



STATE OF CONNECTICUT

Department of Developmental Services

**DDS**

Dannel P. Malloy, Governor

Terrence W. Macy, Ph.D., Commissioner

Joseph W. Drexler, Deputy Commissioner

**FIVE YEAR PLAN 2012-2017**



**People and Families First**

## ACKNOWLEDGMENTS

I would like to thank Linda Goodman and Christine Pollio Cooney for their many hours of recording information at our listening tours and for their significant work on this document and to Horizons for allowing us to use several of the photos in this document. I would especially like to acknowledge the contributions by everyone who participated in the many listening tours we conducted from May through September 2011 and to all others who provided their input.

We conducted listening tours with Self Advocate Coordinators, individuals we support and their families, providers, and DDS staff. Meetings were also held with many advisory councils and advocacy groups. In each case we were careful to include those that represented the diversity of the individuals and families we support as well as the many types of services provided. We hope that everyone sees their perspectives reflected here.



Terrence W. Macy, Ph.D.  
Commissioner  
Department of Developmental Services  
February, 2012

The initial draft of this Five Year Plan was posted on the DDS website from mid-October to the beginning of December, 2011. Notices in English were sent to 14,000 families and notices in Spanish were sent to 700 families. Two public hearings were held at which 23 individuals testified in person and another 240 comments were received via fax, email or mail. All of these comments were considered in the development of the final plan.

## ABOUT OUR COVER

In 2011 a national group of self advocates was convened to respond to proposed rulemaking by the Centers for Medicare & Medicaid Services (CMS) that would define federally funded “community living” for individuals with developmental and intellectual disabilities.

The resulting March 2011 document entitled “Keeping the Promise: Self Advocates Defining the Meaning of Community Living”, outlines their definition of integrated and respected community living for people with developmental disabilities. The Wordle, or word cloud, depicted on our cover is a graphic representation of what self-advocates have to say about what “community living” really means to them. The highlights of their definition were:

- Supporting families as the most important and permanent unit of development, protection, and lifelong assistance to persons with developmental disabilities
- Increasing self-determination and personal control in decisions affecting people with developmental disabilities and their families
- Providing opportunities for people with developmental disabilities to live and participate in their own communities
- Improving quality of life for individuals and families as they define it for themselves
- Investing in each individual’s developmental potential and capacity to contribute in age-related roles as productive and respected community members
- Ensuring access to sufficient, high-quality health and social supports to protect each person’s health, safety, rights, and well-being
- Moving people with developmental disabilities out of poverty by significantly increasing opportunities for real work with real pay



**“Do those served  
grow as persons?  
Do they,  
*while being served,*  
become healthier,  
wiser, freer,  
more autonomous....?”**

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Greenleaf, R. K. (1977/2002). *Servant Leadership: A Journey into the Nature of Legitimate Power and Greatness* (25th anniversary ed.). New York: Paulist Press

## ABOUT THE DEPARTMENT OF DEVELOPMENTAL SERVICES

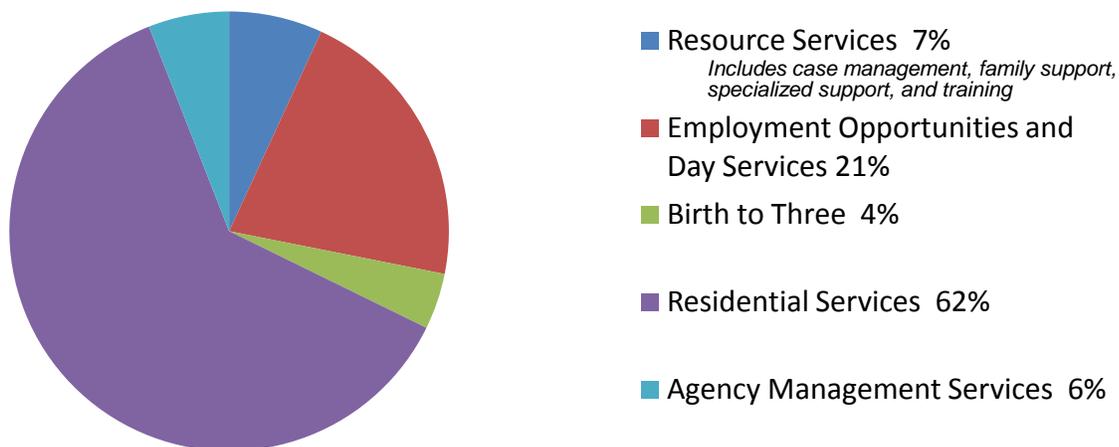
### The Workforce

The department employs more than 3,700 people, full time and part time, and its contracted providers employ approximately 16,000 workers.

### Finances

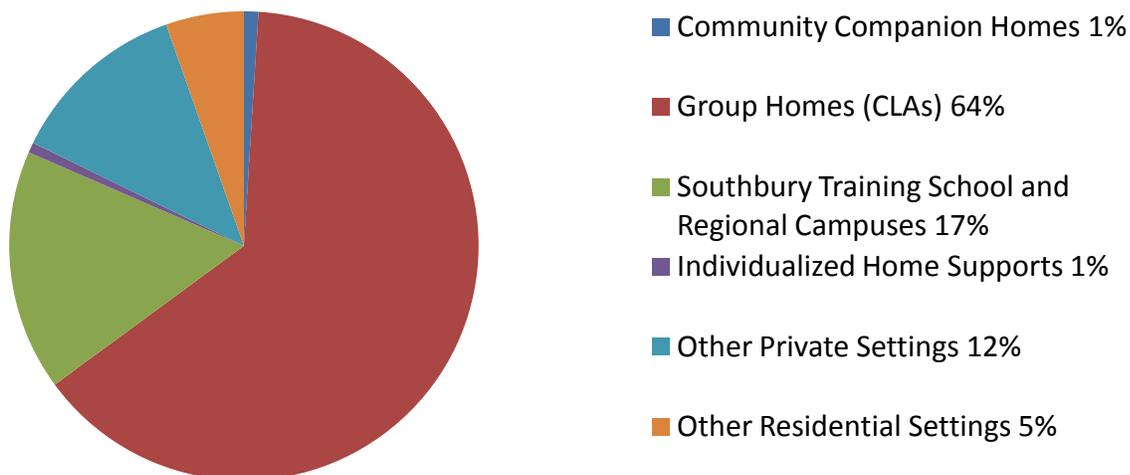
The overall operating expenses of the department have increased to \$1 billion in fiscal year 2012. The state's fiscal year runs from July 1<sup>st</sup> to June 30<sup>th</sup>. Since fiscal year 2008, the federal Medicaid funding reimbursed to the state's General Fund has grown from \$332 million to \$515 million.

### FY12 Budget

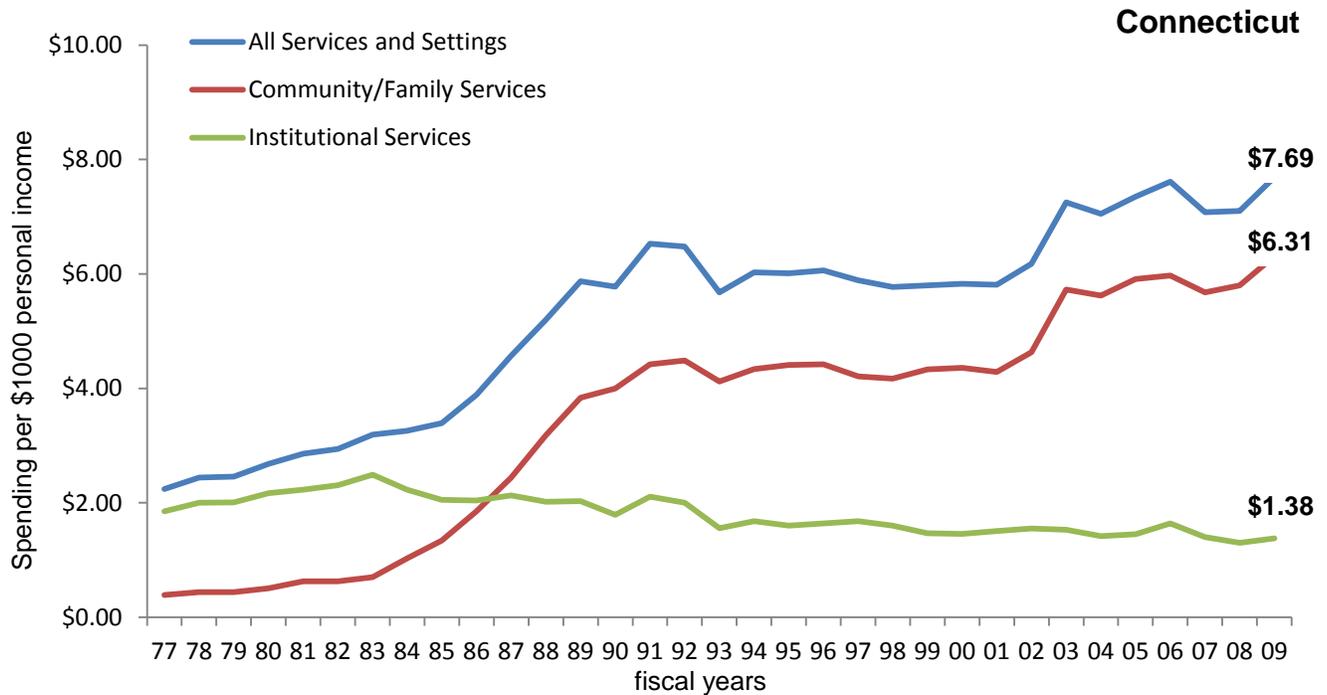


If we examine only the \$700 million in residential services, the breakout is:

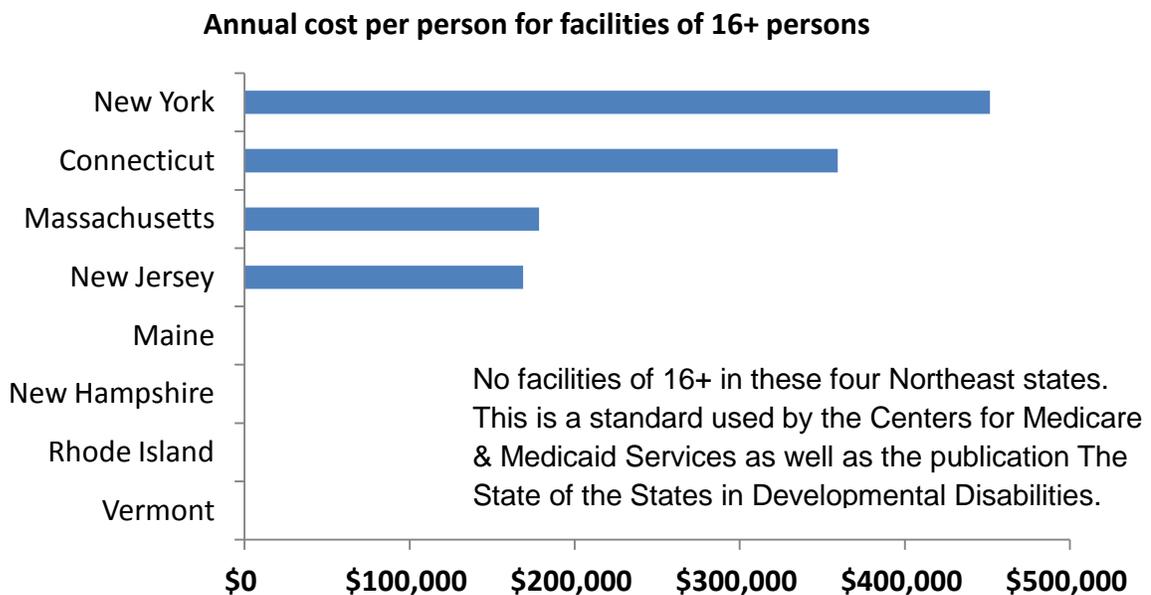
### Residential Supports Only



Thirty-two years of data show that spending for institutional services has decreased somewhat, while spending for community services has increased substantially. (The source for all multi-year and state comparison data is Braddock, D., et al. (2011). *The State of the States in Developmental Disabilities: American Association on Intellectual and Developmental Disabilities.*



In the Northeast, Connecticut's cost per person for state-operated facilities for 16\* or more persons is higher than all other states except New York. As shown below, four Northeast states do not operate any 16+ person facilities.



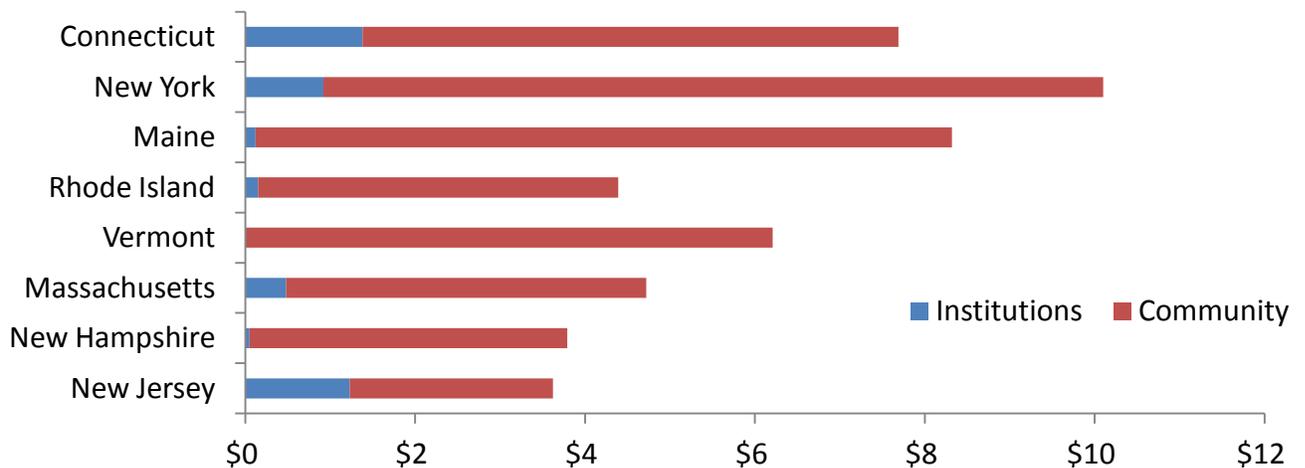
## Medicaid Revenue

The department has been able to offset more than half of the state's \$1 billion expenditures by capturing federal Medicaid reimbursement for the state's General Fund. In the most recently completed fiscal year (Fiscal year 2011) the Medicaid revenue by source was:

Individual Support Waiver	\$ 70,540,751
Home and Community Based comprehensive waiver	\$315,823,597
Southbury and Regional Center Campuses	\$109,953,730
Birth to Three	\$ 8,599,252
Targeted Case Management	\$ 10,237,538
Total (after minor billing adjustments)	\$515,152,087

In comparing Connecticut DDS expenditures to the other Northeast states, New York and Maine spend more per \$1000 of aggregate personal income than Connecticut. But Connecticut spends a greater proportion on congregate care (facilities of 16+ persons).

Spending on developmental disability services per \$1000 aggregate personal income  
*State of the States in Developmental Disabilities, 2011*

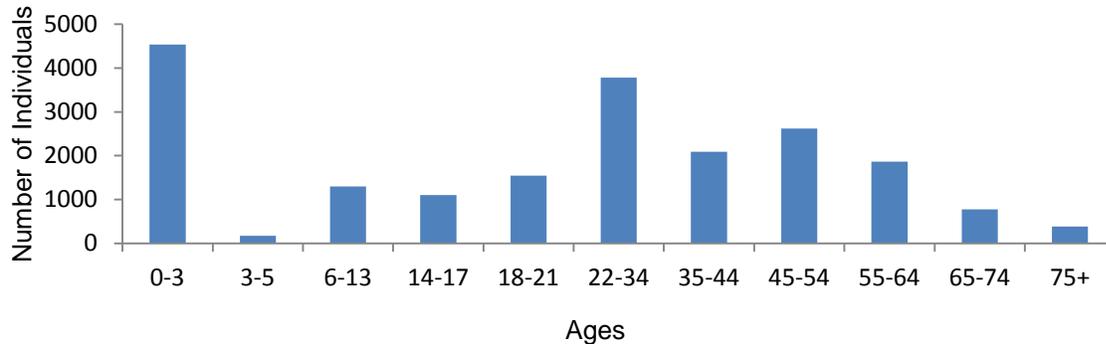


## Administrative Structure

Since the department's organizational structure changes from time to time, please see the DDS website [www.ct.gov/DDS](http://www.ct.gov/DDS), "Office of the Commissioner", to see the most current table of organization.

## The People and Families

Approximately 20,000 individuals and their families are eligible for some types of services from the Department of Developmental Services. This includes 4,540 infants and toddlers enrolled in the Birth to Three System and 15,640 individuals older than three (June 30, 2011 DDS Management Information Report). Included in the 20,000 are 365 infants and toddlers and 2,991 persons over the age of three with autism spectrum disorder. Of the individuals over the age of three, 69% (10,848) are receiving either residential or day services or both. Each year approximately 160 persons over the age of three are found newly eligible for DDS services. The age distribution of all eligible individuals is:

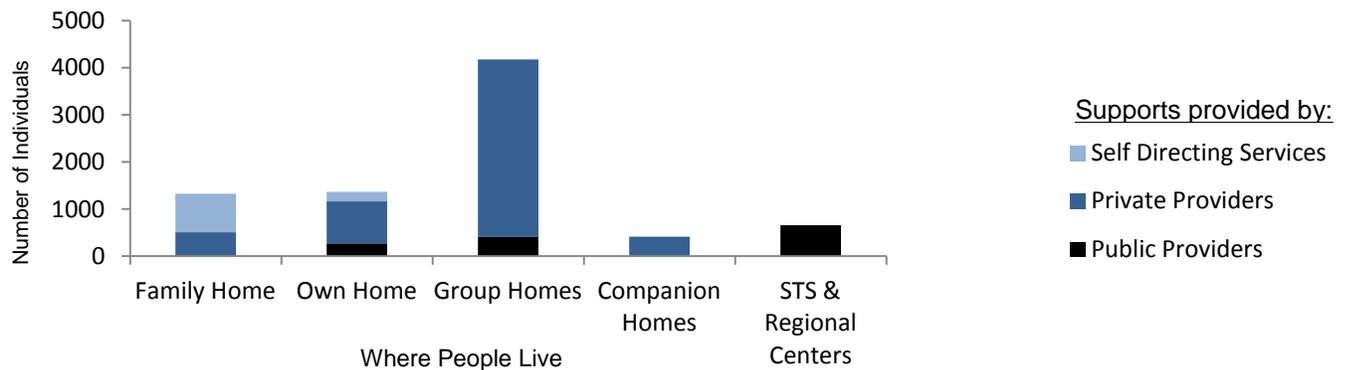


## Residential Supports

As of June 2011, 8,697 individuals (approximately 44% of consumers over the age of three) received some type of residential support provided through state or federal funding, including those receiving in-home supports. There were 549 individuals living with their families or on their own who were on the waiting list for residential services with assigned statuses of “Emergency” or “Priority 1”. From June 2006 to June 2011, the size of that list decreased from 745 to 549.

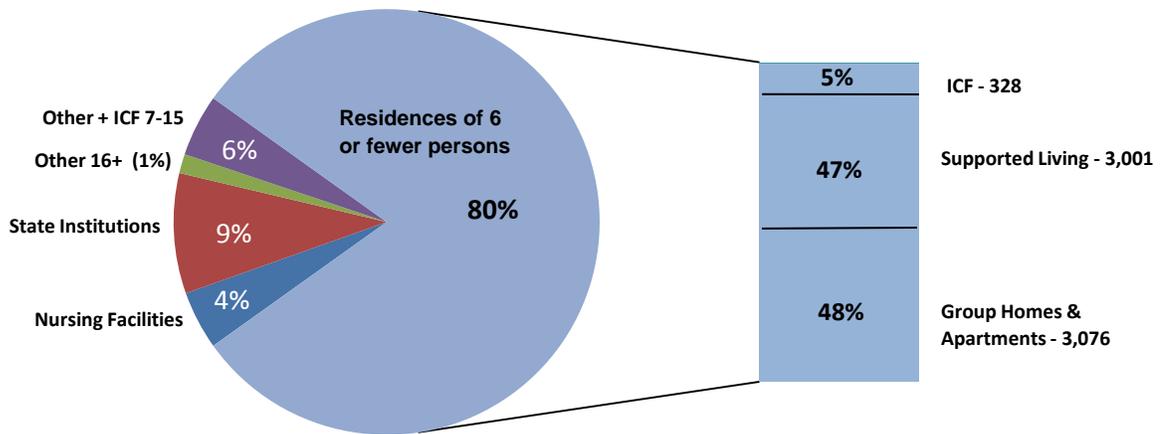
Of 7,931 individuals who receive residential supports directly from DDS or private providers, 1,064 (13%) live in DDS-operated congregate facilities or group homes, 3,383 (43%) live in privately operated group homes, and 3,101 (37%) use more non-traditional supports that offer greater flexibility and individualization. One of those non-traditional forms of support is the hiring and managing of one’s own staff, called self-directing services. From 2008 to 2011, the number of individuals self-directing their services increased from 709 to 1,014.

As of June 2011, the number of individuals by the types of residential settings in which they received support from DDS, from private providers, or by self-directing services was:



Another way of looking at this data according to the *State of the States in Developmental Disabilities* (based on June 2009 figures) shows that the overwhelming majority of persons receiving residential support live in residences for six or fewer persons:

**Connecticut**

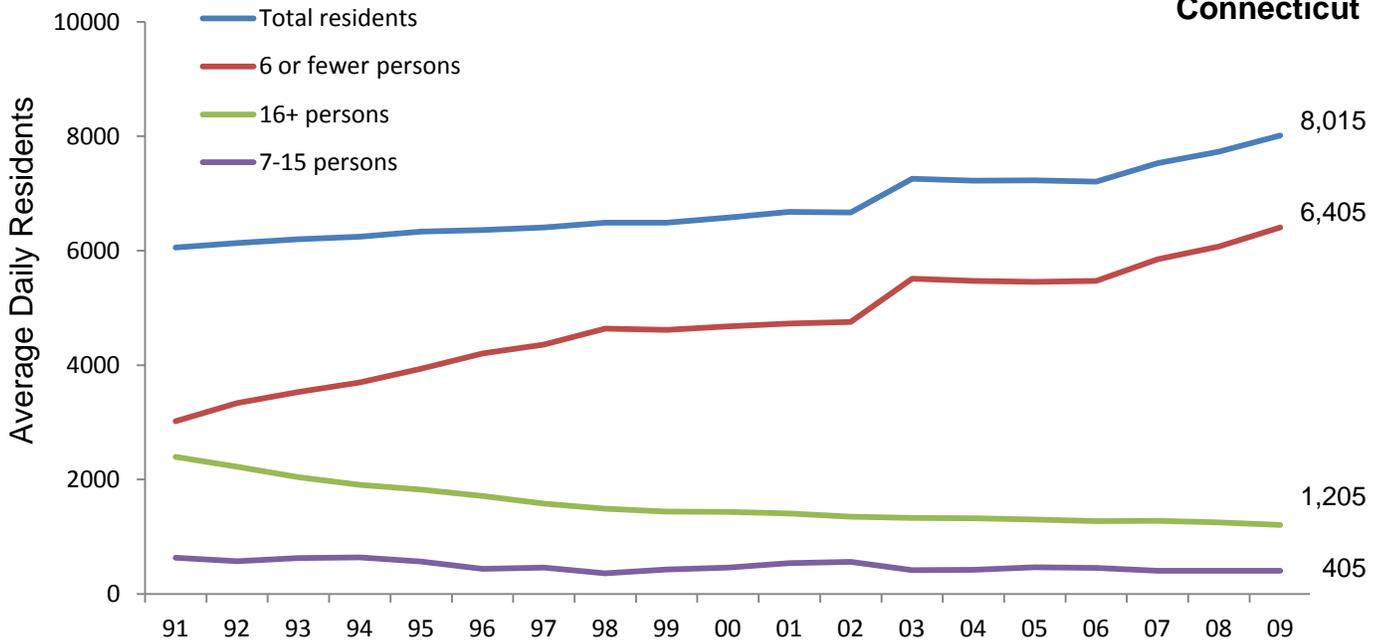


ICF = Intermediate Care Facilities

State of the States in Developmental Disabilities 2011. June 2009 data.

From 1991 to 2009, the total number of individuals receiving residential supports increased, with the largest increase in settings for six or fewer persons.

**Connecticut**



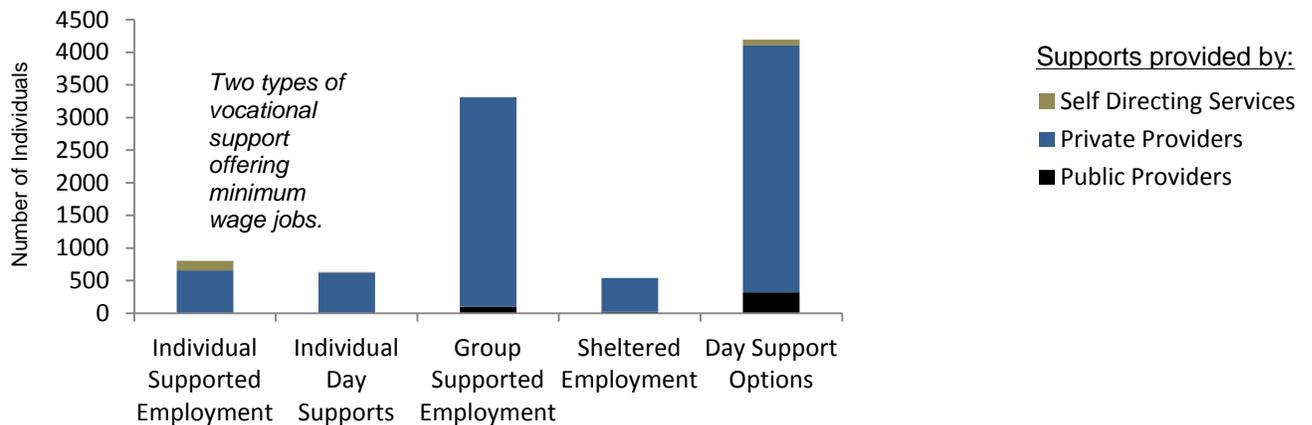
*Southbury Training School and the DDS Regional Centers*

At the end of December 2011, there were 420 residents of Southbury Training School (STS) and 216 individuals living in the department's five remaining regional centers. The Settlement Agreement in *Messier v. Southbury Training School* requires that the teams

supporting people living at STS exercise professional judgment regarding recommendations as to the most integrated setting in which the needs of each person can be met. The department believes that the implementation of the Settlement Agreement provides people living at STS and their families or guardians with the means to make what is called an “informed choice” regarding the most appropriate and integrated setting for each individual. The chance for individuals and their families to find out what opportunities are available for them in the community is a critical first step in determining the best next step for each person. The department envisions extending the team training required by this settlement agreement to the regional centers, as recommended by the Legislative Program Review and Investigations Committee’s study on the “Provision of Selected Services for Clients with Intellectual Disabilities: Staff Findings and Recommendations, December 20, 2011”. Because the department is fully committed to ensuring person centered supports for people (focusing on the strengths and gifts of an individual and putting that person in charge of defining the direction of his or her own life), the plan is for any transition from Southbury Training School or the regional centers to occur in a thoughtful and purposeful way.

**Employment and other supports for adults**

There are 9,482 individuals receiving support either through some type of supported employment or in some type of non-employment day program as well as an additional 371 who work in competitive jobs without any specialized support. The department uses the specific categories of individual supported employment, individualized day support (vocational), and competitive employment to represent types of jobs that pay minimum wage or better, however only 15% of individuals work at these types of jobs, compared to other forms of vocational or day programs, including:



**Family Support**

Most families who have a child with intellectual disability need extra support to help care for their child at home. Family supports include goods, services, resources, and other forms of assistance such as respite services and DDS family support teams. Family supports help children grow up in nurturing family homes and assist adults to continue living at home with

their families. DDS respite centers provide 24-hour care for extended weekends in comfortable, home-like environments.

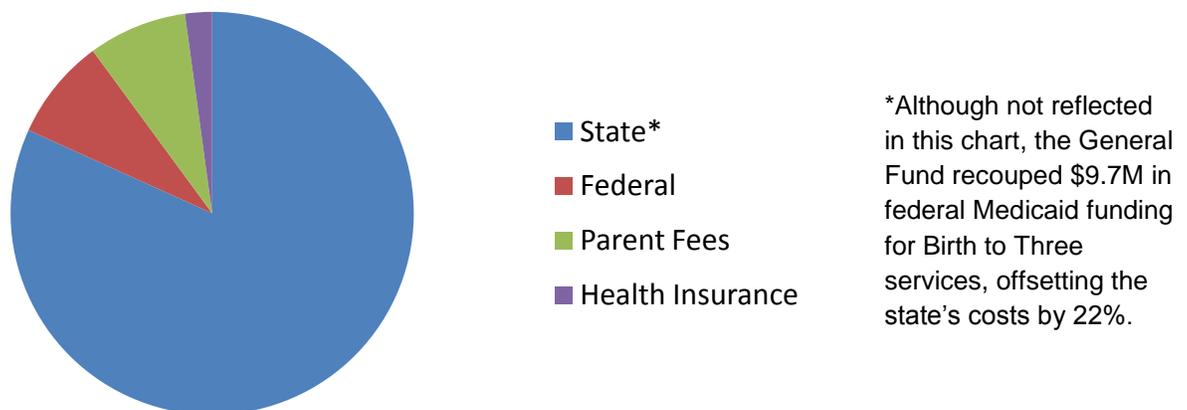
Family support teams of DDS staff offer in-home and community supports such as respite, skill building, implementation of behavior programs, activities to promote health and wellness, transportation to medical appointments, and support with transitions to adult programs.

In FY11, 813 individuals living with their families (293 children and 520 adults) received services from the Individual and Family Support teams in the three regions. This represents 9% of the 6,588 individuals living with their families who do not receive other forms of residential support. Of those living with their families, 1,328 individuals (346 children and 982 adults) were able to take advantage of the 11 DDS respite centers located in the regions. Approximately 12% of the department's budget is designated for family support services. This figure does not include funding for day programs.

### The Birth to Three System

The Birth to Three System, Connecticut's implementation of Part C of the Individuals with Disabilities Education Act (IDEA), delivered services to 9,468 eligible children in FY11. In a retrospective look at 40,000 children born in Connecticut each year from 2000 through 2008, Birth to Three has consistently evaluated 15% and provided services to 10% of them. The U.S. Department of Education monitors how well each state implements the IDEA. In each of the past five years, the Birth to Three System has submitted an annual performance report of its efforts in 14 different categories and has received the highest rating of "meets requirements" all five years.

The Birth to Three System depends on several sources of revenue to support its operational costs. For FY11, expenditures by each of those revenue sources were:



Birth to Three has created a network of autism-specific early intervention programs covering all towns in the state. As of June 2011, 315 children with autism spectrum disorders were enrolled in those programs and another 50 were enrolled in general Birth to Three programs. In a review of the Connecticut children born in 2008 (the last of whom exited Birth to Three as of 1/1/12), the department's data indicates that 445 of those children had received autism services prior to their third birthday, a rate of 1 out of every 90 Connecticut children born that

year (1.1%), compared with the Centers for Disease Control's estimate of a 1% prevalence rate based on a review of 8 year-olds. It appears that Connecticut is doing a commendable job of offering the earliest start to services for very young children with autism spectrum disorder.

The department is working with the Governor's Office and other agencies to implement Public Act 11-181 and Governor Malloy's Executive Order #11 that requires a planning director to work with a number of state agencies and the State Early Childhood Education Cabinet to design a coordinated early childhood system for Connecticut in order to ensure that children with high needs receive quality early childhood services and programs. Although the department thinks that its programmatic and fiscal administration of the Birth to Three System and the family-centered nature of its early intervention services make it a good fit to remain within the department, the department will seek to do what is best for families and local communities as it works through this process.

### **The Division of Autism**

As Connecticut's lead agency for autism, the department established a division in 2007 that provides case management and self-directed services for adults with autism spectrum disorder who do not have intellectual disability.

The department is currently in the process of recruiting and hiring a new director for the division who will be able to focus full-time on taking a leadership role in state government in this area. DDS, along with the Department of Social Services, is in the process of working with two other state agencies to develop a comprehensive array of Medicaid waiver services for individuals with autism spectrum disorder. The director will also coordinate with state agencies such as the Departments of Mental Health and Addiction Services, Children and Families, and Education on other cross-agency issues and will advise the Commissioner of DDS on state policy and legislation in the area of autism. A key focus will be recruiting and training qualified providers.

The state budget for fiscal years 2012 and 2013 specifies that the department will fund a study on the "feasibility of an autism center." Representatives from six state agencies met in June 2011 to discuss the potential scope, including prevalence of and need for specialized services for individuals with autism spectrum disorder. The company Value Options was chosen to complete the study under an existing contract with the Department of Social Services. The final report is expected to be completed in fiscal year 2012 and will be posted on the DDS website.

## CELEBRATING OUR ACCOMPLISHMENTS SINCE 2007

1. *Renaming the department and promoting respectful language* – In 2007, after years of efforts by self advocates, the name of the department was officially changed to the Department of Developmental Services. In 2010, the department issued a Respectful Language policy requiring DDS staff to remove the term “ mental retardation” and to use “people first language” in all policies, procedures, materials, and communications. In 2011, again with the help of self advocates, the legislature passed Public Acts 11-4 and 11-16 applying the terms “intellectual disability” and “autism spectrum disorder” and the use of “people first language” to state laws governing DDS, the Probate Courts, and the Office of Protection and Advocacy for Persons with Disabilities.
2. *Expanding private sector services* – As of June 2011, 83% of persons receiving residential supports and 95% of persons receiving employment or day supports or Birth to Three services received those supports and services from private or contracted providers.
3. *Communication* – The department established an intranet site for its employees in 2008 and created a Consumer Corner section of the DDS website in 2011 for individuals with intellectual disability.
4. *Health and Safety* - The department expanded its culture of preventing and addressing health and safety problems through the Abuse and Neglect Registry; collaboration with the Department of Emergency Services and Public Protection on abuse/neglect investigations; reporting and tracking of all critical incidents including choking and falls; and through mortality reviews. The department’s emergency preparedness which was tested by Tropical Storm Irene and the October Nor’easter in 2011 was found to be effective.
5. *Southbury Settlement Agreement* – The department negotiated an end to the 1994 class action *Messier v. Southbury Training School* lawsuit through the 2010 *Messier v. Southbury Training School Agreement*. The Settlement Agreement requires that interdisciplinary teams at STS be trained to assess residents’ needs and make professional recommendations on the most integrated setting appropriate for each resident and the appropriateness of community placement. The teams need to ensure that the residents, guardians, and family members have sufficient information to make informed decisions.
6. *Autism Division* - In 2007, the department implemented Public Act 07-04 by creating an Autism Division to oversee a 2006 pilot program for 65 adults with autism spectrum disorder who did not also have intellectual disability. Since then, the division developed three autism waivers that will allow Medicaid funding for waiver recipients with autism spectrum disorder. Those waivers are currently under review.
7. *Voluntary Services Program for children* – The program, designed for children who have an intellectual disability and a mental health diagnosis plus challenging behaviors that substantially interfere with or limit the child’s ability to function in the family or community, was expanded to serve 426 children and their families. Additionally, from 2005 to 2011,

an average of 35 children per year aged out of the program. Children enter either by applying directly to DDS or they are enrolled first with the Department of Children and Families and then transferred to DDS.

8. *Respite Services* - Respite services were provided to 1,328 individuals (including 346 children) and their families during FY11 through the 11 DDS respite centers. This is an increase of approximately 300 individuals over the FY08 numbers.
9. *Waiting List Settlement Agreement* – The terms of the 2005 Settlement Agreement from which was the result of the ARC/Connecticut, et al. v. Peter H. O’Meara et al., lawsuit were completed in 2009. In 2005 there were 1,086 individuals on either the Emergency (needing residential services within 30 days) or the Priority 1 (needing residential services within one year) waiting lists. Although the agreement called for 150 individuals from the Emergency or Priority 1 waiting lists to receive residential services each year (750 over the five years), a total of 1,526 individuals were able to access residential services (through either newly funded residential services or through existing vacancies) over the five years and an additional 502 received enhanced family supports with funding from this initiative during the same period. As of June 2011, there were 549 individuals living at home who were on either the Emergency or Priority 1 waiting lists.
10. *Birth to Three* - The Birth to Three System’s eligibility criteria had been narrowed in 2003, but in 2007 they were restored. This was particularly helpful to families of extremely premature infants and children with speech delays. However, the state budget increased monthly parent fees by 60% in January 2010. Outcomes for children and families, reported annually to the federal government beginning in 2007, showed that at least 80% of children made significant developmental gains and 50% of eligible children that exited the system did not need to receive special education services when they entered kindergarten. In an annual survey, 98% of families reported that as a result of Birth to Three services, they know how to help their children develop and learn. There have only been six due process hearings held since 1996.
11. *Employment* – The department developed a new employment policy requiring all individuals with a Level of Need (LON) score of 1, 2, or 3 and each new school graduate to have an employment goal in their Individual Plan that leads to community-based competitive employment. The design of this employment policy was influenced by the State Employment Leadership Network, an interstate initiative of the Institute for Community Inclusion at University of Massachusetts, Boston and the National Association of State Directors of Developmental Disabilities Services.
12. *Level of Need* – The department implemented a Level of Need assessment for all consumers receiving or seeking services that will eventually serve as the framework for future rate setting.
13. *Greater access to dental services* – The department developed close working relationships with the University of Connecticut Dental School as well as Yale-New Haven, St. Mary’s, and St. Francis Hospitals. These hospitals help coordinate complicated dental cases including those requiring general anesthesia. The department’s dental coordinator meets quarterly with staff from the two DDS dental clinics, addresses

dental neglect and arranges dental care for DDS consumers. She is a resource for DDS case managers, individuals, and families on dental issues and she publishes the DDS Dental News. The dental coordinator also gives lectures to dental and dental hygiene students on the best way to provide dental care to individuals with intellectual disability.

14. *Medicaid Waivers* - With the approval of the legislature, the department renewed and amended its Home and Community Based Services and Individual and Family Support Medicaid waivers. A new waiver entitled Employment and Day Supports was also approved by the legislature in 2011. As a result of all three waivers and other DDS Medicaid billing, the annual federal revenue brought by DDS to the state's General Fund increased by 55% from \$332 million in fiscal year 2007 to \$515 million in fiscal year 2011.
15. *Regional Help Lines* – In 2009 the department had to withdraw case management services for families of 3,000 children living at home who were not Medicaid-eligible and a help line was established in each region to assist those families. The three help lines receive approximately 2,400 calls each year and in FY11, responded to 96% of calls within two business days.



*Governor Dannel P. Malloy signed into law, the Department of Developmental Services' (DDS) Respectful Language Bill, Public Act No. 11-16 "An Act Concerning Revisions to Statutes Relating to the Department of Developmental Services Including the Utilization of Respectful Language When Referring to Persons with Intellectual Disability" at a ceremony in the State Capitol. DDS Commissioner Terrence W. Macy, Ph.D.; former DDS Deputy Commissioner Kathryn du Pree; DDS Self Advocate Coordinators Jamar Cherry, Carlos Colon, Carol Grabbe, Genna Lewis, Jamie Louchen, Varian Salters, Jossie Torres, Ivan Villa; and State Senator Terry Gerratana, Co-Chair of the Public Health Committee; Jennifer Carroll, a member of the Council on Developmental Services; Lisa Sheppard, Co-Chair of the Family Support Council; and Quincy Abbott, a member of the Arc Connecticut all were on hand for the signing.*

## A PARADIGM SHIFT

For years, the lifespan expectations of families and service providers has been that individuals with intellectual disability would receive early intervention services as infants or toddlers, special education services beginning at age three, and upon graduation from high school or when they turn age 21, they would receive some kind of state or federally-funded day program followed by housing and residential services in a state or federally-funded group home. But that paradigm (the current way of thinking) must change based on what we know about the state and national landscape.

Dr. Valerie Bradley, President of the Human Services Research Institute, described this landscape to the leadership of the American Association on Intellectual and Developmental Disabilities in February 2011 in a presentation called “In Crisis, Opportunity?: Finding Ways to Thrive in Hard Times.” We find that disability issues in Connecticut mirror this national picture and the following challenges and opportunities presented by Dr. Bradley are also representative of where we find ourselves in Connecticut.

### The Current System is Unsustainable

#### Challenges

Waiting lists are growing

More families are in crisis and more adults are living at home

Roles of direct support staff are changing and labor markets are shrinking

The old models are too expensive

#### Opportunities

Assist families to understand options

Work with case managers to understand family dynamics

Think through the best ways to recruit and train direct service providers

Phase out programs that don't align with the desired outcomes

### Legacy Services are Persistent

#### Challenges

Public institutions are still a factor

More individuals are in sheltered workshops or receiving non-work day supports than are employed

We need to use the current economic downturn to focus on what works

#### Opportunities

Help taxpayers to understand the cost tradeoffs and impact on young families

Identify barriers to employment

Make performance transparent

## The State Needs to do More with Less

### Challenges

There is shrinking staff at the central level and the community system has grown rapidly

There is pressure to manage systems based on performance data

We need to get value for our investment

### Opportunities

Need to have the analytic capacity to review data and act on trends

Find a way to keep canvassing the experiences of individuals and families

Align funding with performance including rewarding valued outcomes such as employment

## Collective Consciousness is Fading

### Challenges

The baby boom generation is retiring

There is a loss of institutional memory

We need to develop new leadership

### Opportunities

Conduct leadership training initiatives

Do a history of the state system

Work to instill values throughout the system

## Funding Methods Will Change

### Challenges

The current level of funding for some services can't be supported

Funding needs to reflect individual need

Use of individual budgets should be expanded

### Opportunities

Align funding with functional capabilities

Increase access to individual budgets

Re-inspect old rate structure  
Get ready for Medicaid rate caps or rate reductions\*

*\*originally stated by Dr. Bradley as "Get ready for capitated health care and potentially Long Term Care systems"*

## Self Advocacy Needs Support

### Challenges

Self-advocacy groups are experiencing generational changes

It's hard to organize when people aren't in conventional settings

Self-advocacy groups need mentors and organizational support

### Opportunities

Sponsor self-advocacy leadership opportunities

Include self-advocates in review of performance data

Use self-advocates as trainers and lecturers

## There is a Need for Greater Transparency

### Challenges

Stakeholders are often out of the loop with respect to policy decisions

It is difficult to engage individuals and families given the complexity of systems and materials

Without stakeholder support, public managers lose important political support

### Opportunities

Increase opportunities for stakeholder input and insure that their input is meaningful

Help to train families and people with disabilities regarding the use of data

Use multiple outlets to disseminate information including the web, consumer friendly alerts, etc.

*\*originally stated by Dr. Bradley as "Get ready for capitated health care and potentially Long Term Care systems"*

Dr. Bradley is not the only expert weighing in on the change in the national landscape. Nancy Thaler, Executive Director of the National Association of State Developmental Disabilities Directors reported in her February 2010 Managed Care Tracking Report that: "States are changing what services they provide. For some time state I/DD directors have been witnessing no growth or slower growth in funding even as waiting lists grow and concluding that traditional models of service are not only unsustainable but for many are undesirable. Twenty-four hour residential arrangements and services to adults that do not lead to employment and are giving way to an emphasis on real work for real pay, increased support to families, and exploration of relationship-based alternatives to 24-hour residential services."

"States are looking to: (1) change their service paradigm from one that is facility based to one that is community, employment and family based; (2) change the management and reimbursement structures of state Medicaid systems; while also (3) building self-direction, choice, and quality management into the program; and (4) running parallel to these efforts is the federal push to reconfigure services to the dual eligible population. The coordination and

integration of these change agendas has the potential to significantly improve the lives of people with I/DD and their families while building a system that has long-term sustainability. Responding to these challenges and opportunities requires each state to begin to think differently about the role of service providers and service systems in the lives of individuals with intellectual and developmental disabilities and their families.”

Hanns Meissner,  
Executive Director of  
The Arc of Rensselaer  
County, New York has  
described it as a new  
perspective. We call it  
a new paradigm.

**“If we see people with developmental disabilities as fundamentally vulnerable and incapable,** the role of service providers is to take care, protect and decide for people and the role of service systems is to create rules, incentives, and mechanisms of inspection and enforcement that assure safety and adequate care.

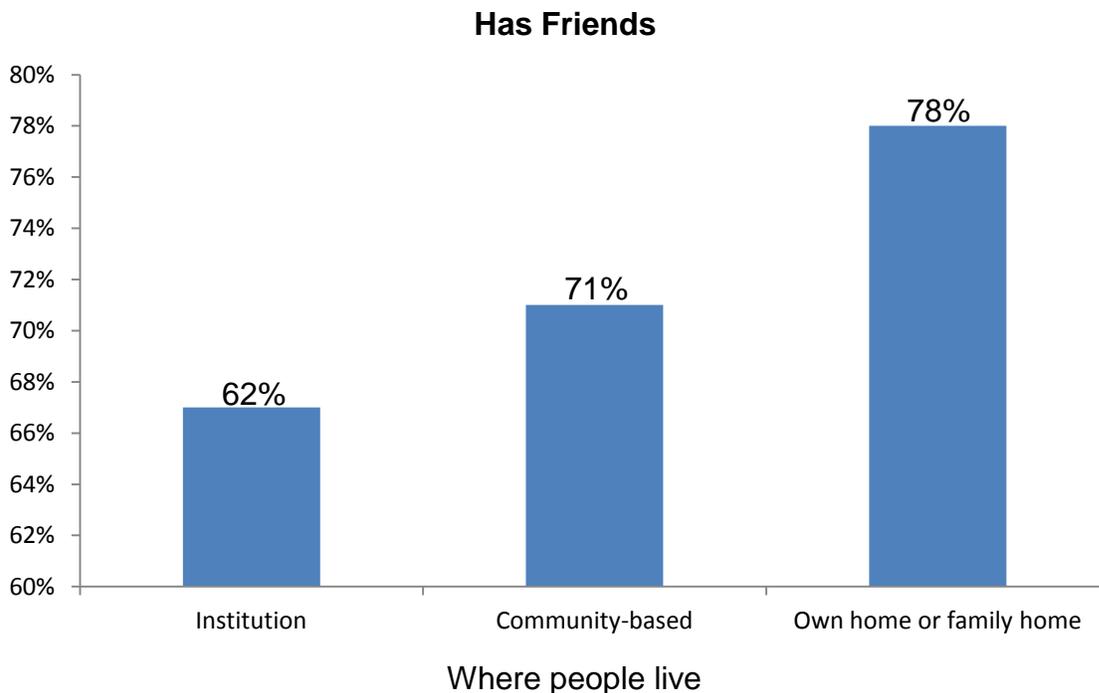
**On the other hand, if we see people with developmental disabilities as capable of contributing meaningfully to community life,** the service provider is one partner in discovering and offering the individualized supports, interest-based opportunities, and safeguards that enhance participation, satisfaction, and resilience.

The service system holds responsibility for investing public funds that are sufficient and flexible to sustain individualized supports, developing an adequate supply of capable and ethical service providers, and offering an additional level of safeguards to people’s autonomy and community membership.”

*Intellectual and Developmental Disabilities*, Vol. 49,  
No. 5: 383-387 October, 2011).

The Department of Developmental Services, its workforce, and its provider community will all need to embrace this new paradigm in the following ways described by Dr. Bradley and based on actual data from the multi-state National Core Indicators Project\* in which thousands of individuals with intellectual disability and their families are interviewed or surveyed annually:

1. Concentrate on what works because:
  - people have more choice and are less lonely in small settings
  - people who are employed have more choices about important areas of their lives – people in day habilitation settings make fewer choices
  - people in smaller settings are more involved in their communities
  - people living at home have more friends (see data chart below)
  - people who control their budgets are more likely to control other aspects of their lives
2. Recognize that in crisis there is opportunity to:
  - seize the moment to reduce reliance on congregate settings
  - use data to make the case for a reallocation of resources to more productive and person-centered program models
  - work on ways to preserve the values that have animated our field by sharing stories and history
  - take advantage of new opportunities
  - engage stakeholders in conversations about the future



*\*Valerie Bradley, President of the Human Services Research Institute, "In Crisis, Opportunity?: Finding Ways to Thrive in Hard Times." American Association on Intellectual and Developmental Disabilities presentation, February, 2011*

## CONVERSATIONS FOR CHANGE

From July through September 2011, Commissioner Macy and his staff conducted multiple listening tours; five with families, three with private providers, and three with DDS regional staff. The Commissioner held many additional meetings with or received input from DDS program managers, Self Advocate Coordinators, the Autism Advisory Council, the Council on Developmental Services, DDS Regional Advisory Councils, the Family Support Council and many others. In total, the opinions of over 250 stakeholders were sought. Participants were asked to reflect on things that DDS could do better and ways that individuals and their families could be better supported in a sustainable way. The following, in no particular order, summarizes the key points or themes expressed by each group:

Who said it	What they said
Individuals	<ul style="list-style-type: none"> <li>• Promote rewarding work</li> <li>• Real work for real pay</li> <li>• Help people who hire their own staff and teach them how to be the boss</li> <li>• Develop a policy and training on healthy relationships</li> <li>• Use the word “consumer” only when you can’t say person or individual</li> <li>• Make the website and written materials more understandable</li> <li>• Promote and improve public transportation</li> <li>• Train all staff in respectful language</li> <li>• Make available more information about all benefits, including health</li> <li>• Find ways for self advocates to collaborate more with case managers and providers</li> <li>• DDS needs to work with the whole family, including parents with intellectual disabilities and their children</li> </ul>
Families	<ul style="list-style-type: none"> <li>• Communication is extremely important. Parents need “just in time” information. DDS is very complicated. The website is not helpful.</li> <li>• We can’t navigate DDS eligibility and eligibility re-determinations</li> <li>• It is not clear who is eligible for DDS services</li> <li>• We have no way to determine the quality of various service providers</li> <li>• The process of transition from school to career is not very smooth</li> <li>• We need help in coordinating with school districts, DCF, and DDS</li> <li>• We need more services for children with autism</li> <li>• We need more help with in-home behavioral services</li> <li>• DDS needs to make all of its information available in Spanish</li> <li>• We need help with transportation</li> <li>• Case managers can be invaluable in navigating the system</li> <li>• Parents need guidance on how to advocate with the legislature and how to have input on budget decisions</li> <li>• Supports for caregivers ultimately benefit the person with a developmental disability</li> <li>• Respite is very valuable</li> <li>• We’re concerned about what residential supports will be available</li> <li>• We would like more regional family forums on various topics</li> </ul>

Who said it	What they said
Private Providers	<ul style="list-style-type: none"> <li>• We need more consistency among the three DDS regions on processes</li> <li>• DDS has onerous paperwork requirements</li> <li>• Transportation is an issue for families</li> <li>• Case management quality varies</li> <li>• There needs to be more collaboration between DDS and providers to send a unified message to families</li> <li>• Transition from DCF to DDS needs to be better coordinated</li> <li>• We need more funding and opportunities to provide in-home supports</li> <li>• DDS needs to better educate families on various support options</li> <li>• The Level of Need assessment doesn't work for everyone, especially individuals with autism and those involved in the criminal justice system</li> <li>• Aging caregivers need more supports to allow a person with a person with a developmental disability to remain at home</li> <li>• Linkages and supports for autism are critical</li> <li>• Increase DDS communication to providers</li> <li>• Abolish the Quality Service Review. It is process, not outcome based. It does not allow providers to correct a minor issue immediately. It is intrusive to individuals with developmental disabilities</li> <li>• Case managers need to understand the financial impact of the Individual Plan when changes are recommended.</li> <li>• Residential and Day funding needs to be combined for individuals</li> <li>• DDS needs a true and clear vision, strategic plan, and actionable steps that build in providers as part of the solution</li> <li>• Re-visit the rules for the Continuous Residential Support model</li> <li>• We should be able to help families who call us to navigate the DDS system</li> <li>• Make sure that providers are involved in developing the Advanced Planning Document for an integrated data system</li> <li>• When DDS makes changes they need to consider the impact on all parts of the system since everything is inter-related; we need more time to implement changes</li> </ul>

Who said it	What they said
DDS staff	<ul style="list-style-type: none"> <li>• Reduce paperwork, give direct care staff access to computers for daily progress notes</li> <li>• Revamp quality management</li> <li>• Implement recommendations of case management study group and 2007 case manager survey results</li> <li>• Improve transfer of knowledge and skills from DDS staff to provider staff</li> <li>• Address elderly issues better to allow aging in place</li> <li>• Educate families effectively and early on natural supports</li> <li>• Educate other service systems</li> <li>• Increase the role of DDS as consultants, training, family support, not providers of day and residential services</li> <li>• Develop new methods to assure quality</li> <li>• Develop the IT infrastructure and add IT support staff to the regions</li> <li>• Ensure adequate staff resources to sustain core functions</li> <li>• More services for children earlier, especially those placed out-of-home</li> <li>• Need better transition planning for families</li> <li>• Use more “green” processes</li> <li>• More tolerance for reasonable risk</li> <li>• Define the role of Medicaid waivers to reinforce the principle of supplementing natural supports</li> <li>• Update the DDS Mission to reflect employment and other contemporary concepts</li> <li>• Expect employment for the people we support</li> <li>• Assure consistent practices across the DDS regions</li> <li>• Increase case manager work hours from 35 hours per week to 37.5 or 40 hours per week and increase caseload sizes</li> <li>• Build capacity in the private sector for complex and unique service needs</li> <li>• Develop an assessment tool for the needs of children</li> <li>• Make respite services economically feasible for private providers including Community Companion Homes, increase respite services overall</li> <li>• Increase family support workers and family support dollars</li> <li>• Make the website and staff more accessible to Spanish-speaking families</li> <li>• The regional helplines are good, case management is better</li> <li>• Put someone in charge of the VSP program</li> <li>• Consumers need more dental and psychology supports and resources</li> <li>• Increase maintenance staff</li> <li>• Dedicate a position in each region to recreation</li> <li>• Review disparities in funding</li> <li>• Have more positive activities for staff to boost morale</li> <li>• Ensure that we are in the loop on information being shared with families about system changes such as the loss of case management</li> </ul>

Who said it	What they said
Advisory Councils	<ul style="list-style-type: none"> <li>• Retain the successes and flexibility of the autism pilot, including case conferences and planning meetings</li> <li>• Need better collaboration with the Department of Children and Families (DCF) and the Department of Mental Health and Addiction Services (DMHAS) for individuals with autism</li> <li>• DDS needs an autism director who has only an autism focus but who can coordinate a multi-agency system for children and adults with autism</li> <li>• Increase access to intensive behavioral supports</li> <li>• Eligibility redetermination is a problem at ages 16-18. It is confusing for families and for the other agencies involved. IQ scores for people with autism spectrum disorders may vary over time</li> <li>• The state budget should have a “flex fund” for people with autism that DDS or DMHAS or DCF could tap, depending on which agency had the most appropriate services. It could function like “Money Follows the Person.” (a program of the Department of Social Services to move people to the community from institutional settings)</li> <li>• There is no comprehensive training or management infrastructure for autism services</li> </ul>

### **Feedback Received on the Draft Plan**

During the comment period for this plan, the department received testimony at two public hearings as well as written comments and information from 150 people including individuals we support and their family members, guardians, advocates, private providers, DDS staff, and others.

The general themes of the comments and testimony included:

- liking the new paradigm and its emphasis on individuals and families;
- general suggestions for adding goals to the plan;
- requests that some terms used in the plan be clarified;
- requests that the plan better address the health and safety needs of individuals with severe or profound intellectual disabilities; and
- a desire by some families that their family members remain in their current residential or day settings for fear that any other setting would be of lesser quality.

### **Clarifications about the DDS Five Year Plan**

During the listening tours and in some of the comments on the Five Year Plan, certain misunderstandings on the intent of the plan were put forward. Here are clarifications on several of these points.

**Sheltered Workshops:** The goal of decreasing the number of individuals in sheltered workshop and day habilitation programs (typically called day support options) is not new to the department. It has been the department’s practice over the last several years and, in

fact, many provider agencies have been engaged in this gradual progression. The department has no plans to shut down sheltered workshops; however, DDS is fully committed to promoting an increase in the number of individuals who are gainfully employed. As stated by the Legislative Program Review and Investigations Committee in its December 2011 Staff Findings and Recommendations report on “Provision of Selected Services for Clients with Intellectual Disabilities”, the objective for each DDS consumer should be that he or she is participating in the most productive, meaningful work or day program in the most inclusive environment possible. DDS would like to see more people with intellectual disability finding employment opportunities that provide more competitive salaries and better opportunities to learn and grow. This direction is also consistent with federal Medicaid policy as it moves toward ending reimbursement for work programs that do not facilitate gainful employment in inclusive community settings. For those individuals who cannot successfully function in that type of work environment, appropriate work and day program options will still be available to them. There is no plan to end a program and leave individuals currently receiving day supports with none.

Southbury Training School and the Regional Centers: There is no current plan to close Southbury Training School nor any of the DDS regional centers in any set number of years. First and foremost, Commissioner Macy respects the people who call STS or any of the regional centers their home as well as the staff who support them. He also fully supports the Settlement Agreement in *Messier v. Southbury Training School* as stated on page seven of this plan and the recommendation of the Legislative Program Review and Investigations Committee to extend the team training in that Settlement Agreement to staff at the regional centers.

Siblings: Increasing opportunities for sibling participation does not mean that brothers and sisters are expected to take on the overall care of their family members. What it means is that there is room for siblings to be more involved in their family members’ lives earlier on. The department needs to create opportunities to help support siblings so that they can, in turn, provide support to their brothers and sisters throughout their lives.

Paradigm Shift: Experiencing a paradigm shift (a different way of viewing an issue) does not mean families will be asked to take individuals out of their current residential programs to care for them. It means that the current appropriations are unable to support the current needs of individuals if we don’t look at other less costly options. Along with many partners, DDS needs to examine better ways to support individuals with less expensive natural, family, and community supports. This doesn’t mean that there will be no future need for residential services. However, some individuals may not need the level of support that they are currently receiving. We are not looking to jeopardize anyone’s health and safety. We only seek to do the most good for the largest number of people within the generous resources allocated by the state.

## GOALS FOR 2012 – 2017

Based on the information about national and state trends, listening to our diverse stakeholders, and reviewing the comments submitted about the draft plan, the following are the department's proposed goals for the next five years.

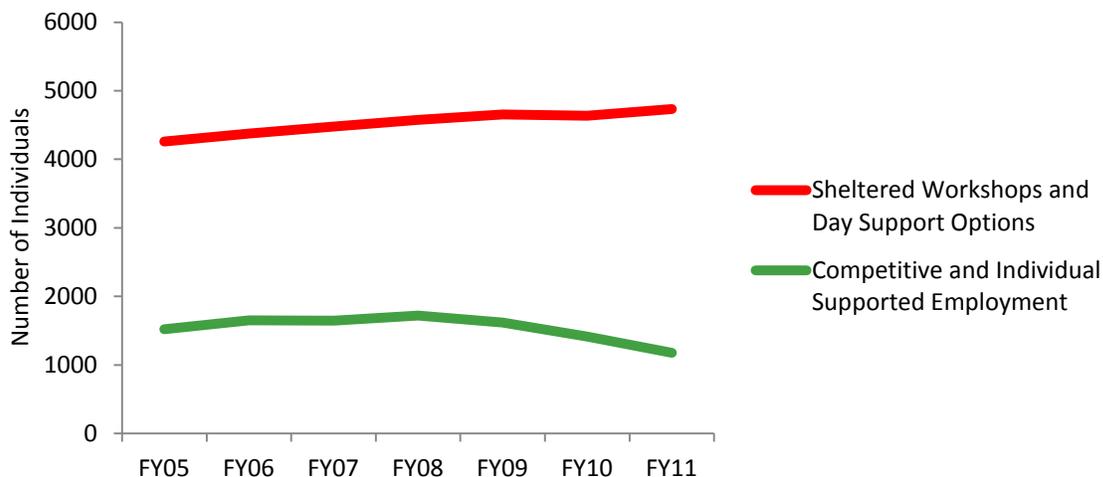
### Employment

Individuals with developmental and intellectual disabilities must have opportunities to work in jobs as part of the general work force, among people who do not have disabilities. Their opportunities for earning wages and benefits should be the same as everyone else's. The department will work to create a position to focus full-time on these important employment issues. The goals are to:

1. increase the number of individuals who are gainfully employed, including self-employment and double the number of people who are competitively employed.
2. decrease the number of individuals in sheltered workshops and non-work day habilitation programs that are typically called day support options (DSO).

On the chart below, the bottom trend line shows that the number of individuals supported by DDS who work in competitive or individual supported employment has decreased since FY 2005. For the June 2010 graduates receiving DDS supports, only 10% went on to be employed in jobs making least minimum wage.

The upper trend line shows that the number of individuals supported by DDS who spend their days in activities that do not pay real wages has increased since fiscal year 2005. This number includes those attending sheltered workshops and programs called day support options. Originally called "community experience programs", DSO was designed for older individuals who wished to retire from competitive or supported employment. Currently, only 11% of those attending such programs are individuals over the age of 64 with the youngest being age 21. The largest enrolled group is made up of those between the ages of 22-34.



The data show that if nothing is done, especially in the current economic climate, these two lines will continue to diverge and fewer and fewer individuals will experience work that pays

at least minimum wage. The goal is to “turn the curve” of these trend lines and show that we can cause the bottom trend line to turn upwards and change the direction of the top one to turn downwards. The department will begin by targeting the June 2011 through 2016 high school graduates (approximately 250 per year) to require real employment outcomes for those graduates. Connecticut has a state team, headed by DDS, that participates in the National Alliance for Full Participation. The alliance has developed a state team scorecard to help states review their policies, practices, and strategies that impact opportunities for integrated employment. The scorecard will serve as a framework for the employment stakeholders group that will be convened to work on the employment goals.

### **The person and family have key roles**

3. Update the DDS Mission and Vision to reflect more emphasis on the family’s continued involvement across the lifespan, employment, and other socially valued roles for individuals with intellectual disability.
4. Increase the number of individuals who self-direct their services (hire and manage their own staff).
5. Increase the involvement of families and consumers in DDS policies.
  - Self advocates will meet with the Commissioner quarterly to review DDS policies
  - There will be a new position of Individual/Family Advocate reporting to the Commissioner
  - Contracts will specify that all provider agencies serving adults will have self advocates on their governing boards or will support self advocacy groups within their agencies or both
  - Each Regional Advisory Council will include at least one self advocate
6. Finalize and implement a new policy on healthy relationships as developed by the self advocate coordinators and provide training for consumers, providers, and staff.
7. Improve communication with families, providers, and staff.
  - Increase family opportunities for networking
  - Redesign the website to be more user-friendly by recruiting families to be part of the design team
  - Provide materials that will better help families to navigate the complex systems of DDS
  - Provide more information for families on available resources both within and outside of DDS
  - Increase opportunities to share information with families that meets their needs
8. Increase outreach to siblings of persons supported by the agency by establishing “Sibshops” or other sibling networks.

## **Community Living**

9. Increase the diversity of person-centered residential options.
10. Reduce the reliance on nursing homes by requiring the Commissioner's approval before any individual supported by DDS funding is placed into a long-term care (nursing home) facility. Develop a process by which private sector ICF/MR-certified homes will notify DDS prior to placing individuals in long-term care facilities.
11. Expand the number of private agencies that have the skills to support persons with complex behavioral or forensic needs which will allow more people to move through DDS transition units into private sector residential settings. Develop more responsive public/private pilot projects in this area.
12. Increase the number and availability of behavioral and psychiatric supports for individuals living with their families and develop effective public/private pilot projects in this area.
13. Develop policies on end-of-life decisions for individuals with intellectual disability and their families.
14. Expand the availability of supports that will allow more individuals to age in place wherever they live by building new partnerships with organizations that provide services to seniors.

## **Quality Services and Supports**

15. Redesign the Quality Service Review, incorporating input from both the public and private sectors and increasing family and consumer involvement.
16. Redesign the DDS-required Continuous Improvement process for all providers, incorporating consumer reviews.
17. Examine all Medicaid waiver requirements to seek a balance between quality and compliance.
18. Do more with less by streamlining processes to eliminate redundant paperwork and make processes electronic where possible.
19. Find valid ways to make information on provider quality available to individuals, families, and the general public.
20. Minimize inconsistency in processes across the three regions.
21. Continue to assess the effectiveness of current methods for assuring health and safety protections for all individuals and assess the need for additional protections.
22. Fully implement day service rates and design a rate conversion for residential supports from annual contracts to fee-based rates tied to each individual's level of need.

## **Informed Workforce**

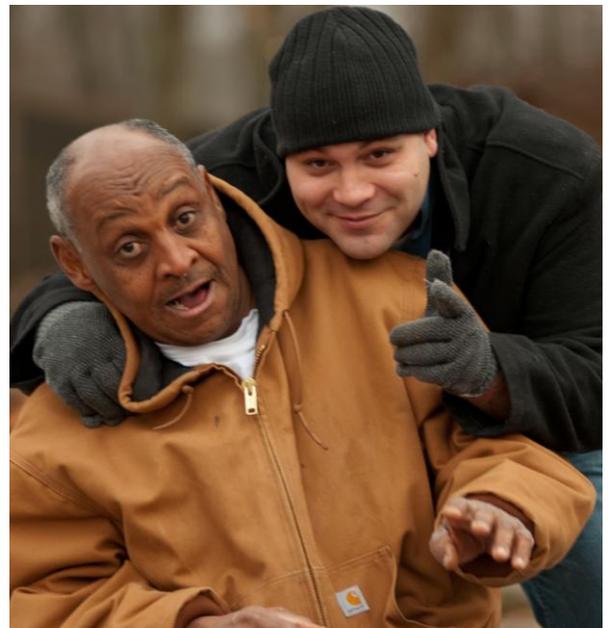
23. Ensure training for all staff and providers on the new paradigm and revised Mission.
24. Create a pilot project for a public/private partnership for all types of training.
25. Expand training for service providers about evidence-based practices for autism spectrum disorder.

## **A CALL FOR PARTNERS**

Progress on the 25 stated goals will require partnerships with public and private providers, individuals and their families, advocates, and advisory councils. The department intends to create several stakeholder groups to begin the work over the next two years. But, most of all, it calls for the department's self-advocates to become true policy partners in transforming their own service system. It is anticipated that stakeholder groups will have specific objectives, defined leadership, and timeframes.

Not every goal requires a stakeholder group, but many do. The department will ensure that membership in the groups includes individuals we support, families, private providers, and DDS staff. That, in itself, should advance goal #5 to increase the involvement of families and consumers in DDS policies. The stakeholder groups currently envisioned by the department are:

- Mission (Goal 3)
- Residential Options (Goal 9)
- Communication with families, private providers, and staff (Goal 7)
- Employment (Goals 1 and 2)
- Training (Goals 23, 24, and 25)
- Quality Service Review (Goal 15)
- Continuous Improvement Process (Goal 16)
- Medicaid waiver requirements (Goal 17)



## TIMEFRAMES

This chart presents the department's anticipated timelines for the implementation of each of the 25 goals in this plan.

Goal	2012	2013	2014	2015	2016
1 - ↑ employment					
2 - ↓ non-employment programs					
3 - revise the mission					
4 - ↑ self-direction					
5 - ↑ involvement families/consumers					
6 - healthy relationships policy					
7 - ↑ communication					
8 - ↑ outreach to siblings					
9 - ↑ person-centered residential options					
10 - ↓ reliance on nursing homes					
11 - ↑ private sector behavioral supports					
12 - ↑ behavioral supports for families					
13 - policy on end of life decisions					
14 - ↑ aging in place					
15 - redesign Quality Service Review					
16 - redesign continuous improvement					
17 - examine waiver requirements					
18 - streamline processes					
19 - provider quality ratings					
20 - ↑ consistency among regions					
21 - health and safety protections					
22 - day and residential rates					
23 - training on new paradigm & mission					
24 - training partnership					
25 - training in autism					

**“Do those served  
grow as persons?  
Do they,  
*while being served,*  
become healthier,  
wiser, freer,  
more autonomous....?”**

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Greenleaf, R. K. (1977/2002). *Servant Leadership: A Journey into the Nature of Legitimate Power and Greatness* (25th anniversary ed.). New York: Paulist Press