

## **Appendix A**

### **AUTISM SPECTRUM DISORDER FEASIBILITY STUDY**

#### **Description:**

Representatives from the Departments of Social Services (DSS), Mental Health and Addiction Services (DMHAS), Children and Families (DCF), Developmental Services (DDS), Office of Policy Management (OPM) and Education (SDE) convened a meeting on May 24, 2011 to address the prevalence of and need for specialized services for individuals with autism spectrum disorders (ASD) who reside in Connecticut. .

The Departments agreed to utilize ValueOptions Connecticut, the Behavioral Health Administrative Services Organization, for management of the task. Part of what was tasked to ValueOptions Connecticut by the Departments was to perform a broad study, beyond publically funded clients and programs inclusive of all individual and service needs in the state. ValueOptions Connecticut was tasked with assisting the Departments in the review of the population as part of a contract deliverable that would include quantitative and qualitative information regarding individuals with ASD. As currently agreed upon, this clinical study will satisfy two of the three studies required by year two of the contract; one adult and one child study.

#### **Progress to date:**

The Departments met on a monthly basis throughout the second half of 2011 with the primary goal of assembling data regarding the types of services used, the cost of those services, and gaps in services from all involved departments. In January 2012 the group was opened up to include the Hospital for Special Care, a provider invested in providing services to the Autism population at both an outpatient and inpatient level, other providers, advocates, consultants and educators. The ultimate goal of the expanded group is to identify gaps in services for this population and to make recommendations to the Office of the Governor by June 2012.

The scope of the two studies includes:

#### **A. Literature and Benchmark review**

It was agreed that since there have been multiple peer reviewed literature reviews of ASD within the past few years, that ValueOptions Connecticut would gather the completed literature reviews and complete an analysis of their contents. The focus of the analysis of the literature review was

- To identify any studies of prevalence of ASD in order to compare prevalence information from CT with prevalence in other states or countries.
- To determine whether there are curriculum-based, evidence-based or promising treatments available for this population.
- To identify any benchmark standards regarding services and the identification of states or entities that are providing curriculum-based, evidence-based or promising treatments.

**Progress to date:**

Peer-reviewed articles on ASD were identified via a search of Pub-Med. The majority of literature identified and reviewed focused on interventions and treatments for youth with ASD. Very few studies of the prevalence and/or treatment of ASD in adults were identified. Since this finding corresponded to the data collected from the departments, the project has been heavily slanted towards the youth with ASD.

While a large number of articles published by individuals who conducted studies were identified and reviewed, the decision was made to focus on the meta-analyses of the efficacy of treatment of ASD identified in the literature. The meta-analyses reviewed included comparative analyses of treatments that included but were not limited to Applied Behavior Analysis (ABA), communication-focused interventions, developmental interventions, integrative interventions, sensory motor interventions and social skills development interventions.

Eight meta-analyses were reviewed and summarized. None of the reviewed meta-analyses concluded that any current interventions were both established and evidence-based. In the absence of any evidence-based and established treatments, ABA treatment had the strongest recommendations for use with this population. However, most studies ultimately concluded that there is inadequate evidence that ABA has better outcomes than standard care.

**B. Data Collection and Analysis**

Possible sources of data concerning the ASD population were expected to include CT BHP authorization data, claims data from DSS, encounter data from DCF, DMHAS and DDS, and State Department of Education (SDE). The data collection aspect of this study includes the following information regarding the ASD population when available:

- Prevalence
- Demographics
- Diagnosis and co-occurring diagnoses
- Services Used
- Service gaps
- Costs
- Discharge Delay
- Utilization Statistics (length of stay, readmission rates, follow-up services)

Under the category of utilization statistics, the data analysis included the use of inpatient services and congregate care services including residential, group home, psychiatric residential treatment facilities (PRTF) for both in and out of state providers. Additionally, data was collected regarding the use of community based services including partial hospitalization, intensive outpatient treatment, home-based services and outpatient services.

**Progress to date:**

All available data was collected from the state agencies. Data collected during 2011 included CT BHP utilization data, SDE prevalence data, DDS research on the Autism waiver pilot, DCF and DMHAS encounter data. Due to the way it is reported, DMHAS data was unable to be integrated into the analysis.

**Prevalence:** A literature review was conducted to review national prevalence rates for the ASD spectrum. Most literature reported rates for youth with ASD. Rates ranged from a low of 0.07% to a high of 1.25%. Only two studies were found that reported prevalence of ASD in adults. Those rates ranged from 0.7% among college students to 1.4% among adults in outpatient behavioral health treatment. Anecdotal information from both DMHAS and CT Autism advocates are that there is an increasing number of newly diagnosed adults with ASD requiring services in the state of CT.

Data provided by state agencies and from CT BHP authorization data was used to estimate the prevalence of ASD in Connecticut. SDE data consistently reported a 1.1% prevalence among youth in special education under the Autism category across all school districts in CT. DCF data showed a 3.9% prevalence rate among youth receiving Outpatient Services from DCF licensed outpatient providers.

Based on the SDE prevalence an estimated CT prevalence was calculated. CT representatives from the SDE caution that these figures should not be used as an overall statewide prevalence rate for two reasons. First, students with autism are not always classified as special education students under the autism disability category. Youth with autism whose special education needs are not driven by their diagnosis of autism but instead by co-occurring disorders would not be included in this statistic. They are often categorized in one of the other special education eligibility classes. Second, not all students in CT are represented in this data. For example, students who are not part of the public education system would not be included in the data.

The 2006 CDC study found that children with ASD diagnoses were classified into one of ten primary special education eligibility classifications. Of the eleven states included in the study, the CDC only had access to education records in six states. Overall, the study found that between 34.1% and 75.7% of children diagnosed with ASD received special education services under the Autism designation. The most common other designations for children with ASD to receive special education services included Intellectual Disabilities, Emotional Disturbance, Speech and Language Impairments and Specific Learning Disabilities. In total, the CDC found that between 75.9% and 96% of all children diagnosed with ASD received special education services in the six states where data was available.

The state of Connecticut was not one of the states included in the 2006 CDC study. The only east coast state to be included was Maryland. In Maryland, 84.8% of all students diagnosed with ASD received special education services, 75.7% of which received those services under the autism eligibility designation. Data from the CT DOE shows that 5,831 students are receiving special education services with an autism eligibility designation. If we assume that CT special education data has the same characteristics as the Maryland data, then we can estimate a total of 7,703 students with autism are receiving special education services. When the number of total students in CT with an ASD diagnosis (estimated to be 9,083) is divided by the total number of students served by public education in CT (536,283) a 1.7% prevalence rate is projected. The calculations performed are demonstrated below in table 1.

**Table 1**

	<b>MD # Cases</b>	<b>MD %</b>	<b>CT # Cases</b>	<b>CT %</b>
Primary special education eligibility: Autism	156	75.7%	5,831	75.7%
Total ASD in Special Education	206	84.8%	7,703	84.8%
Total # ASD cases	243	100%	9,083	100%
Total Student Population	26,489		536,283	
ASD prevalence	0.009 or 0.9%		0.017 or 1.7%	

Obviously, true prevalence rates are difficult to obtain. One study conducted in Korea assessed the entire population of eight year olds for autism. They reported a 2.7% prevalence rate. The repetition of this methodology is an unreasonable expectation of US states.

Another barrier to accurately assessing the prevalence of ASD is related to the diagnostic category itself. Since release of DSM IV in 1990's, diagnosis of this disorder has increased significantly. This has been hypothesized to be related to the current range of diagnoses included in this category in the Diagnostic and Statistical Manual of Mental Disorders IV-Text Revision (DSM IV-TR, 2000; American Psychiatric Association). The range of diagnoses is extremely broad and currently includes both people with mild characteristics of autism as well as the very seriously impaired. Frequently, this diagnosis is found concomitantly with other behavioral diagnoses. These issues, combined with lack of accuracy in applying the diagnosis, results in the inability to clearly differentiate between different sub-populations within the ASD broader population

DSM V, due to be released in May 2013, is expected to significantly revise the criteria for this diagnostic category. The revisions are expected to decrease the number of people who will fall into the ASD diagnostic categories by as much as 33%. The revised categories included are expected to focus on the more seriously impaired population of people with ASD.

#### **Utilization Statistics based on Authorization data:**

Data was collected in two ways for the analyses of service utilization by people with ASD. First, data was collected by determining a cohort of members with an ASD diagnosis utilizing the following methodology:

1. CT BHP's CareConnect and AIS table's databases were queried for all ASD related DSM-IV diagnoses on Axis I and/or Axis II.
2. The DSM IV diagnostic codes used are as follows: 299.00, 299.80, 299.0, 299.01, 299.91 and 299.90. To ensure inclusion of as many possible members with an ASD diagnosis in the study, any review for authorized services documenting the above diagnoses during the periods CY2009, CY2010 and Q1 '11 were included in the cohort.

3. To be included in the original cohort a member needed to have only one day authorized during the study period; authorizations did not need to start or end during the study period.
4. Once a member was included in the original cohort, all authorizations for that member were included in all subsequent data queries, regardless of diagnosis in that particular authorization.
5. There were no age constraints for cohort inclusion.

A total cohort of 2,208 members was found through the original data query.

Below is a prevalence comparison between Unique HUSKY members (age 0-18) excluding the ASD cohort members and ASD cohort members (age 0-18) where the ASD denominator is 5411 (an assumed 1.7% of total population (318,319)).

A	B	C	D	E	F	G	H
LOC	ASD Unique ID's	Unique ALL MEMBERS (Excludes ASD)	Adjusted Total population (excludes ASD 5411)	Penetration rate ASD (B/5411)	IS ASD Penetration greater than or less than general pop?	Penetration rate ALL (C/D)	Difference (E-G)**
CMS	51	434	312908	0.0094	>	0.0014	0.0080
CRE	38	352	312908	0.0070	>	0.0011	0.0059
CRS	35	352	312908	0.0065	>	0.0011	0.0053
EDT	53	579	312908	0.0098	>	0.0019	0.0079
FFT	5	270	312908	0.0009	>	0.0009	0.0001
FST	31	246	312908	0.0057	>	0.0008	0.0049
GHA	26	180	312908	0.0048	>	0.0006	0.0042
GHB	3	85	312908	0.0006	>	0.0003	0.0003
GHC	1	32	312908	0.0002	>	0.0001	0.0001
HBS	189	1,189	312908	0.0349	>	0.0038	0.0311
IOP	106	1,943	312908	0.0196	>	0.0062	0.0134
IPD	1	43	312908	0.0002	>	0.0001	0.0000
IPF- exclude riverview	214	1,558	312908	0.0395	>	0.0050	0.0346
Riverview only	26	155	312908	0.0048	>	0.0005	0.0043
IPM	7	33	312908	0.0013	>	0.0001	0.0012
MDF	2	178	312908	0.0004	<	0.0006	0.0002
MST	1	89	312908	0.0002	<	0.0003	0.0001
OBS	8	65	312908	0.0015	>	0.0002	0.0013
OTO	11	77	312908	0.0020	>	0.0002	0.0018
OTP	779	18,442	312908	0.1440	>	0.0589	0.0850
PHP	75	1,053	312908	0.0139	>	0.0034	0.0105
PRT	31	86	312908	0.0057	>	0.0003	0.0055
RTC	46	557	312908	0.0085	>	0.0018	0.0067
TST	71	366	312908	0.0131	>	0.0012	0.0120

\*\* For column H, lines highlighted in yellow use the formula (G-E)

Please note:

- For all levels of care, with the exception of Outpatient (OTP), the total population (ALL) does not exceed a penetration rate of 1%.

- For all levels of care, with the exception of MDF and MST, two home based services, penetration rates for members with ASD exceeded those of members in the total population (ALL).
- In only four levels of care do the penetration rates of the ASD population exceed by 10X or more those of the general HUSKY population. They are as follows: Riverview (10X), IPM (12X), PRT (21X) and TST (11X).

A full analysis of data collected from the cohort population was completed, however, it was decided by both the Departments and the ValueOptions Connecticut that the data is over-inclusive and does not give an accurate indication of utilization patterns and gaps.

Data was next collected for calendar years 2009-2011. Episodes of care were included in the data collection *only* if an ASD diagnosis of 299.00 or 299.80 appeared on any axis I or II diagnosis field. In this way, not all episodes of care were present for any particular member as the diagnosis may not have been included on all authorizations for all levels of care. For example, a member who had five IPF authorizations during 2009 only appears three times in the query as two of the admissions do not include an ASD diagnosis.

Demographics of those included in this data are below. As can be seen from the number of members included in the demographics, utilization by adults age 18+ was quite limited and further analysis excludes this population as conclusions cannot be drawn from an analysis with so few members included.

Child ASD population (age 0-17) - unduplicated -Riverview excluded

	<b>Gender</b>	<b>Average Age (In years)</b>	<b>% DCF involved</b>	<b>Race</b>
<b>2009</b>	12 F (13 %) 84 M (88%)	11.4	47 % (45 of 96)	83 White (86 %) 13 Black (14 %)
<b>2010</b>	20 F (16%) 107 M (84%)	12.0	49 % (62 of 127)	110 White (87 %) 17 Black (13%)
<b>Q1 '11</b>	6 F (19 %) 25 M (81 %)	11.9	35 % (11 of 31)	30 White (97 %) 0 Black, 1 Asian

Adult ASD population (age 18+) - unduplicated – Cedarcrest excluded

	<b>Gender</b>	<b>Average Age (In years)</b>	<b>% DCF involved</b>	<b>Race</b>
<b>2009</b>	6 F (40 %) 10 M (63%)	20.1	50 % (8 of 16)	15 White (94 %) 1 Asian
<b>2010</b>	3 F (38 %) 5 M (63 %)	18.8	50 % (4 of 8)	7 White (88 %) 1 Asian

Inpatient psychiatric (IPF) utilization data for child member's age 0-17 is as follows:

	<b>ASD Out of State Inpatient Days (# episodes)</b>	<b>ASD In-State Inpatient Days (# episodes)</b>	<b>Total ASD Inpatient Days (Excluding Riverview)</b>	<b>Total ASD Discharges (Unique Members) Counts Excluding Riverview</b>	<b>ASD Riverview Days</b>	<b>Total Riverview Discharges</b>	<b>Total ASD Inpatient Days</b>
<b>2009</b>	902 (12)	1,664 (117)	2,566	129 (96)	2,410	16	4,976
<b>2010</b>	1,394 (20)	2,897 (140)	4,291	160 (127)	3,694	17	7,985
<b>2011</b>	488 (15)	2,157 (117)	2,645	132 (107)	1,544	11	4,189
<b>Total</b>	2,784 (47)	6,718 (374)	9,502	421	7,648	44	17,150

In CY 2011 there were a total of 15 Out of State (OOS) hospital discharges, 13 of which were from hospitals specializing in ASD. All youth with ASD admitted OOS came from CT emergency departments. Out of State (OOS) hospitalizations occurred most frequently during 2010. There is a significant decrease (65%) in OOS hospital days in 2011 from 2010 as in-state hospitals agreed to treat this more acute population. It is assumed that those ASD members with the most significant needs were treated OOS.

Inpatient length of stay In-state and OOS is reported below. During 2009 and 2010, OOS average length of stay was more than 3 times that of in-state. OOS inpatient lengths of stay decreased significantly in 2011 as a focused plan to work with out of state facilities to expedite access to appropriate in-state services after discharge was implemented.

	<b>ASD In-State ALOS</b>	<b>ASD Out of State ALOS</b>	<b>ASD Total ALOS</b>
<b>2009</b>	14.2	75.2	19.9
<b>2010</b>	20.7	69.7	26.8
<b>2011</b>	18.4	32.5	20.0

Acute versus discharge delayed lengths of stay were examined for youth with ASD and compared to the total HUSKY population. As seen below, youth with ASD have a longer acute (medically necessary) and delayed inpatient length of stay when compared to all HUSKY youth.

	<b>ASD Acute ALOS</b>	<b>ASD Delay ALOS</b>	<b>HUSKY Member Acute ALOS</b>	<b>HUSKY Member Delay ALOS</b>
<b>2009</b>	15.3	25.7	12.3	18.0
<b>2010</b>	16.8	35.5	12.0	23.7
<b>2011</b>	16.3	22.7	11.2	17.7

Inpatient readmission rates were calculated for members with 30 days continuous eligibility after discharge. All IPF admissions after the initial IPF discharge are included in readmission counts/rates, regardless of diagnosis on the subsequent admit. Youth with ASD were found to have 7 and 30 day readmission rates similar to that of all HUSKY youth.

A report was run to look at authorizations in the six months post inpatient psychiatric discharge (IPF). Below the results are for child members 0-17 only. Please note, that "None" would not include any services not authorized by the CT BHP. This might include DCF Flex funded services or some DDS and DMHAS services. In addition, services that began prior to the IPF admission and more than 2 days prior to the IPF discharge are not included. For example if IPF stay is in the middle of a group home (GH) authorization, the GH would not be seen as a d/c level of care because the authorization began before the IPF admission.

In CY 2009, three children did not have 30 day continuous eligibility but they are included in the counts below. In CY 2010 4 members did not have 30 day continuous eligibility; they too are included in the counts below.

<b>Level of Care</b>	<b>2009 (96 ASD Youth)</b>	<b>2010 (127 ASD Youth)</b>	<b>Q1 '11 (31 ASD Youth)</b>
<b>Inpatient</b>	74 (33.9%)	79 (29.7%)	30 (36.1%)
<b>Psychiatric Rehabilitation Treatment Facilities (PRTF)</b>	15 (6.9%)	18 (6.8%)	5 (6.0%)
<b>Residential Treatment Centers (RTC)</b>	7 (3.2%)	19 (7.1%)	2 (2.4%)
<b>Partial Hospital Programs</b>	24 (11.0%)	13 (4.9%)	6 (7.2%)
<b>Intensive In-Home Services</b>	24 (11.0%)	25 (9.4%)	7 (8.4%)
<b>Intensive Outpatient Programs</b>	16 (7.3%)	17 (6.4%)	9 (10.8%)
<b>Outpatient Services</b>	27 (12.4%)	48 (18.0%)	16 (19.3%)
<b>All Other</b>	31 (14.2%)	47 (17.7%)	8 (9.6%)
<b>Total</b>	218 (100%)	266 (100%)	83 (100%)



Based on the utilization data analysis completed using both methodologies, the following summation and conclusions were presented at the Autism Feasibility Study work-group.

- Outpatient services are the most frequently used service for entire HUSKY population
- Psychiatric Residential Treatment Facility services are authorized 21 times more often for members with ASD when compared to the entire HUSKY population
- Riverview inpatient stays are used 10 times more frequently
- Intensive In-Home Services are used 9 times more frequently
- Psychological Testing Services are used 11 times more frequently

**Conclusions:**

- ASD population uses outpatient services nearly 2.5 times more often than the entire HUSKY youth population (14.4% vs. 6%)
- Riverview Hospital is used as an alternative to OOS hospitals for this population
- In-Home Services are widely used with this population

**Calendar Year 2012 Goals:** During Q1 '12 the CT BHP will secure DSS claims data and analyze its contents with the goal of quantifying monetarily healthcare costs associated with ASD in CT. By May 2012 a final set of conclusions, gaps and recommendations will be developed by the Autism Feasibility Study workgroup. During the month of May these recommendations will be vetted through the various commissioners of all the involved state departments with the ultimate goal of presenting the analysis and recommendations to the office of the governor.