Autism Services in Connecticut
A report from the Autism Feasibility Study Workgroup

Recommendations to Enhance and Improve the Service System to Support Individuals with Autism and their Families

January 2013
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Understanding Autism

Autism Spectrum Disorder (ASD) is a developmental condition caused by neurological dysfunction that is yet to be well understood. ASD is more common in males than females and there are genetic factors that contribute to its prevalence. ASD is defined by three central areas of challenge: social interaction, communication and involvement with restricted interests and repetitive activities. In most cases, there are also difficulties with sensory processing, creativity/imagination and learning. Autism is a “spectrum” disorder because there is wide variation in its severity. Some individuals present severe cognitive challenges and are unable to speak or respond to people. Also, within the autism spectrum, there are individuals who are intellectually gifted who are able to succeed in school with minimal supports. Many individuals with ASD also experience other behavioral health and medical conditions, further complicating their course of treatment.

There is no cure for autism, but individuals can improve their functioning through behavioral and developmental treatments, specialized educational programming, social skills interventions, speech therapy and adaptive skills training. The approach to helping individuals with ASD is somewhat different than traditional clinical and educational practice; research has identified a group of evidence-based practices that are effective in facilitating the development of people with ASD. The importance of effective services cannot be overstated, particularly early intervention services. With appropriate programming, many individuals with ASD can lead independent lives as adults, working and participating in community life. Without effective services, individuals with ASD are much less likely to live independently, become productively employed, or establish social relationships.
What is Connecticut Doing for Individuals with Autism?

Connecticut does not have a comprehensive or coordinated service system to address the needs of individuals with autism or their families. Services are available through individual school districts, small programs in state agencies and private practitioners, but these are inconsistent in approach and quality and do not meet the level of need.

Consequently, Section 27 of Public Act 11-6 required a study of issues related to the needs of persons with ASD, including the feasibility of a Center for Autism and Developmental Disabilities. This study was begun in May 2011 led by the Department of Social Services (DSS) and included the Departments of Developmental Services (DDS), Mental Health and Addiction Services (DMHAS), Education (SDE), Children and Families (DCF) and the Office of Policy and Management (OPM). ValueOptions, the administrative services organization (ASO) for the Connecticut Behavioral Health Partnership (CT BHP), provided assistance with literature reviews, data analysis and summary documentation of the activities and findings of the ASD Workgroup Committee. Besides the state agency representatives, a larger workgroup, the Autism Feasibility Study workgroup was formed, including providers, academics, advocates, and consumer representatives.

Over the past year, the workgroup examined the following issues:

- Prevalence of Autism Spectrum Disorder in Connecticut
- A focused literature review of the behavioral treatment of ASD focusing on evidence-based or promising treatments available for this population
- Utilization of state funded or provided services by the ASD population
- Identification of service gaps based on utilization data as well as input from professionals, advocates, families, and state agencies
What is Connecticut Doing for Individuals with Autism?

- Recommendations for system changes necessary to enable Connecticut residents with ASD to access effective services.

The pages that follow represent the findings and recommendations of the ASD Feasibility Workgroup. The Workgroup developed their recommendations based on the simple principle that all individuals with an Autism Spectrum Disorder (ASD) should receive effective clinical and support services that are person-centered, culturally competent and provided by qualified professionals.

This report represents a summary of a larger report that is available to those interested in a more in-depth review of each section that follows.
Prevalence of Autism

According to the most recent study from the Centers for Disease Control (CDC; March 2012), the estimated prevalence of autism in eight-year-olds is 1 in 88 (1.14%) and 1 in 54 boys (1.85%). This represents a 23% increase since the CDC’s last report in 2009. There are numerous reasons for this increase, including, but not limited to, an actual increase in the number of individuals with the disorder, improved access to evaluation services, a greater public awareness of the disorder leading to less stigma, and more professionals with specialty of evaluating the disorder. It is likely that these numbers do not include undiagnosed adults because of the lack of knowledge regarding ASD during their youth and adolescent years.

Connecticut’s Status Update

Data was collected and reviewed from state agencies that serve individuals with ASD in order to compare the national prevalence estimates and the estimated prevalence rates in Connecticut for those receiving services through the state agencies.

<table>
<thead>
<tr>
<th>State Agency</th>
<th>Estimated Prevalence Rate*</th>
<th>Age</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>State Department of Education</td>
<td>1.09% of total CT youth who receive special education service in the “Autism” category**</td>
<td>K-12</td>
<td>2010</td>
</tr>
<tr>
<td>Department of Children and Families</td>
<td>3.9% of youth being treated in community based behavioral health services funded by DCF</td>
<td>0-18</td>
<td>2010</td>
</tr>
</tbody>
</table>
### Prevalence of Autism

<table>
<thead>
<tr>
<th>State Agency</th>
<th>Estimated Prevalence Rate*</th>
<th>Age</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid HUSKY A and B</td>
<td>1.7%</td>
<td>0-18</td>
<td>2010</td>
</tr>
<tr>
<td>Department of Developmental Services: Birth to Three Program</td>
<td>1.04%</td>
<td>0-2</td>
<td>Children born in 2007</td>
</tr>
</tbody>
</table>

* It should be noted that state agencies do not necessarily define autism the same way. For example, the State Department of Education data cited above references the educational classification of autism, not the medical diagnosis.

**The State Department of Education (SDE) prevalence rate is likely an underestimate; many youth with ASD are included in other SDE special education categories.

Using the 1.14% prevalence rate and the 2011 United States Census estimates for the number of youth 18 years or younger, the estimated number of Connecticut youth with ASD is approximately 9,143 (based on US Census Bureau, 2011 count of 802,079 youth in CT <18 years old). Because ASD is not considered curable, it is also assumed that the number of Connecticut residents with ASD across the age span is approximately 40,820 (based on US Census Bureau, 2011 count of 3,580,709 people in CT).
Effective Services

Background

There has been a tremendous amount of research published in peer-reviewed journals on the effectiveness of various interventions for people with Autism Spectrum Disorder (ASD). Two national organizations performed systematic literature searches to determine what best practices exist for the treatment of autism. In 2008, The National Professional Development Center (NPDC, 2009) on Autism Spectrum Disorders identified 24 interventions that met their criteria for evidence-based practices for children with ASD. The National Autism Center (NAC, 2009) also completed a comprehensive, multi-year review of the literature on autism interventions entitled “The National Standards Project”. The intention was to identify the scope of research available for interventions for children and adolescents with ASD. Evidence based practices are applied to a wide range of programming addressing both instruction and changing maladaptive behaviors. This includes academic teaching in school, behavioral treatment, vocational and life skills coaching, speech therapy, and social skills training.

These two research projects determined that there are a number of interventions for individuals with ASD that have evidence supporting their effectiveness. Examples of evidence-based interventions include behavioral interventions such as Applied Behavior Analysis (ABA), Early Intensive Behavioral Intervention, and Comprehensive Behavioral Treatment for Young Children. Applied Behavioral Analysis (ABA) is the most well-known and best-researched intervention for children with ASD. ABA is considered to be both an established intervention and an “evidence-based practice” by both national organizations. Meta-analyses indicated medium to large effect sizes for changes in IQ, language, communication, and behavior using ABA techniques. There are also several evidence-based interventions that focus on naturalistic teaching strategies and building relationships between the individual and the
Effective Services

Data collection and data driven decision making are hallmarks of best practice and should be utilized in all program development.

therapist. Some naturalistic teaching strategies include: Pivotal Response Treatment (PRT), Joint Attention Intervention, Peer-Mediated Instruction and Intervention (PMII), and Social Narratives.

The current emphasis on evidence-based practice does not negate the need for individual practitioners to use their clinical judgment in designing and implementing interventions; evidence-based practice is a complex process that requires the knowledge and skills of well-trained professionals. Therefore, professional judgment is extremely important in the process of intervention selection. In their work, clinicians are presented with many intervention options and must rely on their knowledge of the individual as well as their environment and history with certain interventions. Data collection and data driven decision making are hallmarks of best practice and should be utilized in all program development.

Connecticut’s Status Update

Young children in the Connecticut Birth to Three Program have access to effective intensive home-based services as part of their general early intervention program. Once children turn three however, it can be challenging for families to access effective services.

The gaps in services for individuals over the age of three with ASD may lead to ineffective or even harmful treatments for individuals on the autism spectrum in Connecticut. This problem appears to be particularly evident in providers working with adult populations. Beyond the interventions listed in both the NPDC and NAC reports, evidence-based practice includes collecting and utilizing data in planning and monitoring treatment plans. Based on the conclusions of the workgroup, it appears that few providers collect or use data in their decision making.

Another issue surrounding evidence-based practice interventions is how families can access them. The workgroup found that there is inadequate funding for services in both the public and private sectors. Most insurance
carriers and Medicaid do not reimburse for evidence-based services and when they do, often the rate does not encourage practitioners to provide the related services and collateral contacts that are needed. As an example, Public Act 09-115, *AAC Health Insurance Coverage for Autism Spectrum Disorders*, was intended to have been an insurance mandate to assure adequate coverage of ABA services, but thus far has been ineffective in increasing access to autism services for people with commercial insurance coverage.

Beyond the financial and funding challenges mentioned above there is also a gap in a qualified workforce to provide effective services. Expanded access to effective services and appropriate reimbursement for those services should improve the workforce capacity in the future.
Utilization Data

Background

State agencies were asked to collect and report utilization data associated with individuals with autism. *The service utilization information cited below is limited to data available to the state agencies through state agency databases and Medicaid claims data.* It does not include commercial/private insurance service utilization and is therefore not inclusive of all individuals with autism nor does it include all services provided to individuals with autism in Connecticut. Utilization by state agency showed:

**Department of Children and Families (DCF)**

<table>
<thead>
<tr>
<th>Program</th>
<th>ASD Episodes</th>
<th>Percent of all ASD episodes</th>
<th>Percent for this program in all PSDCRS episodes, age 0-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient Psychiatric Clinics for Children</td>
<td>773</td>
<td>53.1%</td>
<td>53.7%</td>
</tr>
<tr>
<td>Intensive In-Home Child and Adolescent Psychiatric Service</td>
<td>216</td>
<td>14.8%</td>
<td>5.7%</td>
</tr>
<tr>
<td>Continuing Care</td>
<td>178</td>
<td>12.2%</td>
<td>2.8%</td>
</tr>
<tr>
<td>Emergency Mobile Psych</td>
<td>131</td>
<td>9.0%</td>
<td>21.4%</td>
</tr>
<tr>
<td>Extended Day Treatment</td>
<td>60</td>
<td>4.1%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Therapeutic Foster Care</td>
<td>43</td>
<td>3.0%</td>
<td>3.0%</td>
</tr>
</tbody>
</table>

53% of the behavioral health episodes of care for youth with ASD were at the outpatient level of care in 2010.
Approximately 15.2% of the general DDS population is listed as having an Autism Spectrum Disorder on their most recent Level of Need assessment.

<table>
<thead>
<tr>
<th>Program</th>
<th>ASD Episodes</th>
<th>Percent of all ASD episodes</th>
<th>Percent for this program in all PSDCRS episodes, age 0-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Support Team</td>
<td>35</td>
<td>2.4%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Medically Complex Foster Care</td>
<td>5</td>
<td>0.3%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Functional Family Therapy</td>
<td>4</td>
<td>0.3%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Safe Homes</td>
<td>4</td>
<td>0.3%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Therapeutic Mentoring</td>
<td>2</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Short Term Assessment and Respite Home</td>
<td>2</td>
<td>0.1%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Family Substance Abuse Treatment</td>
<td>1</td>
<td>0.1%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Multisystemic Therapy</td>
<td>1</td>
<td>0.1%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Problem Sexual Behavior</td>
<td>1</td>
<td>0.1%</td>
<td>0.2%</td>
</tr>
</tbody>
</table>
Based on data collected from DCF-funded Community Based Services Organizations:

- For both ASD episodes of care and overall, a little more than half of all episodes are with Outpatient Psychiatric Clinics for Children (OPCC’s).
- Individuals with ASD are substantially more likely than others to use Intensive In-Home Child and Adolescent Psychiatric Service (IICAPS) and Continuing Care.
- Individuals with ASD are substantially less likely than others to use Emergency Mobile Psychiatric Services (EMPS).
- Individuals with ASD receiving DCF-funded services consistently have a longer length of stay in Community Based Services than do youths without an ASD diagnosis.

**Department of Developmental Services**

The Department of Developmental Services (DDS) serves individuals over the age of three with ASD through two different programs. Approximately 15.2% of the general DDS population is listed as having an Autism Spectrum Disorder on their most recent Level of Need assessment. This designation of autism is not necessarily based on a clinical diagnosis and so the numbers may represent a slight over estimate. 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 January 1, 2013, thirteen children with autism who do not have intellectual disability were receiving services through DDS.
CT Behavioral Health Partnership (CT BHP) Medicaid HUSKY A and B Data

The following data are based on behavioral health treatment authorized for youth and adults enrolled in HUSKY A and B by Connecticut Behavioral Health Partnership (CT BHP). Only youth with an ASD diagnosis during the episode of treatment authorized are included in the ASD categories. As a result, the counts may underestimate the number of members with ASD as they may not have carried the diagnosis during every episode of care.

Use of Inpatient Psychiatric Services by HUSKY A and B Youth and Adults

Total Inpatient Hospital Admissions and Average Length of Stay (ALOS)

<table>
<thead>
<tr>
<th>Year</th>
<th>Child 0-17 Admissions</th>
<th>Child ALOS</th>
<th>Adult 18+ Admissions</th>
<th>Adult ALOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>2,212</td>
<td>14.41</td>
<td>1,659</td>
<td>8.2</td>
</tr>
<tr>
<td>2010</td>
<td>2,268</td>
<td>14.87</td>
<td>1,745</td>
<td>7.0</td>
</tr>
<tr>
<td>2011</td>
<td>2,335</td>
<td>12.2</td>
<td>1,427</td>
<td>8.7</td>
</tr>
</tbody>
</table>
Utilization Data

Total Inpatient Hospital Admissions and Average Length of Stay (ALOS);

Youth with ASD Enrolled in HUSKY A and B and HUSKY A Population

<table>
<thead>
<tr>
<th>Year</th>
<th>Child 0-17 Admissions*</th>
<th>Child ALOS</th>
<th>Adult 18+ Admissions</th>
<th>Adult ALOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>129 (96)</td>
<td>19.89</td>
<td>16 (9)</td>
<td>13.63</td>
</tr>
<tr>
<td>2010</td>
<td>160 (127)</td>
<td>26.82</td>
<td>6 (2)</td>
<td>23.67</td>
</tr>
<tr>
<td>2011</td>
<td>132 (107)</td>
<td>20.0</td>
<td>11 (8)</td>
<td>5.5</td>
</tr>
</tbody>
</table>

*The number in parentheses represents the discrete count of members hospitalized.

- Between 6 and 7% of behavioral health inpatient hospitalizations for youth enrolled in HUSKY A and B are for youth with an ASD diagnosis.
- Youth with ASD have a significantly longer length of stay in the hospital than youth without an ASD diagnosis.
- Among adults enrolled in HUSKY A, <1% of behavioral health inpatient hospitalizations are for adults with an ASD diagnosis. This is at least partially explained by the composition of this population (parents of children enrolled in HUSKY A and B) as well as by the current under-diagnosis of ASD among adults.
- For those adults with ASD, the length of stay in the hospital is typically longer than that of the overall population enrolled in HUSKY.
### Hospitalizations for Youth ASD in In and Out of State and Riverview Hospital

<table>
<thead>
<tr>
<th>Year</th>
<th>Out of State</th>
<th>In State</th>
<th>Riverview</th>
<th>Total Hospitalizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>12 (8.3%)</td>
<td>117 (80.7%)</td>
<td>16 (11.0%)</td>
<td>145</td>
</tr>
<tr>
<td>2010</td>
<td>20 (11.3%)</td>
<td>140 (79.1%)</td>
<td>17 (9.6%)</td>
<td>177</td>
</tr>
<tr>
<td>2011</td>
<td>15 (10.5%)</td>
<td>117 (81.8%)</td>
<td>11 (7.7%)</td>
<td>143</td>
</tr>
</tbody>
</table>

- Between 2009 and 2011, just over 10% of youth enrolled in Medicaid with ASD who required hospitalization, were hospitalized in out of state hospitals that specialize in treating this population.
- In CY 2011, there were a total of 15 Out of State (OOS) hospitalizations, 13 of which were in hospitals specializing in the treatment of ASD.

### Hospitalizations of Adults with ASD in In and Out of State and State Hospital(s)

<table>
<thead>
<tr>
<th>Year</th>
<th>Out of State</th>
<th>In State</th>
<th>State Hospital</th>
<th>Total Hospitalizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>4 (25%)</td>
<td>12 (75%)</td>
<td>0</td>
<td>16</td>
</tr>
<tr>
<td>2010</td>
<td>0</td>
<td>6 (85.7%)</td>
<td>1 (14.3%)</td>
<td>7</td>
</tr>
<tr>
<td>2011</td>
<td>0</td>
<td>11 (91.7%)</td>
<td>1 (8.3%)</td>
<td>12</td>
</tr>
</tbody>
</table>
• Adults enrolled in HUSKY A are less likely to be hospitalized in out of state hospitals specializing in the treatment of ASD. However, as the number of adults identified is so small, significant caution should be used in interpreting these findings.

**SUMMARY OF UTILIZATION DATA**

• Outpatient services are the most frequently used service for the entire population of youth enrolled in HUSKY A and B, including youth with ASD.
• Youth with an ASD diagnosis stay longer in inpatient care than their peers not identified as having ASD while utilizing the same services.
• Approximately 10% of hospitalizations of youth with ASD occur in out of state hospitals that specialize in the treatment of ASD. Riverview Hospital is also utilized as an alternative to out of state hospitalization when youth with disabilities related to their ASD diagnosis are identified.
• Based on inpatient days used by youth with ASD, it was determined that, on average, less than two beds are needed on any given day to accommodate those members currently being treated in out of state hospitals (488 inpatient days/365 days in year = 1.3 beds/day).
• As a result of the small number of adults enrolled in HUSKY A identified with ASD and also requiring hospitalization, it is currently not possible to assess their utilization of services or to extrapolate from their utilization to the services needed.

*Less than 1% of behavioral health inpatient hospitalizations of adults enrolled in HUSKY are for adults with an ASD diagnosis. This is at least partially explained by the current under-diagnosis of ASD among adults.*
Gaps in the Connecticut Autism Service System

Background

The workgroup focused much of its effort on identifying gaps in services needed by the ASD population. The group approached the identification of gaps in services in Connecticut from several perspectives; analysis of data from the state agencies regarding utilization of services by the ASD population, soliciting input from professionals, advocates, families, and state agencies, and reviewing the literature on service gaps for this population.

The workgroup sought feedback from a range of stakeholders (including families, providers, university personnel and state agency representatives) and conducted a series of discussions about the current state of affairs in Connecticut. From this process, the following gaps were identified:

There is inadequate availability of effective services, including behavioral treatment, psychiatric care, primary medical care, social skills and communication training, individualized educational support within the public and private education system, transition services, vocational support, housing, social/ recreational opportunities and specialized residential/inpatient placement.

A relatively small group of providers and agencies are diagnosing and delivering effective services and successfully helping individuals with autism and their families, but:

There is inadequate provision of healthcare providers who have specialized training and experience in ASD, leading to misdiagnoses, ineffective treatment recommendations and reluctance by practitioners to work with individuals with ASD.

There is inadequate access to effective services for individuals with ASD and their families utilizing evidence-based practices.
Even in programs offering effective care, access to services is inconsistent.

For families, securing effective services is very difficult. The system is complex with few resources. Inconsistent reimbursement across carriers and services and limited collaboration between state agencies obstruct efforts to access what individuals and families require. Furthermore, there is no clear user-friendly map of how to access what individuals need.

Many school districts struggle with supporting individuals on the autism spectrum. Both public and private schools may have difficulty effectively teaching academic and behavioral skills through evidence-based interventions. Many public and private school teachers across the grade span lack the tools and initiative necessary for this population.

There are a small number of individuals with clinically complex cases for whom intense behavioral challenges require hospitalization. A few of these individuals need highly specialized hospitalization out-of-state. An average of less than two Medicaid patients per day receives specialized, out-of-state treatment. These cases are poorly served in two ways: (1) there is no effective in-home behavioral intervention to prevent the need for hospitalization or residential placement; and (2) there are few psychiatric hospital beds with specialized care for individuals with autism.

There is inadequate funding for services in both the public and private sectors. Most insurance carriers and Medicaid do not reimburse for autism-related services and when they do, often the rate does not encourage practitioners to provide the related services and collateral contacts that are needed. Public Act 09-115, *AAC Health Insurance Coverage for Autism Spectrum Disorders*, was intended to have been an insurance mandate to assure adequate coverage of autism services, but it has been ineffective in increasing access to autism services for people with commercial insurance coverage. The lack of commercial and public insurance coverage forces most practitioners who work with individuals with ASD to only accept private payment for services, making it virtually impossible for many families to access needed evaluations and service
Individuals with ASD require a myriad of services throughout the lifespan in order to live successfully in the community. Currently there are very few services available to assist adults with ASD in achieving this goal. Services such as life skills coaching, employment assessment, job coaching, supervised and supported housing options, clinical, case management, social and leisure opportunities are just a few of the needs that individuals with ASD have throughout the life span.

There is inadequate access to training, consultation, and learning opportunities for providers, professionals, families, first responders, and peers (youth and adult).
Recommendations

Discussions by the workgroup emphasized the following principles which guided the recommendations:

- Any investment of resources needs to build on existing infrastructure and resources in Connecticut, while drawing on innovative ideas from colleagues in other states.
- Efforts should focus on expanding the capacity for the evidence-based practices that research has found to be effective for individuals with ASD.
- Service delivery should be person and family-centered, culturally competent and provided by qualified professionals.
- An effective service delivery system needs to be easily accessed and understood by consumers and their families. This demands outreach/dissemination of information, collaboration among different state agencies and a fair and responsive system of reimbursement for services.
- Responsible utilization of state and private resources requires a cost-effective service delivery model that leads to positive, measurable outcomes.
- Meeting the needs of Connecticut individuals with ASD and their families requires long-term solutions. The challenge is to begin to build a foundation that will allow subsequent efforts to succeed.

Based on the gaps in the service system and the principles outlined above, the Autism Feasibility Study workgroup recommends development of a multi-year coordinated plan to expand and improve the existing ASD service system. The Department of Developmental Services’ Division of Autism will be the responsible administrative agent for system development. An advisory committee and task oriented sub-committees will support the Department of Development Services in the implementation of the following recommendations.
Goal 1: Improve and Expand Access to Qualified Professionals and Effective Services (Clinical Interventions and Community Support Services)

Establish an ASD Credentialing Committee (target formation date 4/01/13)

- Develop an ASD Qualified Credentialing Application (QCA) for identification and endorsement of providers and agencies currently providing quality services to individuals with ASD and their families and to those providers desiring to provide services in the future.
- Use QCA to credential professionals and facilities, possibly using a peer credentialing model
- Identify and endorse evidence-based or promising practice clinical interventions, educational strategies, and support services for both children and adults
- Establish and maintain an ongoing process for renewing credentials

Goal 2: Improve and Expand Access to Training, Consultation, and Learning Opportunities for Providers, Professionals, and Families

Establish an ASD Training Committee (target formation date 4/01/13)

- Develop needed training/education to providers and families
  - Review and expand upon existing training resources for providers and families
  - Review training resources developed by other states
  - Identify an evidence-based or promising practice training curriculum for professionals from each relevant field of practice
  - Identify an evidence-based or promising practice training curriculum for parents and family members (education and training curricula)
  - Implement training for professionals and parents, building on existing resources
  - Establish a process to contract with qualified trainers
  - Coordinate with current state agency credentialing and licensing authorities
Goal 3: Improve and Expand Access to a Comprehensive Service Resource Guide

Establish an ASD Resource Committee (target formation date 4/01/13)

- Create a user-friendly clearinghouse to facilitate access to services
  - Catalogue resources currently available (federal, state, private)
  - Catalogue qualified professionals/facilities based on QCA
  - Catalogue existing training opportunities for parents and professionals

Goal 4: Implement Effective Services

Establish an ASD Service Delivery Implementation Committee
(Target formation date 4/01/13)

- Develop an RFP for up to three (3) specialized inpatient hospital beds for individuals experiencing the most acute and complex ASD and co-occurring psychiatric disorders
- Develop models for two pilot programs addressing areas of critical need:
  - in-home behavioral supports for adolescents;
  - Social/recreational/respite capacity for individuals with ASD across the life span.

Goal 5: Analyze Public and Private Reimbursement for ASD services

Establish a State Agency Reimbursement Committee (target formation date 4/01/13)

- Review the current reimbursement process and rates for ASD services
- Review reimbursement strategies used by other states
- Review Medicaid funding options related to reimbursement for ASD services (e.g. state plan amendment, waiver, etc.)
Recommendations

- Review current statutory language regarding coverage requirements by private insurance companies for ASD services
- In order to ensure that the recommendations are implemented and managed in a coordinated manner, the workgroup is making a final recommendation regarding the oversight of the committees:

Establish a new ASD Implementation Advisory Committee to provide advice and counsel to the Commissioner of DDS regarding the implementation of the recommendations of the Autism Feasibility Study workgroup. Members of the ASD process. It will be convened by DDS no later than 2/28/13. This advisory committee will integrate and coordinate the work of subcommittees. DDS will be the lead agency with representatives from: DSS, DMHAS, DCF, SDE, OPM, Department of Rehabilitation Services (DORS), Department of Public Health (DPH), consumers, families, advocates, professionals (M.D., PhD, and licensed professionals), providers and Higher Education/Academic Institutions. Commissioners will serve or appoint representatives from their respective state agencies to the Advisory Committee and sub-committees. All of the applicable human services agency Commissioners will also play an oversight function to ensure maximum cross-agency integration of services. Specific tasks of this committee will include but not be limited to:

**Design and development of a state-wide service delivery system** for individuals with Autism Spectrum Disorders and their families, by building on existing infrastructure and resources and drawing on the experiences of other states. Specifically, the committee will:

- Create a values statement to guide all efforts
- Establish processes to ensure quality management and assess outcomes on an ongoing basis
- Oversee implementation of pilot programs to:
  - Provide in-home behavioral services for adolescents at risk of needing hospitalization or residential placement
  - Establish social/recreational/respite capacity programs for individuals with ASD
Implementation Timeline

Short Term Goals (January 1, 2013 – June 30, 2013)

- Identify and endorse effective clinical interventions and non-clinical support services
- Identify current professionals and organizations that are qualified to provide services identified
- Initiate training for professionals and organizations to build network capacity of qualified professionals
- Initiate trainings for parents to build their understanding of Autism Spectrum Disorders, teach parenting strategies effective with individuals on the spectrum, and inform them about how to access resources and services
- Investigate reimbursement strategies
- Initiate the development of a resource clearinghouse website where professionals, parents, advocates, and consumers can go to find information on autism spectrum disorders
- Develop a pilot program that delivers in-home services to adolescents at risk of hospitalization or residential placement
- Develop a pilot program for social/recreational/respite capacity, designed to optimize access and participation of individuals with ASD of all ages
- Consider the development of an RFP for up to three (3) specialized inpatient hospital beds for individuals experiencing the most acute and complex ASD and co-occurring psychiatric disorders.
Long Term Goals (July 1, 2013 – June 30, 2014)

- Continue roll-out of service system and recommendations of the ASD Implementation Advisory Committee using available resources
- Refine the strategies and metrics to monitor effectiveness and outcomes of individuals receiving ASD services from the service system
- Implement in-home pilot program for youth with ASD
- Implement pilot program for social/recreational/respite capacity, designed to optimize access and participation of individuals with ASD of all ages
- Continue to expand the pool of credentialed and qualified professionals
- Develop ongoing, continuing education training for professionals, facilities and families.
- Develop additional community-based services within available resources
- If deemed necessary, contract for up to three (3) specialized inpatient beds within available resources
Respectfully Submitted by the Connecticut Autism Feasibility Study Workgroup:

Karen Andersson, Ph.D., CT Department of Children and Families
Jennifer Bogin, M.S.Ed., BCBA
Sheldon Bustow, MA, Hospital for Special Care
Sarah Brdar, ValueOptions, CT
Meredith Damboise, ValueOptions, CT
Judith Dowd, CT Office of Policy and Management
Michelle Drake, Parent
Joseph Drexler, Esq., Deputy Commissioner, CT Department of Developmental Services
Sharon Drexler, CT Office of the Child Advocate
Ruth Eren, Ed.D., Center of Excellence on Autism Disorders, and Southern CT State University
Alison Fisher, CT Office of Policy Management
Tierney Giannotti, MPA, University of CT Health Center
Sue Graham, CT Department of Mental Health and Addiction Services
William Halsey, LCSW, MBA, CT Department of Social Services
Steven Kant, MD, ValueOptions, CT
Mickey Kramer, MS, RN, CT Office of the Child Advocate
James Loomis, Ph.D., Center for Children with Special Needs
Sara Lourie, MSW, CT Department of Children and Families
Terrence Macy, Ph.D., Commissioner, Department of Developmental Services
Julie McKenna, CT Office of the Child Advocate
John Molteni, Ph.D., St. Joseph’s College
Siobhan Morgan, CT Department of Developmental Services
Arnie Pritchard, Ph.D., CT Department of Children and Families
Katherine Ramirez, CT Children’s Medical Center
Linda Rammler, Med, Ph.D., University of CT
Lynn Ricci, Hospital for Special Care
Michael Rice, Ph.D., CT Capitol Region Education Council
Nikki Richer, LCSW, CT Department of Mental Health and Addiction Services
Lois Rosenwald, Autism Spectrum Resource Center
Susan Smith, CT Department of Children and Families
Maria Synodi, CT State Department of Education
Timothy Deschenes-Desmond, CT Department of Developmental Services
Carol Weitzman, MD, Yale School of Medicine
Laurie Vanderheide, Ph.D., ValueOptions, CT
Doriana Vicedomini, Parent and Chair, CT Children’s Behavioral Health Advisory Committee