged DDS to initiate training and policy reviews that resulted in stronger safeguards for people at risk of choking

**Trend:** ◀▶ The trend is mixed. Deaths due to medical neglect have been almost eliminated. Choking deaths are back to 2005—2006 levels.

**Proposed Actions to Turn the Curve:** Quarterly meetings with the Department of Developmental Services to discuss trends and ways to better ensure the safety of their clients. Issuance of periodic reports regarding trends in allegations. Ongoing communication with regulatory agencies such as the Department of Public Health about the need for nursing homes to be competent to care for persons with intellectual disability.

Develop additional data on the length of time PSPs must remain under active monitoring, and identifying any regional or programmatic variables. This information will inform discussions with DDS and other partners. Continue to press for effective and timely PSPs during quarterly meetings with the Commissioner of DDS and his executive team.

**Data Development Agenda:** AID is working to improve its internal database to ensure that when queried the result is 100% reliable. The current database enables detailed case management but is not robust enough to properly track data and spot trends in a timely manner. Currently, it takes much paper, pencil, and time to check the results of the current software. The current AID database functions to maintain day to day operations, but an improved database will help AID keep on top of trends such as those measured in this report card. The better AID keeps on top of these trends the more credibility AID has to alert service providers and others to watch for dangers and opportunities to safeguard people with intellectual disability.

**Trend Going in Right Direction?** ▲ Yes; ▼ No; ◀▶ Flat/ No Trend



## 2013 Program Report Card: Case Advocacy Services (OPA)

*Quality of Life Result:* The civil and human rights of all Connecticut residents are respected and protected.

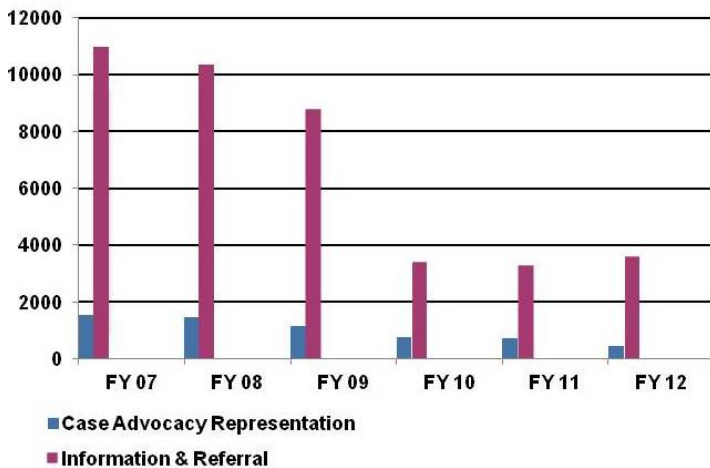
*Contribution to the Result:* Connecticut residents with disabilities have a place to turn to for help when they experience discrimination, abusive treatment or problems accessing relevant, respectful services.

Program Expenditures	State Funding	Federal Funding	Other Funding	Total Funding
Actual FY 12	\$702,249	\$657,431	0	\$1,359,680
Estimated FY 13	\$674,080	\$673,578	0	\$1,347,658

*Partners:* State and federal agencies and organizations serving people with disabilities, including the U.S. Departments of Justice and Education, and the following state agencies: DPH, DSS, SDE, DDS, DMHAS, DOT, DMV, DOL, DCF, CDHI, CHRO, BESB, and DOC; licensing and oversight bodies; state and national disability advocacy organizations including the National Disability Rights Network (the national umbrella organization for Protection & Advocacy Systems), and Connecticut's non-profit legal services organizations.

**How Much Did We Do?** The number of people served by Case Advocacy Services annually.

What level of service did people receive?



**Story behind the baseline:** Most people contacting OPA receive short-term problem-solving assistance (Information & Referral). A smaller number receive Case Advocacy Representation from staff advocates, or, in some cases from agency attorneys. Decisions about accepting cases for representation are based on both program mandates and annual

priorities which are established by the Advocacy Board. Beginning in FY 2010, there was a significant reduction in I&R requests reported. Some of this was due to increased utilization of the agency's improved web-based resource guides; a lot was due to not renewing contracts with regional I&R sub-contractors (due to lack of funding). Reductions in the numbers of people receiving case advocacy representation reflect the loss of staff advocate positions due to various funding cuts.

**Trend:** ▼

**How Well Did We Do It?** Because many people contacting OPA are facing deadlines for things like evictions, special education meetings, fair hearings, etc., we measure the time that elapses between receipt of an initial request for assistance and our response as an indicator of how well we are doing this work. I&R calls are expected to be returned within 24 hours; decisions about requests for case representation may require review of documents or additional information. In almost all cases correspondence is generated summarizing information provided or notifying the requestor of a decision on a request for representation. (In some cases, however, it is more appropriate and more timely to contact individuals by phone, in person, or by another means.)

**Trend Going in Right Direction?** ▲ Yes; ▼ No; ◀▶ Flat/ No Trend

## 2013 Program Report Card: Case Advocacy Services (OPA)

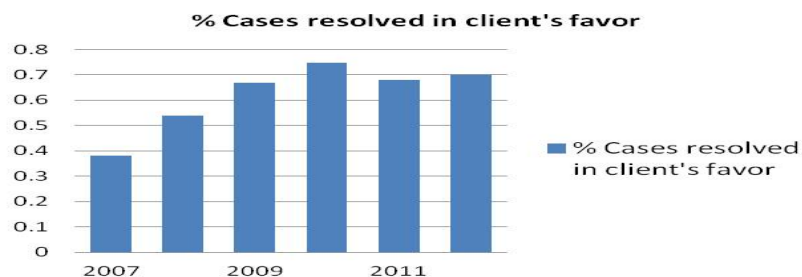
*Quality of Life Result:* The civil and human rights of all Connecticut residents are respected and protected.

**In 2012 OPA committed to develop a way to track the timeliness of decisions. Specifically, we started to track how long it took from initial contact with OPA to when clients were informed whether OPA would take on their case. This year, we have also begun to track I&R response time**

**Story behind the baseline:** As indicated in the 2012 RBA report card, OPA has just begun collecting this data. We are still working to generate this graph. In 2012 187 cases went to case review and it took an average of 16.5 days for case review decisions to be made. This number is misleading—93 of the cases were decided in 10 or fewer days and in many cases, the decision was made the same day. When we are contacted about special education issues, OPA advocates had requested copies of student records and reviewed the records before taking the case to case review. This delayed our response time significantly. Now advocates are bringing situations to case review right away, and if needed the Case Review Team advises the advocate to gather more information. Sometimes a situation is clear enough that the Case Review Team can tell an advocate to go ahead and begin work on a case.

**Trend:** too soon to tell

**Is Anyone Better Off?** The percentage of cases where issues are resolved partially or fully in the client's favor.



**Story behind the baseline:** "Issues resolved partially or fully in the client's favor" can be measured using our case management database. Each client has an Advocacy Plan which spells out how the case will flow and what OPA will do. OPA opened 431 cases and closed 252. Of the closed cases, 176 were resolved in the client's favor. The cases that remain open typically either were opened late in the year or involve a very high level of intervention.

**Trend:** ◀▶ The trend may be leveling off. From a low of 38% in 2007 to a high of 75% in 2010, the success rate increased substantially.

**Proposed Actions to Turn the Curve:** OPA was unable to develop special education clinics as originally planned. OPA was successful in hiring an attorney who has expertise in special education, but not until the first half of SFY 13. This will free up other legal resources to focus on other issues at no additional cost.

**Data Development Agenda:** As indicated in the 2012 RBA report card, OPA has developed a tool to capture the data for measure number 2--the time it takes from initial contact with OPA to when the individual seeking assistance is notified as to the decision made at Case Review on whether to provide Case Advocacy Services. This year OPA has also begun tracking response time for Information and Referral Services. OPA has a stated expectation to respond to calls, e-mails and other contacts within 24 hours.

**Connecticut Family Support Council Annual Report January 2013**  
**Connecticut Department of Children and Families (DCF)**

**Introduction**

Since the dissemination of the 2012 annual report of the Family Support Council, DCF has been involved in active implementation and refinement of a variety of initiatives, including but not limited to:

- Expanding the agency-wide use of Results Based Accountability
- Implementing the Differential Response System (Family Assessment Response)
- Launching Child and Family Teaming
- Securing "family systems managers" for the six DCF regions and the Albert J. Solnit Children's Center
- Continued congregate care rightsizing
- Development of the DCF Community Bridge RFP
- Awarding contracts for the Family and Community Ties program, and
- Expansion of Kinship Care.

DCF has done this work through partnerships with community providers, families, advocates, other state agencies, and with the consultation of experts in various fields and with the participation of Regional and Central Office DCF staff.

This year's DCF Family Support Council report focuses on two initiatives - Differential Response and Kinship Care - both of which are designed to maintain children and youth in family settings either through direct support to biological families or through the creation of relative-based foster care alternatives to congregate care. The first section below describes the Department's current status around evaluating and reporting program outcomes through the Results Based Accountability framework and how it will be applied to this report.

**Results Based Accountability**

The Department of Children and Families (DCF) is in the process of implementing Results Based Accountability (RBA) throughout its system. In addition, DCF has established a Community-Based Services Outcome Committee (CBSO) that provides leadership and direction related to enhancing, standardizing and monitoring client-based outcomes for all DCF purchased services. The goal is to assure that services are provided efficiently, there is clear accountability and evidence of positive outcomes for children and families in all aspects of care.

As part of this joint work, DCF has undertaken the redesign and re-procurement of fee-for-service and contracted community services. This will ensure that all programs are

either utilizing evidence based models (with well-established and tested quality improvement and evaluation components) or they must develop, implement and report on RBA outcomes. As this is implemented system-wide, DCF will be including this expectation in its contracts and fee-for-service provider agreements.

One important focus of these efforts within the Department has been to look specifically at the service categories of family support, child safety and reunification. The overarching goal of these services is to strengthen families so that maltreatment is decreased. We expect and hope that this will also reduce the need for DCF involvement. In order to look at program effectiveness, the CBSO Committee implemented the use of the Protective Factors Survey (PFS) developed by the Administration for Children and Families, funded by the National Resource Center and the University of Kansas. This evaluation tool is used with caregivers receiving child maltreatment prevention service; it employs a pre- and post-survey to measure protective factors in five areas: family functioning/resilience; social support; concrete support; nurturing/attachment; and knowledge of parenting/child development.

Use of the PFS tool began with DCF funded Family Enrichment Services and Intensive Family Preservation and has been expanded to Family Reunification Services and Community Support for Families (see below). The PFS will be utilized until a provider adopts an evidence-based model.

### **Differential Response**

The DCF Differential Response System (DRS) has been named the DCF Family Assessment Response (FAR). FAR and Community Support for Families contracts are parts of an integrated process to modify DCF's approach to working with and supporting families, particularly those families for whom a traditional abuse/neglect investigation is not required.

DRS is an evidence-based practice used in many states to improve how families are engaged around meeting the needs of children. Under a DRS structure, DCF is able to respond flexibly and engage families coming to the agency's attention (via an allegation of abuse) in a way that is best suited to the needs of that specific family. DRS offers an alternative to the traditional adversarial forensic-style investigation with a focus on engaging families in an assessment process that can lead to community services identified by the families themselves.

To implement DRS in Connecticut, DCF has developed an alternative track (to the typical abuse/neglect investigation) called the Family Assessment Response (FAR). A FAR case begins as a report to the DCF Careline (formerly referred to as the Hotline) but goes a very different route through an assessment of safety, risk and identification of family need. When this initial review indicates that the family is better served through referral to a community agency, this allows a family to gain access to services and supports without being subjected to an investigation and puts the focus of care in the

community where the family lives and works. The program is called Community Support for Families and is described further below.

In September 2011, DCF released a Request for Proposals to solicit interested community providers to become Community Partner Agencies (CPA). The CPA is expected to provide a range of services to support families referred through the DCF FAR teams and to cover specific geographical areas corresponding to DCF Area Offices within a Region.

Contracts were awarded to eight community agencies, and the program began in April of 2012:

- Region 1 – Child and Family Guidance Center
- Region 2 – Communicare  
Clifford Beers
- Region 3 - Community Health Resources
- Region 4 – Wheeler Clinic  
The Village for Families and Children
- Region 5 – Wellmore Behavioral Health
- Region 6 – Wheeler Clinic

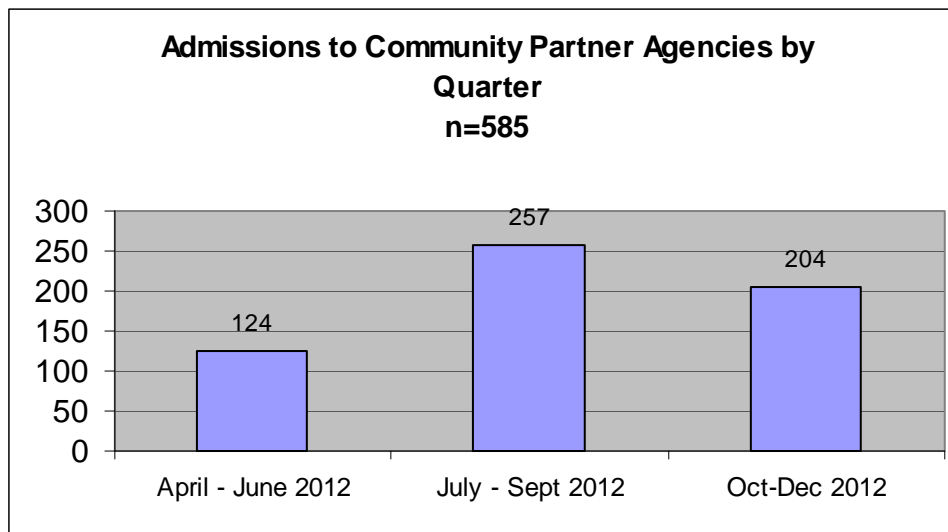
The Community Support for Families program is a short-term, voluntary, family driven service designed to assist the family in finding and using natural and community supports. The family is considered to be in the lead as it goes through an assessment process to identify needs. Then the family works in partnership with the community provider in the development of a plan of care. The Community Partner Agency's role is to empower, assist and support the family, facilitate linkages and connections in the community to obtain needed supports.

Staffing includes both Community Support Workers and Parent Navigators, and while most of the direct services are provided through linkages to both traditional and non-traditional resources found in the community, agency staff are responsible for the provision of individualized case management, parenting education, mentoring and advocacy, as well as facilitating access to wrap funds available through the DCF Regions to help families meet basic concrete needs. The community provider utilizes a wraparound family teaming model that is family-driven, strength based, and culturally and linguistically responsive. Families are equal partners having the most expertise around the care of their children.

The contracts, which were executed in April of 2012, require that the provider agencies complete the Protective Factors Survey (PFS) within 14 days of the referral to assess current strengths and needs of the family to inform referrals and service delivery. The PFS will be re-administered prior to case closing. There is an evaluation component to be completed by the University of Connecticut School of Social Work Performance Improvement Center.

## How Much Did We Do

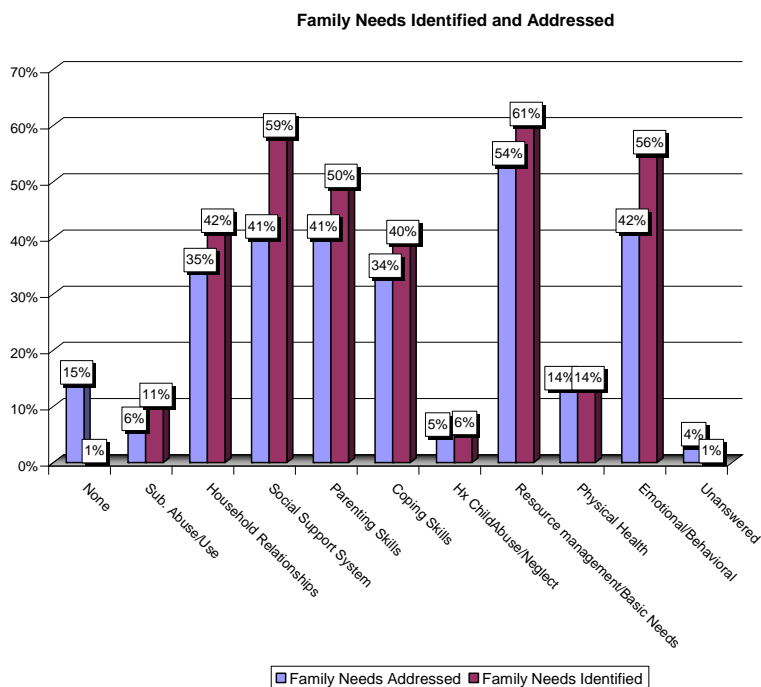
The program was implemented in April of 2012. Since that time, data available from the Department's Programs and Services Data Collection and Reporting System (PSDCRS) starts to show a picture of the early utilization numbers and provides some information about the participating families and children.



With regard to the children in these 585 families, 35% were identified as having one or more service/disability related needs that significantly impacts their functioning. The most frequent needs identified were behavioral health, followed by cognitive/other developmental disability, learning disability and medical.

Also of note is that 33% of the children and 49% of the caregivers reported at program entry to have a history of trauma. This includes being a victim of or witness to violence, sexual victimization, disrupted attachment/multiple placements or arrest of caregiver.

## How Well Did We Do It



This represents nine months of data from the Department's Programs and Services Data Collection and Reporting System (PSDCRS). A full analysis of these data will be completed by the University of Connecticut Performance Improvement Center. While there is a generally positive correlation between what families identified as needs and what was addressed by the programs, additional review is needed to determine if those data elements that reflect greater variability indicate unmet need or if there are other considerations which will inform ongoing administrative, programmatic or systems design and operation.

### Is Anyone Better Off

Of the 155 families discharged from the program between April 2012 and January 3, 2013, only 11 of them (7%) have had another DCF Careline report for which ongoing child protective services were indicated during the Community Partner Agency's involvement with the family.

As mentioned above, a complete analysis of data, including information collected through the Protective Factors Survey will be forthcoming from the University of Connecticut. But, given that this is a new program, this measure shows an early positive outcome for this program. This will continue to be monitored.

In addition, it is important to remember that the 585 families served through this program did not have to go through an intrusive investigation of abuse/neglect to obtain services.

### **Relative/Kinship Care**

On March 13, 2012, DCF Commissioner Joette Katz reported to the Connecticut Legislature's Human Services Committee and the Select Committee on Children as follows:

“Leadership at the Connecticut Department of Children and Families recognizes that the safety, permanency and well-being of children and youth are best achieved within the context of their own homes and communities. When placement *is* needed, research has taught us that children placed with relatives experience much more positive results over the long term, including greater stability and less placement disruption, better prospects of remaining with siblings, greater or equal safety, and more timely permanency.” (cite by name of report and page #)

Expansion of relative family resources for children was identified by Commissioner Katz as a key priority within the first 45 days of her tenure, beginning in February of 2011. In the March 2012 Kinship Care report, Commissioner Katz noted that this work had been in process prior to this administration's tenure, with a major focus and significant administrative and legislative support, and the outcomes have already been positive.

#### **How Much Did We Do: Relative Care**

As of March 2012:

- The proportion of child placements made to relatives increased from 15.3% to 22.7% over the time period from March 2011 to March 2012
- This reflects in real numbers an increase from 731 to 1,035 children placed with relatives

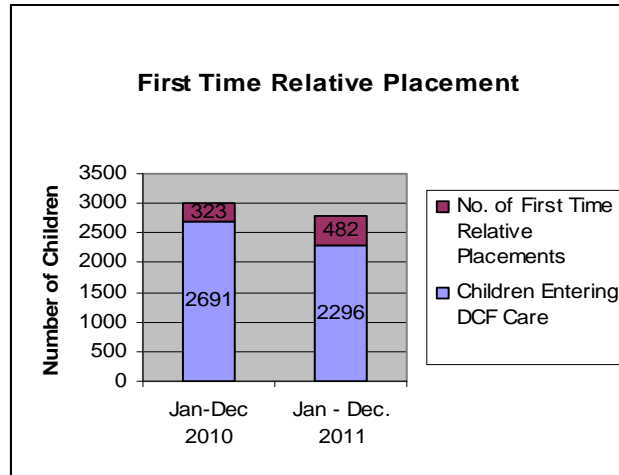
Continuing this upward trend, as of January 3, 2013 point in time data from the DCF LINK system reveals continued increases:

- On January 3, 2013, of the 4,067 children in placement, 984 or 24% are in relative care
- For the youngest children, from birth to age 11 there are 771 children or 40% in relative care



## How Well Did We Do It

Not only have the actual numbers of children in relative placements increased, but there has been a dramatic increase from 12% to 21% in the number of children initially placed with relatives upon first being removed from their home:



DCF has also increased the total number of licensed relative providers from 456 to 545.

## How Well Did We Do: Kinship Care

Kinship Care is a combination of both relative care and what DCF calls "special study" homes. Special study homes are those foster care placements with an identified adult in the child's life who has a pre-existing special relationship with the child and functions as family.

As of January 3, 2013:

1. Of the 4,067 children in placement, 1,151 or 28% are in kinship care homes
2. For the youngest children, from birth to age 11 there are 1,943 children in placement and 858 or 44% are placed in kinship care homes

Expanded use of relative and "special study" placements is one of the strategies through which DCF has been able to decrease its use of congregate care placements. There has been a decrease in admissions to congregate care settings from 679 in state fiscal year (SFY) 2009 to 431 in SFY 2012. The use of out-of-state placements has dropped from 236 in SFY 2009 to 39 in SFY 2012.

In order to provide additional support for families with children and youth who have complex behavioral, emotional and physical needs, DCF will be issuing a Request for

Proposals to develop a community support model called the Community Bridge System which will provide in-home services using evidence based practice models for children/youth aged 11 -18 years of age. These are children who are more likely to need out-of-home care if a successful intervention in the community is not available. The Community Bridge system, in combination with in-patient stabilization and short-term respite options, will provide additional support to families and children to remain in the community.

### Is Anyone Better Off

DCF's data development agenda includes the review of outcomes for children in relative/kinship care including: a reduction in child maltreatment and evidence that children are doing well socially, emotionally and in school/education programs. DCF's commitment will be to continue to reduce the placement of children in out-of-home settings through the provision of more targeted and effective community and family supports. If a child has to be removed from their home, the focus will be on developing and supporting relatives or other adults to be that family the child so needs and deserves.



# STATE OF CONNECTICUT

STATE DEPARTMENT OF EDUCATION



## CONNECTICUT STATE DEPARTMENT OF EDUCATION (CSDE) REPORT OF ACTIVITIES TO SUPPORT FAMILIES OF STUDENTS WITH DISABILITIES AND STUDENTS WITH SPECIAL HEALTH CARE NEEDS

Submitted by: Colleen Hayles  
Education Consultant  
Bureau of Special Education  
CSDE Representative to the Family Support Council  
January 2013

The Connecticut State Board of Education (SBOE) in its 2009 *Position Statement on School-Family-Community Partnerships for Student Success* calls for a shared responsibility among three equal partners to support students' 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 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 SBOE 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/activities to address the needs of families of students with disabilities and/or special health care needs:**

#### **Parent Survey**

In spring 2012, the CSDE, Bureau of Special Education (BSE), conducted a statewide survey of parents of students receiving special education services, ages 3 through 21. The statewide survey is the continuation of an ongoing collaborative effort between the BSE and the Connecticut Parent Advisory Work Group (the Parent Work Group) to collect

information on family satisfaction and parents' involvement in their child's special education program. The 2011-2012 statewide survey represents the first year of the second, six-year sampling protocol for the State Performance Plan (SPP). In 2004-2005, the first annual statewide Special Education Parent Survey was disseminated by the CSDE. The objectives of the survey were to identify, from the perspective of parents, areas of strength in Connecticut's special education programs as well as areas in need of improvement. The development and implementation of the survey was a collaborative effort between the CSDE and the Parent Work Group. The Parent Work Group, which currently continues in its advisory role to the CSDE, includes parents of students with disabilities and representatives from various parent support and advocacy organizations. Each year a report summarizes findings from the survey and is organized into seven sections. Section I presents an overview of survey development and distribution, including a brief description of the survey design and the sampling methodology employed. Section II includes the survey response rate (overall and by district) and Section III presents the demographics of survey respondents. Findings from the survey analysis are provided in Sections IV-VII and include a summary of overall responses, differences by demographics, a summary of open-ended comments and differences across survey years.

District-level parent survey data is reported in a supplemental district report, which can be found on the CSDE Web site. Districts receive their survey results and are encouraged to utilize the information in addressing their school improvement plans and improving their partnerships with parents. The 2011-12 results have been submitted for posting on the CSDE Web site.

#### **Parent Surveys (SPP Indicator 8)**

<http://www.sde.ct.gov/sde/cwp/view.asp?a=2626&q=322094>

#### **SPP Indicator 8 - Parent Involvement**

- Parent Survey District Report 2010-2011 [PDF]
- Parent Survey Summary Report 2010-2011 [PDF]

#### **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. As one component of these ongoing efforts, the CSDE commissioned the Center for Collaborative Evaluation and Strategic Change (CCESC) at EDUCATION CONNECTION to develop an online survey to collect information regarding the status of school health services from school districts throughout Connecticut. 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>.

#### **Parent Work Group**

The Parent Work Group continues to act in an advisory capacity to the CSDE maintaining its primary purpose which is to address the parent involvement question (#12) on the statewide Special Education Survey, for inclusion in the SSP/Annual

Performance Report (APR). The Parent Work Group has also engaged in a variety of other projects, which include but are not limited to: revising the *Helpful CT Resources for Families*; providing feedback on the proposed individualized education program (IEP) Web-based training tool for parents; providing input into the creation of a plain-language companion document for parents to the recently published *Augmentative and Alternative Communication Resource Guide*; developing and disseminating the Resource Toolkit for districts to enhance the school-family partnership; and identifying district and building level contacts for dissemination of special education material to parents. The Parent Work Group meets 5-6 times each year and current activities focus on revising useful documents for parents of students with disabilities (i.e., the *Helpful CT Resources for Families* document and *Before, During and After the PPT* document), as well as finalizing recommendations for the revision of the statewide Special Education Parent Survey.

### **State Advisory Council (SAC)**

The Connecticut State Advisory Council (SAC) on Special Education has been authorized by the Individuals with Disabilities Education Improvement Act (IDEA) since the Act's inception in 1975. The SAC 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 SAC addresses all five goals of the Comprehensive Plan of the State Board of Education and is specifically mandated to:

- Identify the unmet needs of children with special education needs.
- Review periodically the laws, regulations, standards, and guidelines pertaining to special education.
- Comment on any new or revised regulations, standards and guidelines proposed for issuance.
- Participate with the State Board of Education in the development of any state plan for the provision of special education.
- Assist the CSDE in developing and reporting such data and evaluations as may be conducted pursuant to the provisions of said Act.
- Encourage compliance with the IDEA and C.G.S. Section 10-76.
- To provide a forum for individuals or groups to express their ideas related to statewide special education issues.
- Advise the Commissioner and the SBOE on issues related to the provision of special education services.

Membership on the SAC is dictated by IDEA. Members are appointed by an official authorized to make such appointments; are representative of the State population; are comprised of individuals involved in, or concerned with, the education of children with disabilities; and more than 50% of members must be persons with disabilities or parents of children with disabilities under the age of 27. By federal and state law, the composition of the SAC must include the following: parents of children with disabilities under the age of 27; individuals with disabilities; teachers; representatives of institutions of higher education that prepare special education and related services personnel; state and local education officials; administrators of programs; representatives of other State agencies involving in financing or delivery of related services; representatives from

charter schools; representative(s) for vocational, community, or business organizations concerned with the provision of transition services; a representative for the State child welfare agency responsible for foster care; representatives from the State juvenile and adult corrections agencies; a representative from the CT Office of Protection and Advocacy for Persons with Disabilities; a representative from the CT parent training and information center (i.e., CT Parent Advocacy Center, CPAC); and a representative of the Parent Leadership Training Institute of the CT Commission on Children.

### **Connecticut Parent Advocacy Center (CPAC)**

The CPAC is Connecticut's federally-funded Parent Training and Information center (PTI); CPAC's core funding comes through the U.S. Department of Education (USDOE) grants from the CSDE and private donations. The CPAC offers information and support to families of children with any disability or chronic illness, age birth through 26. The 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 the CPAC serves has grown dramatically. The 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.

### **Connecticut Parent Information and Resource Center (PIRC)**

The PIRC is a non-profit organization partially funded by a grant through the USDOE. The 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, the PIRC provides support, referrals to helpful resources, training sessions, presentations at community events, and special programs that celebrate families' cultural and linguistic diversity. For families, teachers, faith-based organizations and other professionals who work with and care for children, the PIRC has developed a Web site with resources and announcements about family learning, family involvement and school-family-community partnerships, as well as a library collection, with family and school-family-community resources. Professional development opportunities for school districts statewide on School-Family-Community Partnerships, Welcoming Atmosphere Tool Kit Training, Action Team Training, No Child Left Behind (NCLB) for family service providers, and Family Literacy Institute are also available for teachers and others. The PIRC also provides support for service providers and school personnel in targeted Title I districts on developing and implementing effective parent involvement policies, programs and activities.

### **Trainings**

Statewide workshops were jointly offered to parents and district staff by CSDE and partners and included workshops on transition assessment and the IEP. Trainings were

provided on writing appropriate, measurable post-secondary goals (e.g., Post-School Outcome Goal Statements) to district personnel and families to improve transition services. Parent advocacy training with respect to secondary transition was provided to: Learning Disabilities Association (LDA), Autism Spectrum Resource Center (ASRC), The Connecticut Association for Children and Adults with Learning Disabilities (CACLD) and African and Caribbean American Parents of Children with Disabilities (AFCAMP) as well as Cadre 1 of the Transition Train-the-Trainers professionals and parents.

Additional workshops topics included but were not limited to:

- Developing the IEP
- Understanding Challenging Behaviors
- Accommodations and Modifications for Children with Learning Disabilities
- Progress Monitoring
- Help: My Child is Struggling in School
- Understanding ADHD
- Resolving Disputes
- Meaningful Collaboration
- Effective Transition
- The Intersection of SRBI and the LD Guidelines
- Faith, Families and Schools Conference
- Connecticut's Revised Guidelines for Identifying Children with Learning Disabilities
- Parent Leadership Training
- Updates in Diabetes Management: What School Nurses Need to Know;
- Role of the School Nurse in Pre-School Programs
- Asthma Management for Schools
- Documentation: Implications in School Health
- Food Allergies at School
- Understanding Section 504

### **Guidance Documents**

Guidance documents are available to parents/families as well as professionals and provide disability specific information, regarding pre referral, referral and eligibility determinations as well as special education and IEP guidance.

- A Family Guide: Connecticut's Framework to RTI
- Parent's Guide to Special Education in Connecticut
- Helpful CT Resources for Families
- PPT Checklist
- A Seven-Step Process to Creating Standards Based IEPs
- Promoting School Success for Children with Disabilities (Least Restrictive Environment; PPT 101; PPT Process)
- SDE: Early Childhood Special Education
- Students with Disabilities and Parental Choice in Connecticut
- The Complaint Resolution Process

### **Disability Specific Information/Guidance**

- Guidelines for Identification and Education of Children and Youth with **Autism** (2005)
- Guidelines for Identifying Children with **Intellectual Disability**
- Guidelines for Identifying Children with **Learning Disabilities** (2010)
- Guidelines for Identifying and Educating Students with **Serious Emotional Disturbance**
- Guidelines for **Speech and Language** Programs (2008)
- Learning and Diabetes: A Resource Guide for Connecticut Schools and Families

### **Other Related Guidance**

- Guidelines for **Assistive Technology** (1999) [PDF]
- Topic Brief: **Evaluation Timelines Guidance** [PDF]
- Topic Brief: **Extended School Year** [PDF]
- Guidelines for **Feeding and Swallowing** Programs in Schools (2008) [PDF]
- Guidelines for **Health Screenings: Vision, Hearing and Postural** (2004) [PDF]
- Guidelines for Blood Glucose Self-Monitoring in School
- Guidelines for Managing Life-Threatening Food Allergies in Connecticut Schools
- Guidelines for a Coordinated Approach to School Health
- Guidelines for **Health Screenings: Vision, Hearing and Postural** (2004) [PDF]
- Guidelines for **Occupational Therapy** in Educational Settings (1999) [PDF]
- Guidelines for Training and Support of **Paraprofessionals** (2008) [PDF]
- Topic Brief: **Post-school Outcome Goal Statements** - Frequently Asked Questions [PDF]
- Guidelines for **Physical Therapy** in Educational Settings (1999) [PDF]
- Guidelines for Developing Policies and Procedures for **Reporting of Child Abuse and Neglect** (2000) [PDF]
- A Guide to Comprehensive **School Counseling** Program Development (2008) [PDF]
- Guidelines for the Practice of **School Psychology** (2004) [PDF]
- Guide for the Training, Use and Supervision of **Speech-Language Pathology Aides** and Assistants in Connecticut (1999) [PDF]
- Topic Brief: **Summary of Performance (SOP)** Frequently Asked Questions [PDF]
- Topic Brief: **Writing Transition Goals and Objectives** [PDF]

### **Other Bureau of Special Education activities, which involve parents:**

**Focus Monitoring:** Parents are involved with Bureau of Special Education Staff and SERC partners in conducting Focus Monitoring of identified districts. As part of the Connecticut State Performance Plan (SPP) and General Supervision System, the focused monitoring system ensures:

- a free and appropriate public education (FAPE) in the least restrictive environment (LRE) is both accessible and available to students with a disability;



- a full investigation of the targeted key performance indicator is conducted; and
- if noncompliance is identified, corrective actions are implemented, evidence-based technical assistance is recommended, deficiencies are addressed and noncompliance is verified for correction within 12 months.

**Connecticut State Personnel Development Grant (SPDG):** Parent engagement in the CSDE’s efforts to increase the implementation of positive behavioral intervention supports (PBIS) and literacy initiatives within an scientifically research-based interventions (SRBI) framework across the state is reflected through the partnership of the state’s PTI (CPAC) in the role out of the recently awarded SPDG.

**Technical Assistance:** The BSE provides on-going technical assistance to parents across the state. Education consultants within the bureau are assigned to specific school districts to field inquiries and concerns and provide guidance to parents related to policy, procedures and best practices as they relate to IDEA and state special education law and regulation.

### **Coordinated School Health (CSH)**

The CSDE promotes a Coordinated School Health Program and provides a nursing consultant and resources to address concerns and questions of parents and professional related to students with **special health care needs**.

- **Vision:** Connecticut’s children and adolescents are healthy, learning and succeeding in life. Components of a Coordinated School Health Program include school health services; health education ; healthy school environment; family/community involvement; physical education; counseling, psychology and social services; school nutrition services and health promotion for staff.

CSH is an effective system designed to improve health and academic achievement. CSH improves students’ health and their capacity to learn through the support of families, communities and schools working together. A coordinated approach to school health effectively aligns health and education efforts and leads to improved physical, mental and developmental outcomes for students. Research studies over the past decade have consistently concluded that student health status and student achievement are directly connected and, in fact, that student health is one of the most significant influences on learning and achievement. Additionally, a coordinated approach to school health reduces fragmentation, duplication of services and provides a streamlined system for service delivery.

To learn more, read the Connecticut SBOE Position Statement at [www.ct.gov/sde/healthyconneCTions](http://www.ct.gov/sde/healthyconneCTions).

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, in partnership with the State Department of Public Health (DPH), receives funding from the Centers for Disease Control and Prevention (CDC) to support CSH activities. The five-year strategic plan has three main goals:

- Expand and strengthen state-level infrastructures to promote CSH.
- Increase the capacity of school districts and schools to implement policies, practices and programs to promote physical activity, improve nutrition, reduce tobacco use (PANT) and decrease higher risk behaviors that may lead to HIV/STD infection and unintended pregnancy.
- Increase awareness of the purpose and benefits of CSH in reducing health and education disparities.

## Connecticut State Department of Education/ The CT Special Education Parent Satisfaction Survey 2011-2012

**Quality of Life Result:** Increase Parent satisfaction in Special Education Programs provided by School Districts in Connecticut. Recommend supports and services for stakeholders at the local level which will impact parent satisfaction related to special education services provided for their child.

**Purpose:** Since 2004-2005, the Connecticut State Department of Education has conducted an annual statewide Special Education Parent Survey. 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. The development and implementation of the survey is a collaborative effort between the CSDE and the CT Parent Advisory Work Group.

**Major Consumers:** The CT Special Education Parent Survey questionnaire asks respondents to answer a series of statements in six topic areas: satisfaction with the child's special education program; participation in developing and implementing the child's program; the child's participation; transition planning for preschoolers and secondary students; parent training and support and the child's skills

**How are we doing?** In May of 2012, surveys were sent to all parents of students with disabilities in 19 of the 21 districts participating in the seventh year of the survey. Surveys were sent to a sample of parents

(according to the sampling design) in the two largest participating districts..

In year seven of the survey, changes were made in an effort to increase response rates through the pilot of an online survey. Close to one in five parents completed the survey online. A second change – made in conjunction with the new online option – was to replace the more traditional stamped return envelope with a business return envelope. Other changes included adding the statement “important parent information from the CT State Department of Education” to the envelope of the initial mailing; sending of follow-up correspondence, developed by the CT Parent Advisory Work Group, to participating districts with specific options to consider for increasing the response rate; and revision of the Spanish survey materials to ensure the content was readily accessible to Spanish-speaking parents, including the availability of CSDE and CPAC representatives who could answer questions in Spanish.

**Key Findings: Are the consumers better off?** Key findings of the 2011-2012 parent survey are presented according to the following three themes: 1) areas of strength; 2) areas for improvement; and 3) trends across survey years.

### **Areas of Strength**

☐ **General Satisfaction:** The majority (86.8%) of survey respondents agreed that they are

satisfied with their child's overall special education program.

☐ **Child Participation:** When asked if their child has the opportunity to participate in school-sponsored activities, 96.8% of parents agreed. In regards to PPT participation, over 90% of parents of secondary students agreed that the school district actively encourages their child to participate in PPT meetings. These two statements received the most parents to *strongly* agree across the 40-item survey (82.7% and 75.8%, respectively).

☐ **Child Acceptance:** When asked if their child is accepted within the school community, 91.5% of parents agreed and more than one-half (59.5%) *strongly* agreed.

☐ **Parents as Partners:** Over 90% of parents indicated that they have the opportunity to talk to their child's teachers on a regular basis to discuss their questions and concerns; that they are encouraged to give input and express their concerns at IEP meetings; and their concerns and recommendations are documented in the development of their child's IEP. In addition, when asked if they are encouraged to be an equal partner in the implementation of their child's IEP, 89.0% agreed with this statement.

☐ **Parent-Friendly Materials and Processes:** Over 95% of parents agreed that they understand what is discussed at meetings to develop their child's IEP and 92.9% agreed that their child's evaluation report is written in terms they understand. In addition, the overwhelming majority of parents agreed that the PPT

## Connecticut State Department of Education/ The CT Special Education Parent Satisfaction Survey 2011-2012

meetings have been scheduled at times and places that met their needs and they have received a copy of their child's IEP within 5 school days after the PPT (92.6% and 92.3%, respectively).

☐ *Satisfaction of Specific Parents:* Parents of children with an intellectual disability, a developmental delay, a speech or language impairment, or a specific learning disability tended to report higher levels of satisfaction than other parents. In addition, parents of children at the opposite ends of the age spectrum (ages 3-5 and ages 18-21) also tended to answer more positively.

### **Areas for Improvement**

☐ *Transition to Adulthood:* Across three of the statements in the secondary transition section of the survey, almost 1 in 5 parents of secondary students disagreed. This included 18.2% of parents who disagreed that outside agencies have been invited to participate in secondary transition planning, 19.4% of parents who disagreed that the PPT introduced planning for their child's transition to adulthood, and 18.3% of parents who disagreed that the PPT developed individualized goals for their child related to employment/ postsecondary education, independent living and community participation.

☐ *Parent Training:* More than one-half (57.9%) of parents disagreed when asked if they have attended parent training or information sessions that addressed the needs of parents and of children with disabilities. In addition,

more than one-third (33.9%) of parents disagreed when asked if these opportunities existed and more than one-quarter (29.1%) did not know if such opportunities existed.

☐ *Parent Support:* Approximately two-thirds (66.9%) of parents disagreed when asked if they are involved in a support network for parents of students with disabilities. In addition, more than one-quarter (29.9%) disagreed that a support network for parents of students with disabilities is available and 31.9% did not know if such a network existed.

☐ *Support for Extracurricular Activities:* When asked if the school provides supports, such as extra staff, that are necessary for their child to participate in extracurricular activities 24.0% of parents disagreed with the statement and 15.0% indicated that they did not know.

☐ *Dissatisfaction of Specific Parents:* Overall, parents of children with an emotional disturbance, multiple disabilities, and ADD/HD tended to report lower levels of satisfaction than other parents. In addition, parents of children ages 13-14 also tended to respond less favorably than parents of children in other age groups.

### **Survey Trends**

Overall, a very slight upward trend in parent satisfaction has emerged across the seven years of the survey. However, the change has been incremental, with few (if any) substantial differences visible across time. Differences in parent agreement were most evident in the transition planning section of the survey where 6 of the 7 statements had a difference of more than 5 percentage points from Year 1 to Year 7.

☐ *Transition to Adulthood:* More than 80% of parents agreed that the PPT introduced

planning for their child's transition to adulthood in Year 7 compared to 60.9% in Year 1, a difference of almost 20 percentage points.

☐ *Course of Study at the High School:* When asked if the PPT discussed an appropriate course of study at the high school for their child, approximately 90% of parents agreed in Year 7 compared to less than three-quarters (71.8%) of parents in Year 1, a difference of roughly 18 percentage points.

### **Survey Impact**

The survey results are shared each year with the appropriate districts. Districts are encouraged to use their survey results to inform their larger school and district improvement plans related to parent participation and their staff development agenda. Results are also considered in recommendations to the CSDE and the Bureau of Special Education to inform statewide initiatives.

**Submission from the Office of the Child Advocate for the  
2013 Report of the Family Support Council**

**January 2013**

**Statutory Mandate:**

Respond to citizen concerns or complaints regarding the provision of state or state-funded services to children.

**Quality of Life Result:**

Oversee the protection and care of Connecticut's children and advocate for their well-being.

**How Much Did We Do?**

In the reporting period July 1, 2011 to June 30, 2012, the Office of the Child Advocate (OCA) documented 353 requests for assistance regarding specific children. These requests came from family members, providers, educators, attorneys, and from children themselves. Caller confidentiality is assured by statute.

**How Well Did We Do It?**

All documented requests for assistance were responded to in a timely manner.

**Is Anyone Better Off?**

Callers were able to navigate public systems effectively to ensure that their voice is heard and their concern is addressed appropriately. OCA provided education, coaching on self-advocacy strategies, individualized and professional technical assistance, and follow-up. When deemed appropriate and necessary, the OCA became directly involved in investigating reported concerns. During the reporting period, OCA opened 57 individual cases, where an OCA staff member identified concerns regarding the safety or unmet needs of a child (or children) and proceeded to take any and all necessary action to ensure child safety and well-being. OCA had direct contact with 175 individual children, many in state run or licensed institutional setting, to assess their needs and assist them through direct advocacy. OCA staff conducted or participated in 629 case reviews. Case investigation and advocacy included 568 documented contacts with public agencies and 70 contacts with attorneys representing children and families. The substantive areas in which families were provided assistance included child protection, health care access, special education, access to counsel, and access to child care.

Program Report Card: Birth to Three System, Department of Developmental Services

*Quality of Life Result:* All Connecticut children are healthy and ready for school success at age 5, contributing to a reduction over time in Connecticut’s achievement gap at Grade 4.

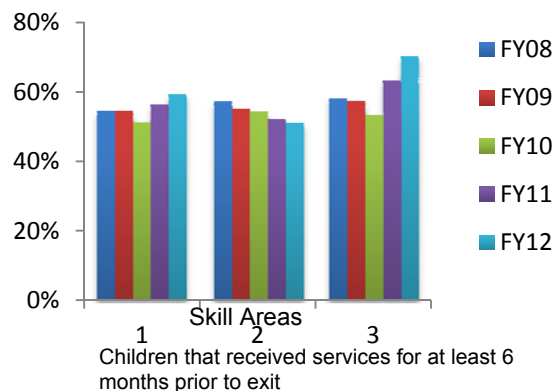
*Program Contribution to Result:* By providing family-centered early intervention services, the program strengthens the capacity of Connecticut’s families to meet the developmental and health-related needs of their infants and toddlers who have delays or disabilities, thereby ensuring that more of these children are ready for Kindergarten. Activities include coaching caregivers to embed intervention in the child’s daily natural routines and learning opportunities.

Program Expenditures	State Funding	Federal Funding	Other Funding	Total Funding
Actual FY 12	\$38,840,094	\$5,432,721	\$5,922,014	\$50,194,824
Estimated FY 13	\$41,467.16*	\$5,103,582	\$7,122,000 (parent fees and commercial insurance)	\$49,180,107

\*Medicaid FFP projection of \$6M will offset state funding

*Partners:* 41 Contracted provider programs; local school districts; Pediatricians and Family Medicine Practitioners; Hospital NICU staff; Office of Policy and Management; The Department of Public Health; Department of Insurance; The State Department of Education; The Department of Children and Families; Board of Education and Services for the Blind; DAS - Fiscal Service Center; DSS - Medicaid Unit, Disability Determination Unit, and Children’s Trust Fund; University of Connecticut UCEDD<sup>1</sup>; Early Childhood Cabinet; HMO Association Members and Anthem; United Way Child Development Infoline (CDI); State Interagency Coordinating Council; Local Interagency Coordinating Councils; Rather than adding new partners, we continue to revise our working relationship with existing partners. e.g.: Revised MOU with DCF around developmental screening of all children who are victims of substantiated abuse or neglect and referral to Birth to Three if warranted.

**Performance Measure 1:** Percentage of Infants and toddlers with disabilities or developmental delays who improve so that at exit, they function *at age level* in three skill areas.



**Story behind the baseline:** The three skill areas on the above graph are: (1) social/emotional; (2) acquisition and use of knowledge (including early language and literacy); and (3) use of appropriate behavior to meet their needs

Each bar represents the percentage of children that performed at age level in each skill area at the time they exited the Birth to Three System. DDS has been able to include children referred from birth since FY10. The national trend is level on this measure. As the quality of the data collection improves, new baselines will be set using FY14 data. Data from this measure is consistent with data from Measure 3.

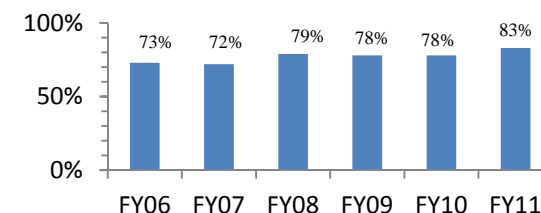
**Proposed actions to turn the curve:** Since Birth to Three only enrolls children with significant delays or disabilities, it is not possible that 100% of children will exit the program at age-level. However, we do expect these percentages to increase from their current levels. The research shows that improvement is most highly correlated with the ability of each provider to ensure that parents and childcare providers know how to incorporate intervention techniques into daily routines so that each child gets the maximum amount of practice, all day, every day. This is a different approach than out-patient rehabilitation services, in which short sessions in therapy rooms are expected to lead to generalization and carry over into other environments. That approach does not work well for infants and toddlers. Since each local program is responsible for overseeing the delivery of early intervention services, the next step will be to rank

each program on its child outcome data and then focus on improving the low-performing programs through technical assistance and additional training for their personnel.

**Trend:** ◀▶

**Performance Measure 2:** Percentage of families who report that, as a result of receiving services from the Birth to Three System, they are better able to help their children develop and learn

**As a result of Birth to Three services I can help my child develop and learn**



**Story behind the baseline:** The blue bars on the above graph show the percentage of families who **strongly or very strongly** agreed with the statement: “Birth to Three has helped me to help my child develop and learn.” The trend in this positive family

## Program Report Card: Birth to Three System, Department of Developmental Services

**Quality of Life Result:** All Connecticut children are healthy and ready for school success at age 5, contributing to a reduction over time in Connecticut's achievement gap at Grade 4.

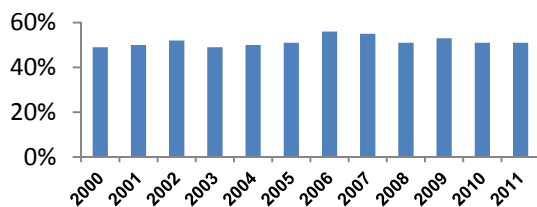
response has increased from 73% to 83% over the past six years, which shows the programs' effectiveness in achieving their mission of helping families to facilitate their children's development. If we add those families who said they "agree", the percentage of families indicating "agree, strongly agree or very strongly agree" for this measure was 98%

**Proposed actions to turn the curve:** This data, like the child outcome data, will be publicly posted by program and used to monitor any low-performing programs and drive improvement of how well staff works with families.

**Trend:** ▲

**Performance Measure 3:** Percentage of children who were found eligible for Birth to Three services and who do not require special education services in Kindergarten.

### No Individualized Education Program (IEP) in Kindergarten



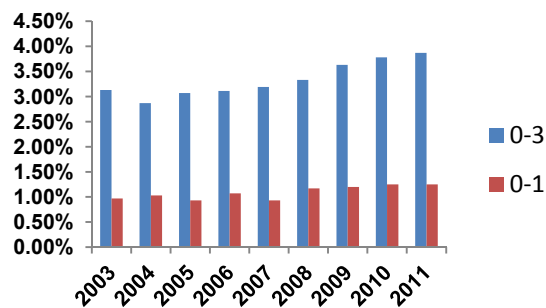
**Story behind the baseline:** The blue bars on the above graph shows the percentage of children who had been enrolled in the Birth to Three System, who were enrolled in Kindergarten as of December 1 of each calendar year, and who were *not* receiving special education services. The trend shows a slightly increased percentage, from 49% in 2000 to 51% in school year 2011-2012 (the most recent data available). This translates to some increased savings in special education costs to the state and municipalities. Data accuracy was enhanced for 2009 when the first of the children who received state

assigned identification numbers while in Birth to Three (2006/2007) were enrolled in Kindergarten.

**Proposed actions to turn the curve:** This is the strongest measure of "Ready for Kindergarten" for children with disabilities, but since children have been out of Birth to Three for two years, only improvement on Measures #1 and #2 will result in improvement on Measure #3. If a higher percentage of children attain age-level by the time they leave Birth to Three (#1) and more parents are confident that they can help their child continue to learn and develop (#2), there should be fewer children receiving special education two years later.

**Trend:** ◀▶

**Performance Measure 4:** Percentage of children under the age of three and under the age of one receiving services from the Birth to Three System.



**Story behind the baseline:** The blue bar on the above graph represents the percentage of all Connecticut children from birth to age three enrolled as of December 1 of each year. The red bar represents the percentage of all Connecticut children under the age of twelve months enrolled as of December 1 of each year.

The increase, from 3.16% in 2003 to 3.87% in December, 2011 demonstrates that the system is serving more children overall, but the percentage of children under the age of 12 months has not increased proportionally.

**Proposed actions to turn the curve:** An interagency agreement with the Department of Public Health has allowed direct mailings to families of very low birth weight and preterm infants who are not enrolled in Birth to Three. In FY12, Connecticut has chosen the measure of "percentage of eligible children under the age of 12 months" as a performance measure to concentrate on for the next 3-5 years. We are looking at selecting more sensitive evaluation tools for children under 12 months, ensuring that an OT or PT is part of the evaluation team for children under 12 months, funding a parent to be present at the state's regional level 3 neonatal intensive care units and creating NICU "ambassadors" at the other level 3 NICUs in Connecticut to encourage parents to enroll their children,

**Trend:** ▲

## Connecticut Department of Social Services (Family Support Council – 2013)

In addition to the Katie Beckett Waiver, the Department of Social Services continues to offer a range of programs and services for children and families with special health care needs. For this report, the focus is on the Children's Trust Fund. The Trust Fund provides the following programs and services that support children and families with special health care needs:

- *Family Empowerment Program*

In partnership with Child Guidance in Bridgeport, the Trust Fund offers programs and training for parents and caregiver that assist them in developing the skills and knowledge to deal with the unique needs of children with developmental disabilities.

- *Help Me Grow*

This program identifies children who evidence early signs of developmental delays. It affords children and families early connection with programs and services, including referrals, that are helpful in responding to the special needs of children and families; it also provides ongoing surveillance of the child's/children's development.

- *Nurturing Families Network*

This program offers training for staff that provides in-home services. The program seeks to ensure optimal services as well as sound parent education, particularly children and parents with special health care needs.









Dannel P. Malloy, Governor

Connecticut Family Support Council

460 Capitol Avenue

Hartford, Connecticut 06106

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

[www.ctfsc.org](http://www.ctfsc.org)