

Appendices

Autism Spectrum Disorder Feasibility Study Committee

February 2013

Appendices

Report from the Autism Spectrum Disorder Feasibility Study Committee

INDEX

	Page
Appendix A: Prevalence of Autism Spectrum Disorder	3
Appendix B: Service Utilization and Demographic Characteristics of the ASD Population in Connecticut	15
Appendix C: Literature Review of Evidence-Based and Promising Practice Treatment of ASD	45
Appendix D: Family Focus Group Summary	57
Appendix E: Lists of Recognized Treatments for ASD from the National Professional Development Center and the National Autism Center	60

APPENDIX A

PREVALENCE OF AUTISM SPECTRUM DISORDER

PREVALENCE-LITERATURE

In order to attempt to estimate the prevalence of Autism Spectrum Disorder (ASD) in CT, a review of the literature was conducted using PubMed. The following primarily peer-reviewed articles were identified that presented data concerning the prevalence of ASD both within the United States as well as abroad. A summary of each of the articles is included in the order in which the articles were published.

A 2001 Swedish study by Nylander and Gillberg examined the prevalence of ASD among adults in outpatient psychiatric care. A total of 1,323 outpatients were surveyed with a screening questionnaire developed by the authors to identify ASD and used by the staff of the outpatient clinic. The authors also reviewed the records of any patients scoring “high” on the questionnaire and eliminated those patients who clearly met criteria for other diagnoses. Finally, the Asperger Syndrome Diagnostic Interview (ASDI) and Asperger Syndrome Screening Questionnaire (ASSQ) were used to evaluate the remaining 31 patients identified by the screening instruments as potentially having ASD. Nylander and Gillberg determined that 19 patients of the total population of 1,323 (1.4%) were found to have ASD, only two (2) of whom had previously been diagnosed with Asperger Syndrome. The authors cautioned that their prevalence rate is more than likely an underestimate as the flaws in their methodology would cause them to overlook rather than over-include cases.

Chakrabati and Fombonne (2005), working in the Midlands of England completed an assessment of ASD rates using the same study design they had previously used to identify ASD for a birth cohort between 1992-1995. Their goal was to repeat a prior survey for replication purposes and to determine if there had been an increase in prevalence rates since the original study using the population of children born between 1996 and 1998. They used the Autism Diagnostic Interview and the Diagnostic and Statistical Manual of Mental Disorders- IV (DSM IV) for diagnostic criteria and both Analysis of Variance (ANOVA) and Mann-Whitney tests for statistical measures. At the time of their study, the study population was between the ages of four and six years. The study found a 58.7 per 10,000 (0.59%) prevalence rate of ASD for the most recent birth cohort. The rate reported in their previous study of the earlier birth cohort for the same area was 61.9 per 10,000 (0.62%). Thus the authors found no increase and no statistical difference in the incidence of ASD disorders in the two birth cohorts. The authors found that the identification of ASD disorders occurred at an earlier age in the more recent cohort than the first, though the finding was not significant.

In 2006, the Center for Disease Control (CDC) conducted a survey of records in the Autism and Developmental Disabilities Monitoring (ADDM) Network. The ADDM Network began in 2000 and includes programs in 15 states. Those states are awarded funds by the CDC to identify children with ASD by the age of eight years. The CDC considers this age to be a reasonable index by which peak prevalence of ASD may be monitored. Many of the studies described below adopt the strategy set forth by the CDC for examining ASD prevalence.

For the 2006 study, data was collected from existing records in 11 ADDM Network sites. At the time of the publication of the 2006 study in 2009, the CDC estimated that the prevalence rate for ASD in the United States is one (1) in 110 (0.9%) eight year old

children (CDC, 2009). In March 2012, based on a follow-up study by the CDC using the same methodology, this figure was revised to one (1) in 88 eight year olds (1.14%) and one (1) in 54 in eight year old males (1.85%) (Baio, 2012).

A 2010 review of Medicaid claims by Mandell et al. examined ASD prevalence among Medicaid members at a national level. The authors used Medicaid data obtained from a 2004 Medicaid database with education data and an area resource file to examine prevalence variability across the United States. Mandell et al. found that ASD prevalence was higher in counties with lower per-student education expenditures, higher per capita numbers of pediatricians/specialists, and a greater portion of Medicaid enrollees and Caucasian students. The authors explained that services associated with the Individuals with Disabilities Education Act (IDEA), a 1990 act requiring free and appropriate education for children with autism, are reimbursed at a rate significantly less than those associated with similar services under Medicaid therefore encouraging states to serve these individuals under their Medicaid programs. The authors suggest that the higher prevalence rates associated with higher per capita pediatricians/specialists may be a result of people migrating to areas where services are available for this population or because of the increased availability of expertise in identifying and treating ASD. This study reported an overall prevalence of 70.1 per 100,000 or 0.07%.

The prevalence rate reported by Mandell et al. is by far the lowest (by ten-fold) of all the prevalence literature reviewed. Possible contributing factors for the discrepancy include lack of diagnostic consistency in diagnoses reported on claims, lack of consistent diagnosis in older members, and demographic indicators among Medicaid populations. A review of HUSKY Medicaid data from Connecticut revealed similar inconsistencies in diagnosis of ASD; youth diagnosed with ASD during an inpatient stay did not have the diagnosis on subsequent stays, nor had different ASD diagnoses across multiple treatments. Claims data, such as that reviewed by Mandell et al., likely required less diagnostic information, possibly reducing the prevalence rate estimate based on claims. The denominator for the Mandell et al. study is the Medicaid population as a whole, inclusive of adult and child members. In studies reviewed later in this report investigating adult prevalence data, it is common that adults identified as having an ASD did not carry the diagnoses prior to the research study. In Connecticut, anecdotal evidence from the Department of Mental Health and Addiction Services (DMHAS) suggests that until the last few years, there was a general lack of ASD diagnosis among the adult population. DHMAS reported that adults are increasingly being diagnosed with ASD and that it is a challenge to identify behavioral health providers able to treat this population.

Durkin et al., 2010, conducted a population-based cross-sectional study to determine if there is a relationship between socioeconomic status (SES) and ASD in eight-year-old children. Durkin et al., found that much like other common childhood disorders, there is an inverse relationship between SES and ASD. They report an overall prevalence rate of 0.70% for children with low SES and 1.25% for children with high SES. However, the prevalence rate identified in this study, even among children of low SES is 10 times the rate published by Mandell et al. for a Medicaid population.

Another study funded by the CDC conducted by Rice et al., in 2010, examined the prevalence of ADD in parts of Arizona, Georgia, Maryland and South Carolina as well as the population characteristics of eight year olds with ASD born in 1992, 1994 and 1996. The authors controlled for geography and changes in diagnostic criteria by studying ASD

symptoms rather than diagnosed cases of ASD over multiple time points in the same geographic areas. The study found increased prevalence of ASD among youth from Hispanic and Asian populations. The authors also found a decrease in diagnosis among lower cognitively functioning children and an increase among children without cognitive impairments. They attributed the increases in prevalence among certain ethnic groups to the increased identification of ASD by culturally competent professionals, and poor documentation of ASD in health records.

The authors suggested that the changes in prevalence related to cognitive functioning were related to a shift in professional thinking around ASD and a better understanding among professionals that ASD can be “present in children with average to above-average intelligence” as well as to improved testing and early-intervention services (196). Overall, the studies found a statistically significant increase in ASD prevalence in Georgia and Maryland, a non-statistical increase in Arizona, and a non-statistical decrease in South Carolina. The 2004 ASD prevalence rates among eight year old children in these sites ranged from 5.3 per 1,000 (0.53%) in South Carolina to 9.8 per 1,000 (0.98%) in Arizona.

In 2011, Kalkbrenner et al., of the University of North Carolina at Chapel Hill, conducted a study partially funded by the CDC that examined the relationship between geographic access to health services in central North Carolina (NC) and the age of the autism diagnosis through a record-based survey. The NC-ADDMN methodology to identify cases was much like the one used by Durkin et al. (2010) and Rice et al. (2010). Similar to Mandell et al. 2010, this study found higher prevalence rates in counties with higher per capita numbers of pediatricians/specialists. Kalkbrenner et al. concluded that individuals were being diagnosed younger where there were higher densities of neurologists and psychiatrists and closer proximity to medical schools. Interestingly, proximity to primary care practitioners (PCPs) and early intervention services were not associated with earlier age of identification.

Manning et al., 2011, conducted an analysis on behalf of the Massachusetts Early Intervention program. These authors used a data system owned by a public-private partnership and, unlike literature mentioned previously, included only children diagnosed with an ASD and enrolled in early intervention services by their third birthday. Birth cohorts between the years 2001 and 2005 were studied. The study found an overall prevalence rate of 77.5 per 10,000 or 0.78%. The authors found an increase in incidence from 56 per 10,000 children (0.56%) in 2001 to 93 per 10,000 children (0.93%) in 2005. The authors also found that while there were racial/ethnic disparities in the 2001 cohort, that the disparities were much less evident in the 2005 cohort. This finding is similar to that of Rice et al. 2010 who found that in two of the geographic areas they studied, there was an increase in identification of ASD in minority populations over their four year cohort period (2000-2004). Despite the fact that both of these studies focus on youth that are five years younger than those in the comparable studies reviewed above, it is important to note that the prevalence rates found are comparable, suggesting that the majority of diagnoses are made prior to age five.

The Manning et al. study also looked at prevalence rates related to certain maternal and paternal traits (including ethnicity, age, education, language, delivery payer source) as well as some infant traits in relation to children with and without an early diagnosis of ASD. All of the factors tested by the authors were found to have statistically significant differences in prevalence rates. Of particular relevance to the feasibility study, Manning

found that children with a public payer source at delivery had only a 66.1 per 10,000 (0.66%) prevalence rate of ASD diagnosis compared with an 83.4 per 10,000 (0.83%) prevalence rate of diagnosis in children with private pay sources; a statistically significant difference suggesting under-diagnosis among the Medicaid youth population.

In a 2011 publication by the National Autistic Society, White, Ollendick and Bray examined the prevalence of high functioning ASD (HFASD) youth among college students at a technology and engineering public university. The authors defined HFASD as the presence of an ASD with no co-occurring intellectual disability. In their sample of 667 students, 13 students (1.9%) scored above the Autism Spectrum Quotient (AQ), a clinical spectrum cutoff for autism, and 5 (0.7%) of those young adults met the diagnostic criteria for HFASD. In a matched group, the 13 students with high AQ scores differed significantly from those with low AQ scores in regard to having GPAs of 3.5 or higher, social anxiety, satisfaction related to their experience at the university and general life satisfaction. After scoring in the clinical spectrum the 13 students were invited to continue on in the second phase of the study. Only 8 of those 13 students identified in phase one of the study continued on to phase two, at which point the Autism Diagnostic Observation Schedule (ADOS) and Early Development Questionnaire (EDQ) were used for further evaluation. Five students were determined to meet diagnostic criteria for HFASD. None of the 5 had ever had a previous diagnosis.

In a 2011 study conducted by Kim, et al. in Korea, the authors reported the highest rates of ASD of any of the studies reviewed. The investigators used a population-based sample that included the entire elementary school population of a South Korean community as well as another group of youth with a high probability of ASDs. The study methodology was approved by the Yale University and George Washington Institutional Review Boards. The Autism Spectrum Screening Questionnaire (ASSQ) was used for the initial screening of the cohorts. Further screening was conducted of those children who screened positive on the ASSQ using several additional instruments. The authors found a “striking difference” between their estimated prevalence of ASD of 2.64% and any previously reported prevalence estimates in the literature. They found that two-thirds of the identified ASD cases in the overall sample were from the mainstream school population, undiagnosed, and untreated. The attributed their finding of higher prevalence rates to the rigorous screening used in the study and in their recommendations, stressed the need for better detection, assessment and services.

The literature reviewed above describes prevalence rates that vary depending upon the population, age and location of subjects and the methodology used in the study. Some authors, such as Rice et al. (2010) and Baio (2012) described above, found increasing rates of ASD diagnoses, though it is unclear if this finding is due to an increase in awareness and/or improved screening by professionals. The variation in prevalence rates may also result from the current broad scope and evolving definitions of diagnoses within the ASD diagnostic category. However, since multiple studies have been based on the methodology used by the CDC, that methodology will be the basis for estimates of the prevalence of ASD in Connecticut.

**PREVALENCE: CONNECTICUT-SPECIFIC DATA;
STATE DEPARTMENT OF EDUCATION (SDE)**

Table 1 summarizes CT SDE data for students in grades K-12 during 2010.

Table 1: CT SDE Special Education Data on Autism by DCF Region

	Total ASD Youth	Total Youth in K-12	DCF Area	DCF Region	Prevalence within Area	% within Region	% PSD Youth of Statewide Total
DCF Region 1							
Bridgeport	517	51,427	Bridgeport	1	1%	50.49%	
Norwalk	232	23,777	Norwalk	1	0.98%	22.66%	
Stamford	275	32,901	Stamford	1	0.84%	26.86%	
Total Region 1	1,024	108,105			0.95%		17.56%
DCF Region 2							
Milford	586	51,292	Milford	2	1.14%	75.61%	
New Haven	189	17,786	New Haven	2	1.06%	24.39%	
Total Region 2	775	69,078			1.12%		13.29%
DCF Region 3							
Norwich	461	37,845	Norwich	3	1.22%	43.37%	
Willimantic	230	20,850	Willimantic	3	1.10%	21.64%	
Middletown	372	32,328	Middletown	3	1.15%	35.00%	
Total Region 3	1,063	91,023		3	1.17%		18.23%
DCF Region 4							
Hartford	393	37,204	Hartford	4	1.06%	38.61%	
Manchester	625	59,994	Manchester	4	1.04%	61.39%	
Total Region 4	1,018	97,198		4	1.05%		17.46%
DCF Region 5							
Danbury	416	35,943	Danbury	5	1.16%	39.51%	
Torrington	229	20,077	Torrington	5	1.14%	21.75%	
Waterbury	408	39,490	Waterbury	5	1.03%	38.75%	
Total Region 5	1,053	95,510		5	1.10%		18.06%
DCF Region 6							
Meriden	168	15,411	Meriden	6	1.09%	18.71%	
New Britain	730	59,958	New Britain	6	1.22%	81.29%	
Total Region 6	898	75,369			1.19%		15.40%
Statewide	5,831	536,283			1.09%		100.00%

The above table shows a 1.09% overall statewide prevalence of students receiving special education services under the disability category of Autism. Representatives from the CT SDE caution however that these figures should not be used to estimate an overall statewide prevalence rate for two reasons. First, not all students in Connecticut are represented in this data. For example, students who are not part of the public education system would not be included in the data. Secondly, students with autism are not always classified as special education students under the autism disability category; they are often categorized in one of the other special education eligibility classes especially when other issues are driving their need for special education. As a result, the prevalence rate based on this data is certainly an under-estimate.

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 other most common 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.

Connecticut was not one of the states included in the 2006 CDC study. The only east coast state was Maryland. In Maryland, 84.8% of all students diagnosed with ASD received special education services, 75.7% of whom received services under the autism eligibility designation. Data from the Connecticut SDE shows that 5,831 members are receiving special education services with an Autism eligibility designation. If we assume that Connecticut special education data has the same characteristics as Maryland data, we can estimate that a total of 7,703 students with ASD are receiving special education services. When the number of total students in Connecticut with an ASD diagnosis (estimated to be 9,083) is divided by the total number of students served by public education in Connecticut (536,283) a 1.7% prevalence rate is projected. The calculations performed are displayed below in Table 2.

Table 2: Calculations for Connecticut Prevalence estimate

	MD # Cases	MD %	CT # Cases	CT %
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	0.9%		1.7%	

PREVALENCE: CONNECTICUT-SPECIFIC DATA; DEPARTMENT OF CHILDREN AND FAMILIES (DCF)

The prevalence data was drawn from DCF's Programs and Services Data Collection and Reporting System (PSDCRS). PSDCRS is an episode-based system; each record represents one stay in a given program by one client. It includes the great majority of community-based behavioral health services funded by DCF. The data is entered by providers.

Episodes involving ASD were identified by the DSM-IV diagnosis codes 299, 299.8 or 299.80 appearing as either the primary or secondary Axis 1 diagnosis. The query looked for all such episodes for any part of Calendar Year (CY) 2010, regardless of when they began or ended. There were 1,456 such episodes or 3.5% of all PSDCRS episodes for those ages 19 and older. All but three of the episodes involved clients age 19 or younger; so when comparing the ASD population to the rest of PSDCRS this study will compare it to the PSDCRS population age 19 and younger.

These episodes involved 1,190 different clients. Two hundred and thirteen clients, 17.9% of the total, had more than one episode with one of the ASD diagnoses. The clients may, of course, have had other episodes with no ASD diagnosis.

In CY 2010 a total of 30,754 unique members were registered in PSDCRS for services during the year. ASD prevalence among members in the PSDCRS database is calculated as 3.9%. This prevalence rate is likely an overestimate of actual ASD prevalence. Providers who are a part of the PSDCRS database are clinic based practitioners, more likely to have experience in treating this population, and have greater availability for intensive treatment of this population. Additionally, for some services, reimbursement is possible by DCF even when clients are covered by private pay insurance.

PREVALENCE: CONNECTICUT-SPECIFIC DATA; CONNECTICUT BEHAVIORAL HEALTH PARTNERSHIP (CT BHP)

The CT BHP authorizes the entire spectrum of psychiatric care in Connecticut and out of state for the Connecticut Medicaid system. The spectrum of authorized services includes inpatient, congregate care, outpatient and home-based levels of care. During the study period, only services for HUSKY A and B Medicaid members were managed by the CT BHP. Data for the analyses below were drawn from CT BHP's authorization databases. All data are based on authorization information entered by CT BHP master's level clinicians.

Data analysis for prevalence of ASD among the CT BHP HUSKY A and B Medicaid population began with the identification of the cohort of members with an ASD diagnosis utilizing the following methodology.

1. CT BHP's databases were queried for any and all instances of ASD related DSM-IV diagnoses on Axis I and/or Axis II.
2. The DSM IV diagnostic codes included in the query are as follows: 299.00, 299.80, 299.0, 299.01, 299.91 and 299.90.
3. To ensure the inclusion of all HUSKY A and B members with an ASD diagnosis in the study, any member with a review for authorized services that included any of the above diagnoses during the periods CY2009, CY2010 and Q1 2011 were included in the cohort.
4. To be included in the cohort a member needed to have only one service authorized during the study period, authorizations did not need to start or end during the study period. Once a member was included in the 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.

While the above diagnoses must have been included in an authorization for the member to be included in the cohort, these diagnoses were not necessarily primary or even secondary but were, rather, a part of the entire diagnostic profile. It should be noted that nearly all of these members carried more than an ASD behavioral health diagnosis. In many instances, especially those related to the use of more intensive levels of care, the symptoms that drove the member's use of behavioral health services were not necessarily those related to their diagnosis of ASD. For this reason we can think of the presence of the diagnosis of ASD spectrum as "ASD co-occurring" to reflect the fact that its presence serves as, in effect, a "marker" of the presence of the disorder, but does not reflect the reasons for or to what extent the intervention was related to the specific symptoms of the ASD disorder. The findings below are still significant though they cannot be in and of themselves fully generalized to the entire universe of those with an ASD disorder, who may or may not have other co-occurring behavioral health disorders.

Since it is assumed that not all HUSKY A and B members with an ASD diagnosis utilized behavioral health services, further attempts to estimate a CT ASD prevalence rate within the HUSKY A and B population were conducted. The literature on the prevalence of ASD found rates ranging from a low of 0.07% to a high of 2.64%. Table 3 below summarizes the estimates for the total number of HUSKY A and B members with ASD in the CY 2010 population.

Table 3: ASD Prevalence Estimates

	Source	Mandell et al. 2010	Durkin et al. 2010	Kim et al. 2011	CT SDE Estimate based on CDC methodology
A	Prevalence Rate	0.07%	1.25%	2.64%	1.7%
B	Total HUSKY Population CY 2010 (0-18)	318,319	318,319	318,319	318,319
C	Estimated # ASD members based on prevalence rate (A*B)	223	3,979	8,404	5,411
D	Unique ASD members CY 2010 (0-18)	1,117	1,117	1,117	1,117
E	Estimated % of HUSKY A and B youth that utilized behavioral health services (D ÷ C)	500.9%	28.1%	13.3%	20.6%

Based on the findings displayed in Table 3, the prevalence rate of ASD among HUSKY A and B youth is between 1.25% and 2.64%. The Mandell et al. (2010) prevalence rate results in an estimate of youth with ASD that is significantly lower than the number of member identified by our data query. Based on these findings, the decision was made to utilize the CDC methodology for estimating ASD prevalence rates in CT; 1.7%.

PREVALENCE OF AUTISM CITATIONS

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APPENDIX B

SERVICE UTILIZATION AND CHARACTERISTICS OF THE ASD POPULATION IN CONNECTICUT

SERVICE UTILIZATION AND CHARACTERISTICS OF THE ASD POPULATION IN CT

This section includes information and data submitted by various CT Departments regarding the services they supplied for CT residents with ASD during Calendar Year (CY) 2010 and CY 2011.

Utilization: Department of Children and Families (DCF)

Below, the demographics of the youth both with ASD and without ASD who received DCF grant-funded behavioral health services are described. The data is based on episodes of service, not on unique members; some of the youth included have received more than one episode of care.

DCF Status at Intake

Table 5 below shows the DCF status at intake of the ASD and non-ASD episodes and the overall cases for which the data were present.

- Just over three-quarters of the clients in ASD episodes were not involved with DCF at intake; this compares to about two-thirds of non-ASD clients.
- ASD clients were also about twice as likely as overall clients to be involved in DCF Voluntary Services (9.8% vs. 4.8%)
- ASD clients were substantially less likely than overall clients to be involved in Child Protective Services, whether in-home (6.5% vs. 12.2%) or out of home (3.7% vs. 10.5%).

Status	ASD Episodes		Non- ASD Episodes	
	Number	Percent	Number	Percent
Child Protective Services - In-Home	87	6.5%	4,212	12.2%
Child Protective Services - Out of Home	49	3.7%	3,630	10.5%
Dual Commitment (JJ and Child Protective Services)	2	0.2%	313	0.9%
Family With Service Needs (FWSN) - In Home	15	1.1%	737	2.1%
Family with Service Needs (FWSN) - Out of Home	7	0.5%	259	0.7%
Juvenile Justice (delinquency) commitment	0	0.0%	188	0.5%
Not DCF	1,015	76.3%	22,918	66.2%
Not DCF - On Probation	0	0.0%	3	0.0%
Termination of Parental Rights	24	1.8%	723	2.1%
Voluntary Services Program	131	9.8%	1,647	4.8%
	1,330		35,960	
The totals exclude episodes for which data on DCF status at intake was missing. This led to the exclusion of 126 ASD episodes (8.7%) and 5,855 overall episodes (14.0%).				

Age

The ASD population was somewhat younger than the non-ASD 0-19 Programs and Services Data Collection and Reporting System (PSDCRS) population. The average client age at intake for ASD episodes was 10.1 years; the median was 10. For non-ASD episodes, the average was 11.4, while the median was 14.

Table 6 shows the distribution within age bands. The ASD episodes have a little over half of their episodes in the 6-11 age band, and just under 37% in the 12-18 band. For non-ASD episodes the pattern is almost exactly the reverse; a little over half in the 12-18 band, and just over 36% in the 6-11 band.

Table 6: Age Band, ASD vs. Non-ASD Episodes				
Age Band	ASD Episodes		Non-ASD Episodes age 0-19	
	Number	Percent	Number	Percent
0-5	172	11.8%	3,947	9.8%
6-11	742	51.0%	14,571	36.1%
12-18	535	36.7%	21,363	52.9%
19+	7	0.5%	478	1.2%
Grand Total	1,456	100.0%	40,359	100.0%

Gender

Table 7 shows the distribution between males and females for ASD and non-ASD episodes. While both groups have a male majority, the majority is much larger for the ASD episodes; 83.4% vs. 55.6% for non-ASD episodes.

Table 7: Gender, ASD vs. Non-ASD Episodes				
Gender	ASD Episodes		Non-ASD Episodes age 0-19	
	Number	Percent	Number	Percent
Female	241	16.6%	17,907	44.4%
Male	1,215	83.4%	22,452	55.6%
Grand Total	1,456	100.0%	40,359	100.0%

Race/Ethnicity

Table 8 shows the distribution of ASD and non-ASD episodes by race and ethnicity. ASD clients are substantially more likely to be White (57.7% vs. 38.6% for non-ASD episodes) and correspondingly less likely to be Hispanic (25.5% vs. 35.6%) or Black (10.4% vs. 17.0%).

Race/Ethnicity	ASD Episodes		Non-ASD Episodes age 0-19	
	Number	Percent	Number	Percent
Black	151	10.4%	6,851	17.0%
Hispanic	371	25.5%	14,350	35.6%
Multi-Racial	26	1.8%	977	2.4%
Other	43	3.0%	1,113	2.8%
Unable to Report	25	1.7%	1,483	3.7%
White	840	57.7%	15,585	38.6%
Grand Total	1456	100.0%	40,359	100.0%

Utilization of Programs

Table 9 shows the distribution of ASD episodes among DCF-funded programs. The last column shows the percentage of episodes in each program for PSDCRS episodes overall. The last column adds up to less than 100% because some PSDCRS episodes are in programs which reported no ASD clients, and those programs are not shown.

Program	ASD Episodes	Percent of all ASD episodes	Percent for this program in all PSDCRS episodes, age 0-19
Outpatient Psychiatric Clinics for Children	773	53.1%	53.7%
Intensive In-Home Child and Adolescent Psychiatric Service	216	14.8%	5.7%
Continuing Care	178	12.2%	2.8%
Emergency Mobile Psych	131	9.0%	21.4%
Extended Day Treatment	60	4.1%	3.0%
Therapeutic Foster Care	43	3.0%	3.0%
Family Support Team	35	2.4%	1.4%
Medically Complex Foster Care	5	0.3%	0.1%
Functional Family Therapy	4	0.3%	1.4%
Safe Homes	4	0.3%	0.2%
Therapeutic Mentoring	2	0.1%	0.1%
Short Term Assessment and Respite Home	2	0.1%	0.2%
Family Substance Abuse Treatment	1	0.1%	0.3%
Multisystemic Therapy	1	0.1%	0.5%
Problem Sexual Behavior	1	0.1%	0.2%

Several conclusions emerge from Table 9:

- For both ASD episodes and overall, a little more than half of all episodes are with Outpatient Psychiatric Clinics for Children (OPCC's).
- ASD clients are substantially more likely than others to use Intensive In-Home Child and Adolescent Psychiatric Service (IICAPS) and Continuing Care.
- ASD clients are substantially less likely than others to use Emergency Mobile Psychiatric Services (EMPS)

Length of Stay

Table 10 compares length of stay (LOS) for ASD and non-ASD episodes. The left-hand side of the table compares those discharged in CY 2010, while the right-hand side compares those who were still in care as of the last day of CY 2010.

ASD episodes clearly tend to have longer LOS's than non-ASD episodes. The difference is much greater for those discharged during the year than for those still in care. This may be partly because a smaller percentage of ASD episodes are in Emergency Mobile Psychiatric Services (EMPS), a program which has many very short stays. EMPS would be concentrated most heavily in non-ASD episodes discharged during the year.

Table 10: LOS, ASD vs. non-ASD Episodes				
Type of Episode	Discharged in CY 2010		Still in Care as of last day CY 2010*	
	Mean	Median	Mean	Median
ASD Episodes	283.3	179	426.5	198
Non-ASD Episodes	174.7	80	373.4	185
Total	178.1	83	375.6	186
Number of Episodes				
	Discharged in CY 2010		Still in Care as of last day CY 2010*	
ASD Episodes	803		653	
Non-ASD Episodes	25,579		14,780	
Total	26,382		15,433	

Reason for Discharge

Table 11 shows the distribution of reasons for discharge for ASD-and non-ASD episodes with a discharge date in CY 2010.

ASD episodes were more likely to meet treatment goals than were non-ASD episodes (51.2% vs. 45.1%). ASD episodes were less likely to end because the family discontinued (18.1% vs. 25.3%) but somewhat more likely to end because the agency discontinued for clinical reasons (9.0% vs. 6.3%).

Table 11: Reason for Discharge, ASD vs. non-ASD Episodes Discharged in CY 2010				
Reason for Discharge	ASD Episodes		Non-ASD episodes age 0-19	
	Number	Percent	Number	Percent
Met Treatment Goals	411	51.2%	11,545	45.1%
Family Discontinued	145	18.1%	6,478	25.3%
Agency Discontinued: Clinical	72	9.0%	1,616	6.3%
Agency Discontinued: Administrative	44	5.5%	1,826	7.1%
Client Hospitalized	31	3.9%	842	3.3%
Child Requires Other Out- of-Home Care	31	3.9%	716	2.8%
Client/Family Moved	30	3.7%	742	2.9%
Evaluation Only	10	1.2%	841	3.3%
Age (Too old)	10	1.2%	169	0.7%
All Other Discharge Reasons*	19	2.4%	804	3.1%
Grand Total	803	100.0%	25,579	100.0%
<ul style="list-style-type: none"> • "All other discharge reasons" in this table includes sixteen reasons for discharge, all of which were below 1% of both ASD and non-ASD episodes. • This table excludes episodes which were still open as of December 31, 2010 				

DCF uses general funds to pay for services for the ASD youth population that would not be otherwise reimbursed by Medicaid. Between 2009 and 2011, DCF spent a minimum of \$2,121,063 for special services for 100 DCF-involved youths. This amount is almost certainly an underestimate; DCF flex fund data does not always include good diagnostic information so that youth receiving services for ASD could not always be identified. DCF estimates that the total expenditure for this population during the same three year time span is closer to \$3,172,400.

Utilization: Department of Developmental Services (DDS)

All data and analysis in this section have been compiled by the Department of Developmental Services for the ASD Feasibility Study Committee.

The Department of Developmental Services (DDS) serves a small number of adults (over the age of 18) with ASD; approximately 65 people annually. Between the calendar years 2009 and 2011, the actual expenditure, \$836,000 and \$1.09 million respectively increased 30.5%. For the DDS autism program, the majority of funding (over 70%) is for Life Skills Coaching and Community Mentor Services. Both of these services provide behavioral supports to the adults in these programs allowing them to participate in jobs and other community activities.

In addition to the adult services provided by the agency, DDS also provides Birth to Three services for children birth to three years of age. Appropriated funds associated with the program total slightly less than \$75,000 and fund two specific positions: an Early Intervention Associate and a teacher. Together, these positions utilize more than 70% of the total budget. Both of these positions provide specialized instruction in accord with the Individuals with Disabilities Education Act (IDEA) guidelines, similar to services provided by board certified behavior analysts. Additionally, they provide programming using the Applied Behavior Analysis (ABA) model.

Utilization: CT Behavioral Health Partnership (BHP)

Introduction: Defining the Cohort of Medicaid Members with ASD

Methodology

Prior to reviewing the data regarding the utilization of behavioral health services by the Medicaid ASD population, it is important to point out that, over the course of the work by the Autism Feasibility Committee, multiple methods were used to attempt to identify the ASD population among Medicaid recipients and then to identify the behavioral health services they utilize and any gaps in those services. The review of the literature on the prevalence of ASD found significant variation in the methods used to identify the ASD populations included in the studies. The choice of the method of identification obviously has an impact on the subsequent calculations of prevalence as well as on measures of the numbers of people with ASD and the types of services those people are using. For example, when we include people with a diagnosis of ASD *at any time* over the past five (5) years and then pull in any behavioral health services used by that cohort of people, we will include a much larger count than when we only include those episodes of care when the member had an ASD diagnosis. Different methods of identifying the ASD population result in different counts of use of services. Over the past three years, three different methods have been utilized for calculating the number of members with an ASD diagnosis within the Medicaid population and the services those members used. All three methods are described below and the findings that resulted from each are displayed.

Methodology I:

In the second half of 2010, ValueOptions provided the Hospital for Special Care (HSC) with data regarding the use of psychiatric inpatient days for all HUSKY youth with a diagnosis of pervasive developmental delay. This method resulted in data that included youth with ASD but that also included youth with mental retardation. The data for CY 2009 that was shared with HSC is displayed in Tables 12 and 13 below.

**Table 12: Psychiatric Discharges: HUSKY Program 2009:
Discharge Diagnosis: Pervasive Developmental Delay and/or Mental
Retardation**

2009	All Inpatient Facility Days	Inpatient Facility Days Other Than Solnit (Riverview)	Solnit (Riverview Hospital) Only
4 to 12 years	2,357	1,228	1,129
13 to 18 years	3,452	2,054	1,398
Total	5,809	3,282	2,527

Additionally, Value Options provided HSC with the count of discharges from inpatient services during 2009 for the same population. These data are displayed in Table 13.

Table 13: Number of Discharges and Length of Stay Associated with HUSKY Youth with Pervasive Developmental Delay and/or Mental Retardation

2009	Discharg	Average Length of
4 to 12 years	53	44.5
13 to 18 years	107	32.3
Total	160	36.3

As will become apparent when these measures are compared to subsequent measures, the inclusion of all diagnoses in the Pervasive Developmental Delay category as well as youth with Mental Retardation almost certainly exaggerated the number of members included in the sample.

Methodology II:

In 2011, at the inception of the Autism Feasibility Project and founding of the committee, a different methodology for identifying the cohort of CT Medicaid members with ASD was utilized. As previously described in the “Prevalence” section above, the identification of the cohort of Medicaid members with ASD for the project focused exclusively on those members with a diagnosis of ASD and did not include HUSKY members with other Pervasive Developmental Disorders or with Mental Retardation *unless they also had an ASD diagnosis*. As a result, the count of members and inpatient days associated with them were not included in the data and thus are different from those provided to HSC.

The identification of the initial cohort of Medicaid members with ASD for the Autism Feasibility Project was done utilizing the following methodology.

1. ValueOptions’ databases were queried for any and all instances of ASD-related DSM-IV diagnoses on Axis I and/or Axis II. The DSM IV diagnostic codes included in the query are as follows: 299.00, 299.80, 299.0, 299.01, 299.91 and 299.90.
2. To ensure the inclusion of all HUSKY members with an ASD diagnosis in the study, any member with a review for authorized services that included any of the above diagnoses during the periods CY2009, CY2010 and Quarter 1 2011 were included in the cohort.
3. To be included in this cohort a member needed to have only one service day or unit authorized with an ASD diagnosis during the study period and authorizations did not need to start or end during the study period. Once a member was included in the original cohort, all authorizations for that member were included in all subsequent data queries, regardless of the diagnosis associated with that particular authorization.
4. There were no age constraints for cohort inclusion.

A total of 2,208 members were included in the total cohort of member’s with an ASD diagnosis during any time in calendar year 2009, 2010 and Quarter 1 of 2011. Nearly all of the members identified carried more than one behavioral health diagnosis.

A summary of the demographics of the CT BHP ASD cohort can be found in the tables below. Demographics summarized include age (Table 14), gender (Table 15), race (Table 16), and DCF status (Table 17). All demographic information is based on the point in time when at least one of the following DSM-IV diagnostic codes first appeared in the member's file: 299.00, 299.80, 299.0, 299.01, 299.91, and/or 299.90.

Table 14: Age of ASD cohort

Age Group	N	Mean (in yrs)
0-13	1598	8.6
14-17	481	15.3
18-30	117	18.9
30+	12	39.9
Total	2208	10.8

Over 72% of HUSKY members in the ASD cohort were between the ages of 0 and 13.

Table 15: Gender of ASD cohort

Age Group by Gender	Female	Male	Total
0-17	365	1714	2079
18+	29	100	129
Total	394	1814	2208

More than 82% are male.

Table 16: Race of ASD cohort

Race	# of Members	Hispanic Indicator
Asian/Pacific Islander	18	0
African American	284	6
Native American	10	6
Pacific Islander	1	1
Unknown	12	3
Caucasian	1883	522
Total	2208	538

Table 17: DCF Involvement of the Youth

DCF Status	
No	1700
Yes	508
Total	2208

Similar to the findings of DCF, a bit more than 75% are not DCF involved.

Utilization of Behavioral Health Services:

Inpatient Psychiatric Hospitalization

In order to develop recommendations regarding how to best serve the ASD population, a quantitative analysis of inpatient psychiatric (IPF) hospitalization and congregate care authorization data was completed. In the tables below, the use of inpatient services by the entire HUSKY A and B population is compared to use by the ASD HUSKY A and B population.

Table 18: Total Number of HUSKY A and B Inpatient Hospital Admissions

Year	0-17	18+	Total
2009	2,212	1,659	3,871
2010	2,268	1,745	4,013
Q1 2011	565	342	907

The numbers in the table below represent the number of hospitalizations of youth and adults with ASD diagnosis who were hospitalized during each of the timeframes. The number in parentheses represents the discrete count of members hospitalized.

Table 19: Total HUSKY A and B youth and HUSKY A Adult Hospitalizations

Year	0-17	18+	Total
2009	264 (172)	38 (19)	302 (191)
2010	315 (209)	22 (16)	337 (225)
Q1 2011	60 (52)	1	61 (53)

Of the total youth with an ASD diagnosis, the following table displays the number youth with an ASD diagnosis who were hospitalized in and out of state during each of the timeframes.

Table 20: HUSKY A and B Youth Hospitalized In and Out of State

Year	Out of State	In State	Total
2009	32	270	302
2010	35	302	337
Q1 2011	4	57	61

The CT BHP uses average length of stay data in many of its initiatives. Below, the average length of stay (ALOS) in days for inpatient hospital stays is reported for the ASD cohort. Table 22 shows the ALOS for the total HUSKY A and B population for comparison purposes. Please note that the comparison data for the entire HUSKY population is for ages 0-18 while the ASD cohort data is for ages 0-17.

Table 21: Average Inpatient Length of Stay for ASD cohort population

Year	ASD Child 0-17 ALOS in Days	ASD Adult 18+ ALOS in Days	Average ALOS Across the ASD Population in Days
2009	18.16	12.63	17.46
2010	22.28	18.18	22.01
Q1 2011	16.02	17.00	16.03

Table 22: HUSKY A and B Inpatient Average Length of Stay, Children and Adults

	Child (0-18)- Total ALOS in Days	Adult (19+) ALOS in Days
2009	14.41	8.2
2010	14.87	7.0
Q1 2011	12.40	8.6

When comparing the child ASD cohort population to the entire child HUSKY population, the ASD population has a longer inpatient average length of stay (ALOS) for all three time periods. In CY 2009, the ASD Inpatient average length of stay is 26% longer than that of the entire HUSKY A and B population. In calendar year 2010 and Q1 2011 the ASD Inpatient ALOS is 50% and 23% longer than the entire HUSKY A and B population, respectively. In the adult population, ASD ALOS in CY 2009, CY 2010 and 2011 Quarter 1 of 2011 are 35%, 160% and 98% longer than the entire HUSKY A adult population, respectively.

Delay in Discharge of the ASD Population

The Length of Stay in inpatient and congregate care is made up of two time components, the acute portion and the delayed portion. In the acute portion of the stay, the level of care is determined to be medically necessary. However, if the individual is forced to remain in that level of care because the level of care that they need is not immediately available, that portion of the stay is labeled as “discharge delayed”. A discharge delay typically occurs when an individual is ready to step down to a lower level of care and that service is unavailable. Further in this analysis, reasons for discharge delay are reviewed and analyzed. Under Medicaid rules, discharge delay is available only to children, aged 18 or less. Thus, only child data is analyzed in relation to discharge delay. Table 23 below summarizes discharge delay days for the ASD population during inpatient stays. Table 24 displays discharge delay data for the entire HUSKY A and B child population for purposes of comparison.

Table 23: ASD Inpatient Discharge Delay, Age 0-17

Year	Total Delay Days	Total Days	% of Delay Days	# of Delayed Cases (% of all)	Average Length of Delay, Delayed Cases Only
2009	1,012	5,273	19.19%	45 (17.05%)	22.49
2010	2,163	7,419	29.15%	73 (23.17%)	29.63
Q1 2011	116	978	11.86%	8 (13.33%)	14.50
Total	3,291	13,670	24.07%	126 (19.72%)	26.12

Table 24: HUSKY Inpatient Discharge Delay, Age 0-18

Year	Total Inpatient Delay Days	Total Inpatient Days	% of Delay Days	# of Delayed Cases (% of all)	Average Length of Delay, Delayed Cases only
2009	5,061	34,290	14.8%	282 of 2,380 (11.8%)	17.95 days
2010	7,212	36,733	19.6%	305 of 2,470 (12.3%)	23.65 days
Q1 2011	914	7,451	12.3%	51 of 576 (8.9%)	17.92 days

While just over 13% of all inpatient discharges were discharges of individuals in the ASD cohort in CY 2010, the ASD cohort used 30% of all discharge delay days that year and 20% of all inpatient psychiatric days. In CY 2009 and 2010, the ASD population’s average length of delay was 25% longer than the HUSKY A and B population. Over all three time periods, just over 24% of all days ASD members spent in the inpatient psychiatric level of care were delayed days.

Table 25 below summarizes reasons for the discharge delay for the ASD population. This table displays the types of services that were not available at the time that the member was ready to leave the hospital.

Table 25: ASD Discharge Delay Reasons

Discharge Delay Reason	2009	2010	Q1 2011	Total
Awaiting Placement – Foster Care/Professional	-	1.37% (N=1)	-	0.79% (N=1)
Awaiting Placement - Safe Home	-	1.37% (N=1)	-	0.79% (N=1)
Awaiting Community Service – Outpatient	2.22% (N=1)	-	-	0.79% (N=1)
Awaiting Community Service - IOP	2.22% (N=1)	-	-	0.79% (N=1)
Educational Program	-	1.37% (N=1)	-	0.79% (N=1)
Family Requires Treatment before child can return home	2.22% (N=1)	-	-	0.79% (N=1)
Awaiting Placement – Therapeutic Foster Care	-	1.37% (N=1)	12.50% (N=1)	1.59% (N=2)
Awaiting Community Service - Medication Management	2.22% (N=1)	-	12.50% (N=1)	1.59% (N=2)
Awaiting Community Service - EDT	4.44% (N=2)	1.37% (N=1)	-	2.38% (N=3)
Awaiting Community Service – Home-based services	4.44% (N=2)	1.37% (N=1)	-	2.38% (N=3)
Awaiting Community Service-Partial Hospital Program	2.22% (N=1)	2.74% (N=2)	-	2.38% (N=3)
Awaiting Placement – Group Home	2.22% (N=1)	1.37% (N=1)	12.50% (N=1)	2.38% (N=3)
Awaiting Placement - Other	4.44% (N=2)	2.74% (N=2)	-	3.17% (N=4)
Other DCF Funded Services	4.44% (N=2)	4.11% (N=3)	-	3.97% (N=5)
Awaiting Community Service - Other	8.89% (N=4)	5.48% (N=4)	-	6.35% (N=8)
Awaiting Placement – State Hospital	15.56% (N=7)	21.92% (N=16)	25.00% (N=2)	19.84% (N=25)
Awaiting Placement – Psychiatric Residential Treatment Facility	20.00% (N=9)	26.03% (N=19)	12.50% (N=1)	23.02% (N=29)
Awaiting Placement – Residential Treatment Center	24.44% (N=11)	27.40% (N=20)	25.00% (N=2)	26.19% (N=33)
Total	100% (N=45)	100% (N=73)	100% (N=8)	100% (N=126)

In general, children with ASD most commonly experience delays awaiting placement (67% in 2009, 82% in 2010). This trend is also true for the entire HUSKY A and B youth population; in CY 2009, 79.8% of all members experienced delays awaiting placement. This number increased to 84.8% in CY 2010. The ASD population differs from the HUSKY A and B population with regard to the percentage of individuals awaiting community services. In 2009, 27% of all ASD delays were related to individuals awaiting community services, while only 10.9% of all HUSKY A and B individuals experienced delays awaiting these same types of services. This finding indicates a lack of

specialized services for individuals with ASD who are stepping down from inpatient services to lower levels of care.

Readmission rates seven (7) and thirty (30) days for the ASD population (0-17) and general HUSKY A and B population (0-18) are compared below. Readmission rates are calculated for individuals with thirty (30) days of continuous eligibility after discharge from the inpatient unit. All inpatient admissions after the initial inpatient discharge are included in readmission counts/rates, regardless of diagnosis on the subsequent admission. In comparing the ASD population to the HUSKY A and B population, readmission rates at both seven (7) and thirty (30) days among the ASD population are slightly higher than the HUSKY A and B population in calendar years 2009 and 2010.

Table 26: ASD Inpatient Readmission rates, Age 0-17

Year	# of Readmissions within 7 Days	# of Readmissions within 30 Days	Total Number of Discharges	% of 7 Day Readmissions	% of 30 Day Readmissions Rate
2009	15	47	256	5.86%	18.36%
2010	13	47	310	4.19%	15.16%

Table 27: HUSKY Inpatient Readmission Rates for In-State Hospitals, Age 0-18

Year	7 day Readmission Rate	30 day Readmission Rate
2009	4.27%	14.20%
2010	3.52%	13.27%

Below, the readmission rates for the adult ASD population (18+) are displayed. Where available, in parenthesis, the readmission rates for the entire HUSKY A adult population (19+) are presented.

Table 28: Adult ASD Readmission Rates

Year	# of 7 Day Readmits	# of 30 Day Readmits	Total N	7 Day Rate	30 Day Rate
2009	1	7	35	2.86%	20.00%
2010	3	4	22	13.64% (3.64%)	18.18% (10.33%)
Q1 2011	0	0	1	0.00% (2.55%)	0.00% (8.36%)

Utilization: ASD Population in Congregate Care Settings

Youth and young adults with ASD who have required inpatient stays sometimes receive longer term treatment in congregate care settings following discharge from the hospital. Congregate care includes the following types of treatment settings:

1. Residential Treatment Care (RTC): An RTC is a 24 hour facility licensed by the State of Connecticut or appropriately licensed by the state in which it is located, and not licensed as a hospital, that offers integrated therapeutic services, educational services and activities of daily living within the parameters of clinically informed milieu and based on a well-defined, individually tailored treatment plan.
2. Group Homes: A Therapeutic Group Home (TGH) is a small, four- to- six bed, DCF licensed program located in a neighborhood setting with intensive staffing levels and services offered within the context of a 24/7 home-like milieu. It is a highly structured treatment program that serves as a step-down from inpatient level of care, or as a step-down from or alternative to residential level of care. It creates a physically, emotionally and psychologically safe environment for children and adolescents with complex behavioral health needs.
3. Psychiatric Residential Treatment Facility (PRTF): A PRTF is a community based sub-acute inpatient facility that provides psychiatric and other therapeutic and clinically informed services to individuals under age 21, whose immediate treatment needs require a structured 24-hour inpatient residential setting that provides all required services (including schooling) on site while simultaneously preparing the child/adolescent and family for ongoing treatment in the community. Services provided include, but are not limited to , multi-disciplinary evaluation, medication management, individual, family, and group therapy, parent guidance, substance abuse education/counseling (when indicated) and other support services including on site education.

Most frequently the youth are transferred to congregate care settings following one or multiple inpatient psychiatric hospital stays. Of the three (3) types of congregate care treatment, only RTCs can continue treat youth up to age 21. RTC as well as Group Home data is typically analyzed separately for care provided within Connecticut (in-state) and outside of state (OOS). The characteristics of the member's treated in-state versus out of state tend to differ. Children placed in out of state residential or group home programs tend to have greater needs that are not able to be met by in-state providers. As a result, these youth tend to have longer lengths of stay in congregate care programs than do youth treated in-state. RTC and group home in-state and OOS data is displayed separately below. The PRTFs utilized by the CT Medicaid population are all located in-state.

(Note: Not all data reported below for the ASD population is compared to the entire HUSKY A and B population. Where all HUSKY A and B data is available, comparisons are made. In those instances where the number of discharges differs from the number of members, some members have been discharged from the level of care more than once.)

The tables below display the number of discharges from congregate care settings during the identified year/quarter. The entire number of discharges is included in parenthesis. All ages are represented in this data.

Table 29: ASD Members Discharges from RTC, PRTF and Group Home (GH) (Total Discharges shown in Parenthesis)

RTC	2009	2010	Q1 2011	Total RTC
In-State	19 (19)	24 (24)	6 (6)	48 (49)
Out of State	21 (21)	26 (26)	9 (9)	54 (56)
Total	40 (40)	49 (50)	15 (15)	100 (105)
PRTF	2009	2010	Q1 2011	Total PRTF
In State	20 (20)	31 (32)	14 (14)	55 (66)
GROUP HOME	2009	2010	Q1 2011	Total GH
In-State	19 (19)	29 (30)	2 (2)	48 (51)
Out of State	3 (3)	2 (2)	0	5 (5)
Total	22 (22)	31 (32)	2 (2)	53 (56)

Although not displayed in a table, in 2009, 29.9% of discharges for all HUSKY A and B members from residential care were from OOS facilities. By comparison, as is shown in Table 29, more than half of all ASD population RTC discharges were from OOS residential facilities. For the ASD population, this percentage remains relatively constant across the time periods displayed. As noted above, children placed in out of state residential programs tend to have greater needs that are not able to be met by in-state providers.

The average length of stay for each of these levels of care is presented in the tables below. Table 30 compares the In-State and out of state (OOS) average length of stay (ALOS) for different congregate levels of care. Please note that the use of out of state Group Homes has been discontinued over the past three years. As a result, information regarding length of stay is only presented for 2009.

Table 30: ASD Members ALOS (in days) for In-State Providers

Level of Care	2009	2010	Q1 2011	Total
In-State Providers				
RTC	582.8	367.2	618.5	481.6
PRTF	150.1	159.1	168.5	158.3
GH-all	578.3	663.6	582.5	628.6
Out of State Providers	2009	2010	Q1 2011	Total
RTC	499.0	502.5	596.2	516.2
GH-all	721.7	N/A	N/A	N/A

The ALOS for the ASD population in out of state RTCs has been increasing between 2009 and Q1 2011. This may be related to recent DCF initiatives designed to bring CT youth back to in-state RTCs leaving only those youth requiring the most specialized services in out of state facilities.

In the following tables, discharge delay data is reported for the ASD population.

Discharge Delay in Congregate Care Settings

Discharge delay in congregate care occurs primarily in the RTC treatment setting. While youth are occasionally delayed for significant periods of time in Group Homes and in PRTFs, the number of youth effected is small and there are no consistent trends from year to year. As a result, the focus of this section is on discharge delay within the RTC setting.

Table 31: Comparison of ASD and Total HUSKY A and B Members: RTC Discharge Delay Information (In State and OOS)

Year	Total Days	Total Delay Days	% Delay Days	# Delayed Cases (% of all ASD cases delayed during specified period)
ASD Population in RTC				
2009	21,552	3,073	14.3%	16 (40.0%)
2010	21,876	2,355	10.8%	11 (22.0%)
Q1 2011	9,077	460	5.1%	2 (13.3%)
Entire HUSKY A and B Population in RTC				
2009	235,984	22,264	9.4%	20.2%
2010	218,885	18,700	8.5%	14.3%
Q1 2011	43,510	3,633	8.3%	10.3%

As can be seen in the table above, the ASD population has a larger percentage of delayed cases and delay days than the entire HUSKY A and B population being treated in RTC for all three time periods.

Table 32: Comparison of In-State ASD and Total HUSKY A and B Members: RTC Discharge Delay Information

Timeframe	Total Days	Total Delay Days	% Delay Days	% of All Discharges Delayed During Specified Period
ASD RTC Population in In-State RTCs				
2009	11,074	2,173	19.6%	52.6%
2010	8,812	1,440	16.3%	20.8%
Q1 2011	3,711	374	10.1%	16.7%
Total HUSKY A & B Population in In-State RTCs				
2009	128,111	12,693	9.9%	18.2%
2010	103,371	8,073	7.8%	10.0%
Q1 2011	22,192	2,351	10.6%	8.2%

The percentage of discharge delay cases among ASD population members at in-state residential facilities is twice that of the HUSKY population for years 2010 and Q1 2011. In 2009, over half of all ASD members being treated at in-state residential programs became discharge delayed while just over 18% of the entire HUSKY population treated in residential treatment programs were delayed. Similarly, in 2009 and 2010, the percentage of delay days for the ASD population is more than double that of the HUSKY population.

**Table 33: Comparison of Out-Of-State ASD and Total HUSKY A and B Members:
RTC Discharge Delay Information**

Timeframe	Total Days	Total Delay Days	% Delay Days	# Delayed Cases (% of all during specified period)
ASD RTC Population in Out of State RTCs				
2009	10,478	900	8.6%	6 (28.6%)
2010	13,064	915	7.0%	6 (23.1%)
Q1 2011	5,366	86	1.6%	1 (11.1%)
Total HUSKY A & B Population in Out of State RTCs				
2009	107,873	9,571	8.9%	24.1%
2010	115,514	10,627	9.2%	20.7%
Q1 2011	21,318	1,282	6.0%	13.6%

Unlike the in-state residential data summarized in Tables 32, discharge delay for ASD members in OOS RTC programs is similar to the experience of the entire HUSKY A and B population in OOS RTCs. As displayed in Table 33, the percentage of delayed cases and days are similar for both ASD members and HUSKY A and B members treated in OOS RTCs.

During an RTC stay, youth with ASD are most commonly delayed awaiting placement in another congregate care setting or in foster care (68.8% in 2009, 90.9% in 2010). This trend holds true for the HUSKY A and B population as well. In CY 2009, 60.8% of all members delayed were awaiting placement. This percentage increased 32.6% from CY 2009 to CY 2010 (80.6%). Typically ASD youth are delayed awaiting placement in a specialized Group Home setting or in Foster Care.

Methodology III:

Early in 2012, the decision was made to re-examine the utilization of behavioral health services by youth with an ASD diagnosis based on a narrower cohort. The idea behind this decision was to identify those Medicaid individuals with more severe ASD symptomatology in order to identify the services they were using as well as the services that might be missing. Additionally, there was concern that Methodology II may have been overly inclusive; to be included in the cohort, the individual needed only to have had a diagnosis of ASD once during any episode of behavioral health treatment. The decision was made to *re-identify a cohort of members with ASD by only including episodes of care when the member had the diagnosis of ASD during the episode of care authorized.*

As a result, utilization data was pulled for calendar years 2009 through 2011 for members with an ASD diagnosis during the episode of care. Episodes of care were included in the data collection *only* if an ASD diagnosis of 299.00 or 299.80 appeared on the Axis I or II diagnosis field in the last review of the authorization. It is important to note that the ASD diagnosis was rarely found to be the only behavioral health diagnosis for the member. Nearly every member included in this revised cohort had several behavioral health diagnoses at the time of the authorization for treatment.

The demographics of individuals included in the cohort data BASED ON Methodology III are displayed below. Table 34 includes youth between the ages of 0 and 17 while Table 35 includes adults of 18 or more years of age.

Table 34: Demographics of the Youth ASD population (age 0-17; HUSKY A and B)

Year	Gender	Average Age (In years)	% DCF involved	Race
2009	12 F (13 %) 84 M (88%)	11.4	47 % (45 of 96)	83 White (86 %) 13 Black (14 %)
2010	20 F (16%) 107 M (84%)	12.0	49 % (62 of 127)	110 White (87 %) 17 Black (13%)
2011	37 F (28%) 95 M (72%)	12.5	36 % (48 of 132)	116 White (88 %) 13 Black (10%), 3 Asian (2%)

Table 35: Demographics of Adult ASD population (age 18+; HUSKY A)

Year	Gender	Average Age (In years)	% DCF involved	Race
2009	6 F (40 %) 10 M (63%)	20.1	50 % (8 of 16)	15 White (94 %) 1 Asian
2010	3 F (38 %) 5 M (63 %)	18.8	50 % (4 of 8)	7 White (88 %) 1 Asian
2011	4 F (44%) 5 M (56%)	19.6	22% (2 of 9)	7 White (78%) 2 Black (22%)

The methodology used for the identification of this cohort resulted in fewer members. Since the previous cohort did not include a count of ASD members identified by year, it is not possible to do a comparison.

Utilization: Inpatient Psychiatric Hospitalization

Please Note: In the following tables, the numbers for 2011 represent the entire year. The data in the previous section based on Methodology II included only the first quarter of 2011.

Table 36 below compares the total number of ASD youth inpatient hospital admissions with the total number of inpatient admissions for the entire HUSKY A and B population. The number in parentheses represents the discrete count of members hospitalized.

**Table 36:
Total Inpatient Hospital Admissions and Average Length of Stay (ALOS);
ASD Youth and Adults**

Year	Child 0-17 Admissions*	Child ALOS	Adult 18+ Admissions	Adult ALOS
2009	129 (96)	19.89	16 (9)	13.63
2010	160 (127)	26.82	6 (2)	23.67
2011	132 (107)	20.0	11 (8)	5.5

All HUSKY A and B Youth and HUSKY A Adult Population

Year	Child 0-17 Admissions	Child ALOS	Adult 18+ Admissions	Adult ALOS
2009	2,212	14.41	1,659	8.2
2010	2,268	14.87	1,745	7.0
2011	2,335	12.2	1,427	8.7

Of the total population of youth with an ASD diagnosis, the following table displays the number and percentages of hospitalizations of those youth in and out of state as well as in Solnit.

Table 37: Youth with ASD Hospitalized in In and Out of State Hospitals and Solnit South (Riverview Hospital)

Year	Out of State	In State	Solnit South	Total Hospitalizations
2009	12 (8.3%)	117 (80.7%)	16 (11.0%)	145
2010	20 (11.3%)	140 (79.1%)	17 (9.6%)	177
2011	15 (10.5%)	117 (81.8%)	11 (7.7%)	143

Similar to the findings using Methodology II, just over 10% of all ASD youth hospitalizations were out of state during 2010 and 2011. 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 were referred there by 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 a result of meetings with in-state pediatric psychiatric hospitals who agreed to treat this more acute population. It is assumed that those ASD members with the most significant needs related to their diagnosis continued to be referred for OOS treatment.

Table 38: Adult Members with ASD Hospitalizations in In and Out of State and State Hospital(s)

Year	Out of State	In State	State Hospital	Total Hospitalizations
2009	4 (25%)	12 (75%)	0	16
2010	0	6 (85.7%)	1 (14.3%)	7
2011	0	11 (91.7%)	1 (8.3%)	12

HUSKY A adults are less likely to be hospitalized in out of state acute care hospitals specializing in the treatment of ASD. However, as the number of adults with ASD identified is so small, significant caution should be used in interpreting these results.

ASD Population Length of Stay

Table 39: ASD Youth Population Average Length of Stay In-State vs. Out Of State Hospitals

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

During 2009 and 2010, the average length of stay in out of state (OOS) hospitals was more than three (3) times that of in-state hospitals. OOS inpatient lengths of stay decreased significantly in 2011 as a result of work with OOS facilities to facilitate access to appropriate in-state services after discharge.

As a result of the finding that so few members with ASD required more specialized inpatient treatment OOS during 2011, coupled with the improved willingness of in-state hospitals to treat this population, an assessment of the number of beds that would be needed on a specialized in-state inpatient unit for the Medicaid ASD population was conducted. It was determined that, on average, less than two beds are needed on any given day to accommodate those members currently being treated OOS (488 inpatient days/365 days in year = 1.3 beds/day). If days spent in Solnit are considered, there is a need for an additional 4.2 beds per day (1544/365). Solnit Hospital serves the children with the most severe psychiatric needs, some of whom may also have ASD.

Discharge Delay during Inpatient Hospitalization

As previously completed with the ASD population based on Methodology II, data concerning discharge delay among members of the new ASD cohort was compared to the total HUSKY A and B population. Consistent with the cohort data based on Methodology II reviewed earlier in this document, Table 40 demonstrates that youth with ASD have both a longer acute (medically necessary) and delayed inpatient length of stay when compared to the entire HUSKY A and B youth population.

Table 40: Acute and Delay ALOS for ASD population vs. entire HUSKY A and B Population

Year	ASD Acute ALOS	ASD Delay ALOS	All HUSKY Youth Acute ALOS	All HUSKY Youth Delay ALOS
2009	15.3	25.7	12.3	18.0
2010	16.8	35.5	12.0	23.7
2011	16.3	22.7	11.2	17.7

MEDICAID EXPENDITURE ASSOCIATED WITH THE ASD POPULATION:

DSS MEDICAID CLAIMS DATA

In an effort to quantify behavioral health spending associated with ASD, all Medicaid claims, both behavioral health and medical, were analyzed for calendar years 2009 and 2010. A cohort methodology similar to the one used for utilization data described above under Methodology II was used to identify members with an ASD spectrum diagnosis. A cohort of 8,253 consumers with an ASD diagnosis on any claims paid between 2006 and 2011 was identified. To be included in the sample, each consumer had to have at least one claim paid with an ASD diagnosis during the five year time period. All related claims were then analyzed for calendar years 2009 and 2010. This resulted in 7,744 members with paid claims in 2009 and 2010. Because of claims lag, 2011 data was not included.

Analysis of the DSS Medicaid claims data revealed a total expenditure for members with an ASD diagnosis of over \$236.6 million in 2009 and \$245.1 million in 2010. The total behavioral health expenditure for 2009 and 2010 was just over \$92 million although this is an underestimate as pharmacy expenditures are not included.

Demographics:

Age

Incomplete demographic data was returned for 27 of the total 7,744 members. These members were excluded from the demographic information reported below. At the advice of DSS, age for all members in the cohort is calculated with a service date of 12/31/2009. Members in the cohort ranged from ages 0 to 98. The average age is 16.22 years. The age distribution of the cohort with claims paid during CY 2009 and CY 2010 is displayed below in Graph 1. Age ranges are shown in five year intervals.

Graph 1: Frequency Distribution of Maximum Age of HUSKY A and B Members with ASD with Paid Claims during CY 2009 and CY 2010

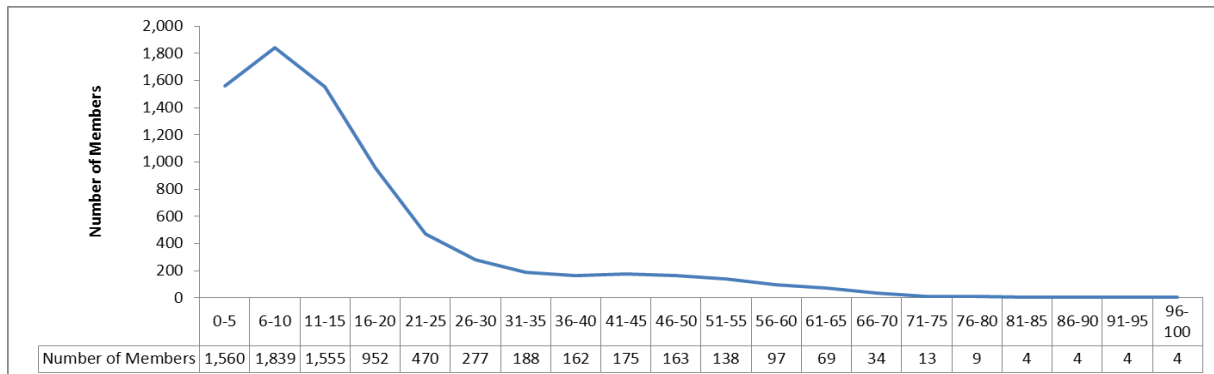


Table 41: Gender of HUSKY A and B Members with ASD with Claims Paid Between CY 2009 and CY 2010

Gender	Count	%
Female	1,816	23.5%
Male	5,899	76.4%
Unknown	2	0.0%
Total	7,717	100.0%

The finding that 76% of members with ASD are male is in line with the findings based on the CT BHP authorization data where from 72% to 88% (varies by year) of HUSKY members receiving behavioral health services for ASD were male.

Table 42: Ethnicity of HUSKY A and B Members with ASD with Claims Paid Between CY 2009 and CY 2010

Ethnicity	Count	%
Caucasian	4,446	57.6%
Hispanic	1,984	25.7%
Black	1,129	14.6%
Asian	95	1.2%
Not Specified/Unknown	32	0.4%
Alaskan Native Eskimo/Native American	16	0.2%
Multiple	10	0.1%
Pacific Islander	5	0.1%
Total	7,717	100.0%

Table 43 below summarizes the behavioral health and medical claim expenditures for the HUSKY A and B members with ASD.

Table 43: DSS Medicaid Expenditures for HUSKY Members with ASD during CY 2009 and CY 2010

Claim Type	Claim Type Description	Behavioral Health	Medical
D	Drug or Compound Drug	\$3,005,903.26	\$31,099,255.72
I	Inpatient	\$33,801,108.36	\$5,969,211.80
L	Dental		\$4,211,241.18
M	Medical	\$35,008,340.16	\$245,371,155.74
N	Nursing Home	\$5,057,927.08	\$82,603,588.62
O	Outpatient	\$14,669,883.69	\$19,277,199.34
X	Crossover	\$500,903.13	\$1,136,599.98
Total	Total	\$92,044,065.68	\$389,668,252.38

A total of 2,876,627 claim lines were returned for a total of 7,744 unique members with either behavioral health or medical claims, 5,847 of which were unique members with

behavioral health claims. Behavioral health claims were defined as claims with a primary diagnosis between 291.00 and 316.99. The total spend for claims paid with dates of service in CY 2009 and CY 2010 was over \$481 million dollars; \$236.6 million in CY 2009 and \$245.1 million in CY 2010.

To simplify the analysis, paid claims were bucketed by “claim type”. Revenue and service codes from the service class grid were used to identify claims for services more specifically related to behavioral health. The resulting claims are summarized in Table 44 for behavioral health services authorized and registered through the CT BHP.

Table 44: Claims Paid by Service Type

Service Type	CY 2009	CY 2010
Inpatient Psychiatric Hospital	\$ 16,859,436.29	\$ 16,719,587.88
Inpatient Detox	\$ 1,053.32	\$ 4,203.48
Short Term Inpatient Evaluation	\$ 30,150.00	\$ 28,743.00
Short Term Inpatient Stay	\$ 142,175.00	\$ 145,700.00
Emergency Department Professional Services	\$ 229,560.70	\$ 250,161.73
Residential Services	\$ 2,222,293.53	\$ 2,251,700.19
Intermediate Services	\$ 2,746,423.49	\$ 2,356,899.78
Home Based Services	\$ 3,953,353.34	\$ 3,932,275.00
Home Health Services	\$ 2,410,089.59	\$ 2,102,488.44
Outpatient Services	\$ 2,625,969.25	\$ 2,775,867.00
Psychological and Developmental Testing	\$ 58,774.69	\$ 89,914.10
Methadone	\$ 703,754.06	\$ 809,580.08
Total	\$ 31,983,033.26	\$ 31,467,120.68

A small group of data experts from the CT BHP, DSS, DCF and DMHAS met to determine if any comparison data could be obtained in order to draw conclusions from the above financial information of the ASD cohort. The group identified several barriers to finding and using comparison data. The barriers included:

- Difficulty identifying what constitutes ASD-related services
- Difficulty identifying and determining cost of these services verses other BH non-autism related services

- Vast expenditure variability within the cohorts

DSS ultimately determined that estimates of costs per member with ASD were invalid and should not be used.

The above claims data was reviewed by the Autism Feasibility Study Committee. The committee determined that no conclusions related to service gaps for Medicaid members could be made based on the findings. In the absence of a robust and appropriate comparison group, the only conclusion to be made is that costs relative to individuals with ASD appear to be higher than other Medicaid members not in this cohort. Additionally, costs associated with in-home services are second only to costs for inpatient care. This finding is consistent with the CT BHP authorization data, DCF PSDCRS data, and the anecdotal reports of the family focus group discussion. Much like the findings of the authorization based cohort data, it was concluded from the claims data that individuals with ASD diagnoses have access to and more frequently utilize the full range of available Medicaid services.

SUMMARY OF THE ASD POPULATION BEHAVIORAL HEALTH UTILIZATION FINDINGS

An analysis of behavioral health services utilized by those with an ASD diagnosis in CT was conducted in an attempt to identify services currently utilized by this population as well as to identify where gaps in necessary services may exist. In reviewing the data on utilization, the Committee concluded that members with a diagnosis of ASD access the full range of available Medicaid services. This conclusion does not

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.

Based on the utilization data and 2010 CT BHP prevalence data, the following summation and conclusions were presented and discussed with the Autism Feasibility Study Committee:

- Outpatient services are the most frequently used service for entire HUSKY population, including the ASD population.
- Youth with an ASD diagnosis stay longer in inpatient and residential care than their non-ASD identified peers 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. Solnit (Riverview) Hospital is also utilized as an alternative to out of state hospitalization when youth with special needs related to their ASD diagnosis are identified.

- Based on inpatient days used by the youth ASD population, 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 HUSKY A adults 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.

Based on Medicaid expenditure data the Autism Feasibility Study Committee concluded that:

- Gaps in behavioral health services could not be identified by analyzing expenditure data
- Expenditures for services for the ASD population are probably higher than for other Medicaid members without a co-occurring diagnosis of ASD
- Youth with co-occurring ASD utilize basic clinic services at the same rate as those with a behavioral health diagnosis exclusive of ASD
- Of the youth who access basic clinic services, a significant portion are being cared for in settings which, while they may be well equipped for the treatment of the non-ASD behavioral health disorder, *do not* have the range of services that might impact their ASD disorder

Of the youth receiving more intensive levels of care, there is some evidence that co-occurring ASD is a “marker” for a more difficult course of treatment, specifically relating to protracted stays, longer delays, and use of community services not equipped to deal with the more severe presentations of ASD. In part, it is believed that youth with ASD receive many services, but that they receive services that are not necessarily designed to have impact on their specific needs. Such services are not readily available or easily accessible in CT. In the rare instance that ASD specific services are available, they may not be part of an individual’s integrated treatment plan. This is further evidenced by the fact that this analysis found few children utilizing services whose only reason for intervention was ASD.

APPENDIX C

LITERATURE REVIEW OF EVIDENCE-BASED AND PROMISING PRACTICE TREATMENT OF ASD

LITERATURE REVIEW ON TREATMENT OF ASD

Introduction

There has been a tremendous amount of research published in peer-reviewed journals on the effectiveness of various treatments for people with Autism Spectrum Disorder (ASD). A goal of the workgroup was to complete a comprehensive review of the literature to determine whether any evidence-based treatments exist for this population in Connecticut and to identify the use of best practices in Connecticut's service system. It is important to note that there are often inconsistencies in the literature regarding how autism treatments are defined as well as the application of the designation of evidence-based practice.

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. See Appendix E for a complete list of their evidence-based treatments. The NPDC definition of evidence-based practice is as follows:

- Randomized or quasi-experimental design studies- two high quality experimental or quasi-experimental group design studies,
- Single-subject design studies- three different investigators or research groups must have conducted five high quality single subject design studies, or
- Combination of evidence- one high quality randomized or quasi-experimental group design study and three high quality single subject design studies conducted by at least three different investigators or research groups (across the group and single subject design studies).

The National Autism Center (2009) also completed a comprehensive, multi-year review of the literature on autism treatments entitled, "The National Standards Project". The intention was to identify the scope of research available for interventions for children and adolescents with ASD.

While both the NAC and NPDC reports described treatment quality for specific age groups, an important difference between the two reports is the fact that the NAC looked at interventions for individuals by age group and with different diagnostic classification within the autism spectrum. As a result, the NAC interventions apply only to a subset of the population based on diagnostic classification and cannot be generalized to the whole population. The three classifications that the NAC focused on are: Autistic Disorder, Asperger's Syndrome and PDD-NOS.

The National Autism Center (NAC) used the Scientific Merit Rating Scale (SMRS) to assess each study's rigor. Using this methodology, five constructs were measured in order of importance: Research Design, Measurement of the Dependent Variable, Participant Ascertainment, Measurement of the Independent Variable, and Generalization of Treatment Effects. They then applied the Strength of Evidence Classification System which takes into account the SMRS score as well as the treatment

effects of the study (beneficial treatment effects, unknown treatment effects, and adverse treatment effects).

Using this classification system, the NAC concluded that there are eleven (11) Established Treatments “that have been thoroughly researched and have *sufficient* evidence for us to confidently state that they are effective”. Further, there are 22 Emerging Treatments that have *some* evidence of effectiveness, but not enough to be declared effective. Finally there are many “Un-established Treatments” for which there is *no* sound evidence of effectiveness. See Appendix E for a complete list of treatments by classification.

In going forward, the discussion is focused on the recommendations of the NAC report due to its more stringent criteria for inclusion and exclusion and its conservative scoring mechanisms. Descriptions of the eleven (11) Established Treatments are identified in the NAC report, including the specific subgroups of ASD subjects they target (if any) and the outcomes they try to affect change in. Later, the discussion focuses on research of treatment effectiveness.

Antecedent Package

Antecedent interventions include a group of treatments designed to modify the environment *before* a problematic behavior occurs. This involves observations of problem behaviors in various settings, with subsequent modification to prevent them from happening again. The goal of this type of treatment is to reduce problem behavior and improve a broad range of developmentally appropriate communication, social, play, and personal responsibility skills.

Behavioral Package

Treatments included in the Behavioral Package are based on an evaluation of what happens in the environment *before and after* a target behavior. The goal is to then modify the environment accordingly. Behavioral interventions have mostly been focused on ASD youth 21 years old and younger, with a primary emphasis on younger children. There are many models that use behavioral interventions, including Applied Behavior Analysis (ABA), Early Intensive Behavioral Intervention, and the Early Start Denver Model.

Behavioral interventions are designed to improve communication, play, social, academic, self-care, work and community living skills, and to reduce problem behaviors for those on the Autism Spectrum. This type of intervention involves intensive behavioral intervention during early childhood (as young as three years of age) and involves breaking down skills into their most basic components and rewarding positive performance. Intervention can last from two to six years and for 20 to 40 hours per week. The Behavioral Package is flexible enough that it can be customized to each individual’s skills, needs, preferences, and family situation.

Comprehensive Behavioral Treatment for Young Children

Comprehensive Behavioral Treatment for Young Children (CBTYC) is based on behavioral principles which come from the experimental analysis of human behavior. CBTYC, sometimes referred to as Discrete Trial Training or Teaching (DTT) is the process of breaking skills down into small discrete pieces. Each skill is then taught systematically using a three term contingency of an antecedent-behavior- and-consequence. Each step is then reinforced or not reinforced depending on the desired

outcome. CBTYC is not limited to DTT; in fact, CBTYC is included in strategies associated with each of the following treatments: Antecedent Package, Behavioral Package, Joint Attention Intervention, Modeling, Naturalistic Teaching Strategies, Peer Training Package, Schedules, and Self-Management. Discrete Trial Teaching of CBTYC is typically geared towards children ages 9 and younger and provides intensive treatment (often for 2 to 3 years) with a higher teacher-to-student ratio (many times 1:1) to ensure that the teacher has adequate time to devote to the child while collecting data on progress towards outcomes. The NAC also specifies that DTT or CBTYC is best utilized for individuals with Autistic Disorder or PDD-NOS. Although based on behavioral intervention, general CBTYC has enough flexibility to adapt to children's communication, cognitive, and social skills. The most well-known and well-researched CBTYC program is the Lovaas model, which initially began as a 40 hour per week Discrete Trial intervention. The most recent recommendation regarding this treatment has been reduced to 25 hours per week.

Joint Attention Intervention

Joint Attention Intervention (JAI) refers to two individuals focusing simultaneously on an activity or object, and each other, with the goal of improving communication and social behavior. JAI is typically used with children ages 5 and younger. An example of JAI is when a child shows an object to another person, or responds when an object is shown to them.

Modeling

Modeling is also based on the principles of Applied Behavior Analysis and is broken out into two types: live (person to person) and video (pre-taped interactions). The goal of modeling, which is typically geared towards children aged 3-18 years, is to improve communication, cognitive functioning, interpersonal, and play skills.

Naturalistic Teaching Strategies

The goal of Naturalistic Teaching Strategies (NTS) is to teach children how to not only attain new skills, but to be able to apply them in other settings with different people. This is done by teaching new skills using a variety of tools and in a variety of settings. NTS is designed to produce improvements in children's communication, interpersonal, and play skills. Central to NTS is the teaching of skills related to the child's interests. This enables the teacher to keep the child focused and motivated. This treatment is also referred to as "incidental teaching" which infuses Discrete Trials into everyday life. For example, an instructor might work on turn taking at a playground.

Peer Training Package

This package involves training peers in how to facilitate positive interactions with ASD children. There are a variety of peer training programs, including Project LEAP, peer networks, Circle of Friends, Buddy Skills Package, Integrated Play Groups, peer initiation training, and peer-mediated social interaction training. Training includes teaching peers how to get and maintain a child's attention, facilitate sharing, provide help and affection, model appropriate play skills, and help organize play activities.

Pivotal Response Treatment

Pivotal Response Treatment (PRT) is similar to Naturalistic Teaching Strategies and is based on the theories of Applied Behavior Analysis. Both PRT and NTS focus on teaching children in their natural environments and using the child's interests to keep

them motivated. PRT differs in its focus on a broader range of skills and a stronger emphasis on self-management. The goal of PRT is to slowly wean children from prompts and instead lead them to greater independence in their natural environment. PRT is typically used with children ages 3-9, and it is thought to affect communication, play, and interpersonal skills.

Schedules

Scheduling, as an intervention, involves using a combination of text and graphics to depict transitions from one activity to other during the day. Clear visual cues allow a child with ASD to keep their focus on their current activity and also to predict upcoming transitions in a typical day. The NAC found this intervention most effective for children and adolescents with Autistic Disorder although there is evidence that this intervention can also be effective for individuals with high functioning autism or Asperger's Syndrome. Schedules are effective for children with ASD as they often have difficulty with transitions and predicting future activities. Scheduling has been used primarily with children ages 3-14 years.

Self-Management

Self-management, used with children of all ages, involves being responsible for monitoring and evaluating your own performance. The critical steps in self-management are creating awareness of your behavior, taking accountability for carrying out a task, and giving immediate self-feedback. Self-management increases the success of multi-tasking and decreases social stigma that occurs when an adult's assistance with simple activities is required. While the NAC found this intervention for children and adolescents helpful with Autistic Disorder, it can also be very helpful for children and adolescents with Asperger's Syndrome and PDD-NOS

Story-based Intervention Package

Story-based interventions involve the use of short stories written in simple language that describe a social situation, including social cues and appropriate behavior. Story-based interventions include information about who, what, when, where, and why related to specified behavior. These interventions are used with children ages 6-18 and have shown positive outcomes for children with ASD in the areas of social behavior, mealtime skills, communication, self-regulation, and interpersonal skills.

Assessment of Treatment Effectiveness

All eleven (11) interventions described above were deemed as Established Treatments by NAC and each has some evidence supporting its effectiveness. The goal, however, was to develop a focused perspective on trends in the research regarding positive outcomes for children with ASD. As a result, the focus of the following review is on eight meta-analyses completed in recent years, each of which includes comparative analyses of treatments of ASD. These analyses allowed the examination of which treatments show the most consistent and positive outcomes. Interventions using the Behavioral and Comprehensive Behavioral Treatment for Young Children models, particularly ABA and the Lovaas method, are represented most frequently in the research.

1) In the first meta-analysis (Ospina et. al.,2008), the authors initially selected 101 unique studies (55 randomized control trials, 32 controlled clinical trials, 4 prospective cohort studies, and 10 retrospective cohort studies) for assessment of the effectiveness

of treatment for ASD. These studies were published between the years of 1977 and 2007.

Of the 101 studies, 13 were included in the meta-analysis; the remaining studies were excluded due to variation in study design, outcomes assessed, and lack of adequate comparison groups. Reporting on weighted mean differences (WMD)/standard mean differences (SMD) and 95% confidence intervals, positive effects were shown primarily in favor of Lovaas treatment, when compared to special education, with seven (7) studies showing positive effects on intellectual functioning, adaptive behavior, communication and interaction, comprehensive language, expressive language, daily living skills, and socialization. Of these seven (7) effects, six (6) also met the criteria for clinical significance. Further, high-intensity Lovaas was shown to be significantly more effective than low-intensity Lovaas in improving intellectual functioning. The only other treatment that showed statistically (but not clinically) significant results was an imitative interaction approach when compared to contingency interaction approaches.

As with many meta-analyses, the results from this analysis should be interpreted with caution. Many of the studies did not adequately report on the severity of symptoms in study subjects, how representative the samples were of the total population, rates of attrition, sources of funding, or fidelity to the specified model. Further, only 11% of the studies included adult subjects, indicating that results are skewed towards children under the age of 18. Little is known at this time about the long term sustainability of documented results, or with whom these interventions may work best. The authors suggest more rigorous research on all types of ASD intervention in order to explore these issues further.

2) The second study reviewed (Reichow & Wolery, 2009) used meta-analysis techniques to provide a comprehensive review of studies on Early Intensive Behavioral Interventions (EIBI). In total, 13 research studies were used in this analysis. Positive impact was shown on IQ as well as expressive and receptive language for EIBI subjects when compared to less intensive EIBI interventions. Further, more exposure to the intervention was shown to be related to bigger gains in IQ.

While this analysis did show significant, positive results with EIBI over other models of treatment or no treatment, there are several caveats that need to be considered. These caveats not only moderate the effects shown in this meta-analysis, but also provide guidance for further research on the measurement of effective treatment for those with ASD.

Examination of the studies indicated the use of a treatment based manual in the interventions, however, no studies in this analysis contained any comprehensive evaluation of how the manual was used, or how often it was used. Lack of measurement of fidelity to the specified model makes it difficult to attribute outcomes to the intervention.

The sample of studies included in this analysis was fairly small. Further, only six (6) of the 13 studies compared EIBI to another treatment model (none of which were widely used or empirically validated), and all six (6) reported greater impacts on IQ, favoring EIBI over other treatments. EIBI treatment was also linked to more positive outcomes on receptive and expressive language when compared to the other treatments. More

rigorous experimental designs are needed to test the effectiveness of EIBI against other empirically validated models in order to determine if EIBI is truly the superior model.

Finally, while studies have shown that EIBI may be effective for some children, in each of the studies there were children that showed no change or negative change over time. This suggests that EIBI may not be the most effective treatment for all children with ASD.

3) The next meta-analysis (Eldevik et. al., 2009) was a response to the Reichow and Wolery study, which Eldevik argued had some threats to validity, namely in the use of multiple instruments to assess intelligence and the use of standardized mean change impact instead of the more conservative weighted mean impact. Eldevik included nine (9) studies in his meta-analysis, all using both control and comparison groups, and concluded that ABA, referred to as EIBI in this article, produced large to moderate positive impact when compared to no treatment. These results were consistent with Reichow and Wolery.

4) The goal of the next meta-analyses (Ma, 2009) was to use the Median of Baseline (PEM) approach to test the effectiveness of various strategies used to treat autism. In total, 163 studies were included in the meta-analysis, including some single-case experimental designs. Treatments were classified as follows: systematic desensitization, priming, self-control, training, positive reinforcement and punishment, presenting preferential reinforcers, response delay, computer-based intervention programs for language training, agent-mediated intervention, stimulus control, social story, punishment, modeling, positive reinforcement, and differential reinforcement of others. Of the 15, six (6) strategies showed large effect sizes: systematic desensitization, priming, self-control, training, positive reinforcement, and presenting preferential activities or reinforcers. The remaining treatments showed moderate effects. This analysis did not test the effectiveness of a specific model, but rather a type of strategy used. It is unclear if treatment employed more than one strategy and, if so, how that was controlled for. Further, no information was provided on the severity of the autism symptoms, the length of treatment, or how dependent variables were measured.

5) Spreckly and Boyd (2009) employed meta-analysis techniques to examine four studies (2 randomized controlled trials (RCT) and 2 quasi-randomized trials) on the effectiveness of ABA with other forms of treatment for autism. These 4 studies used treatment on preschool aged children. Outcomes included cognition, language, and adaptive behaviors. None of the studies used a true control group; ABA was either compared to another type of treatment or less intensive ABA services. Results from this meta-analysis indicated no significant benefits of ABA over other treatments in effecting cognitive, language, or adaptive outcomes. As with the other studies, there were limitations to this meta-analysis. There was no true randomized control group, with the two RCT studies being measured against less intensive ABA services. Further, outcome assessments differed between the 4 studies examined.

6) In 2010, Kokina and Kern used meta-analysis to examine the effectiveness of the Social Stories intervention. Social Stories, developed in 1993, uses short stories written in simple language to illustrate difficult social situations. In total, 18 studies (published between 2002 and 2009) were included in this analysis including single-subject designs with experimental control, participants (all children under the age of 16) with a primary diagnosis of ASD, and the use of Social Stories as the only intervention. The authors

used Percentage of Non-Overlapping Data (PND) to assess the percentage of scores during intervention that were above the highest baseline score. PND scores range from 0% to 100%, with higher percentages indicating more successful interventions. This analysis produced a PND of 60%, which falls into the questionable effectiveness category.

7) Flippin and Watson (2010) conducted a meta-analysis of empirical evidence from 1994- 2009 for the effectiveness of The Picture Exchange Communication System (PECS) (Bondy & Frost, 1994). A total of 11 studies were included in this analysis. The studies were reviewed for quality and additionally the authors reviewed pre-treatment characteristics of the children involved in the study to help identify characteristics of children who might benefit most from the intervention.

PECS is described by the authors as a manual based program used for nonverbal children with ASD to improve communication and speech. The authors described the PECS program and training required to utilize the PECS model. They reviewed previous meta-analyses that included studies involving communication skills with non-verbal children, but noted that, to date, no meta-analysis had examined the use of PECS with children with ASD. The authors began with 2 research questions related to the effects of PECS on communication outcomes and on speech outcomes for children with ASD. After calculating effect size for both the single subject and group designs included in the analysis, the authors concluded that overall PECS has a small to moderate effect on communication outcomes for children with autism. They did not make any strong statements as to any evidence suggesting that skills are maintained after the study or can be duplicated with other communications. The results for speech outcomes were not as strong and in the group design there was even a negative overall impact.

8) In the final meta-analysis, Virues-Ortega (2010) employed strict inclusion and exclusion criteria in his selection of studies. Further, he used advanced meta-analytic techniques (quality assessment, sensitivity analysis, meta-regression, and dose-response meta-analysis) to assess the effectiveness of ABA treatment, including traditional and UCLA/Lovass, as compared to control groups comprised of other treatment models, eclectic models, or no treatment. In order to be included in this analysis, ABA treatment had to be conducted for at least 10 hours per week for at least 45 weeks. In total, 22 studies were included in this meta-analysis, including, but not limited to Randomized Control Trials (RCT). Sensitivity analyses were performed to assess whether or not RCTs had similar effect sizes when compared to quasi-experimental studies. These analyses indicated very few differences in impact. Therefore, only the pooled effect sizes are presented and not just those specific to controlled trials. Three primary outcomes were assessed in this study. Brief summaries are provided for each below.

- Intelligence- All 18 studies in this analysis reported positive effects on general IQ, with an average effect size of 1.19. Effects were reported as stronger for clinic-based programs compared to parent-based interventions. Dose-response meta-analysis indicated that treatment duration did not produce stronger effects. Non-verbal IQ was assessed in 10 studies and results indicated an average effect size of 0.65; however when only controlled studies were assessed the effect size was 0.76.
- Language Skills- Studies that examined receptive language showed an average effect size of 1.48. There were very similar results for expressive language, with an average effect size of 1.47. General language skills were examined in five (5)

studies with an average effect size of 1.07. Program duration had a positive effect on receptive, expressive, and general language skills with more benefits shown for longer durations of services.

- Adaptive Behavior- There was an average effect size of 1.45 for communication skills, 0.95 for socialization, 0.71 for motor skills, and 1.09 for an adaptive behavior composite measure. Service intensity did impact outcomes, with larger effects shown in those receiving more intense ABA services. There were also greater effect sizes for those studies using the UCLA/Lovaas method compared to general ABA.

Overall, this meta-analysis suggests that long-term ABA intervention for individuals with ASD leads to medium to large effects in IQ, language, and adaptive behavior.

Discussion

Evidence-based practices are defined as “the integration of best research evidence with clinical expertise and patient values” (Sackett et. al, 2000). The following are critical factors that must be present in order for a program model to be considered as evidence-based:

- Randomized Control Trial (RCT) designs that demonstrate program effectiveness in comparison to alternative treatments
- Adherence to documented, replicable practice guidelines
- Well-defined target population of subjects
- Independent evaluator

Research on the treatment of autism continues to improve in both scope and rigor; however, there is still much to learn. While NPDC identified 24 evidence-based treatments for autism, the NAC only classified eleven (11) as established treatments. Further, the conclusions from the meta-analyses (which use statistical methods to assess effect sizes and therefore provide a stronger analysis) show less evidence of effective treatments and the need for further, more rigorous studies.

There are several critical factors preventing ASD treatments from being clearly defined as evidence-based. Specifically, the lack of rigorous studies that have 1) delineated the type of ASD populations they are working with (specifically regarding severity of symptoms), 2) a clear differentiation in services between those in the treatment and control groups, and 3) studied treatment for adults with ASD that all impact the determination of effectiveness.

ASD is characterized by varying degrees of challenge with social interaction and communication and the presentation of atypical, repetitive behaviors. Further, ASD is complex, encompassing a wide range of symptoms, severities, and manifestations. This complexity makes finding effective treatment options that are applicable for all, or even most individuals with ASD, challenging. In the 8 meta-analyses described above, the authors frequently mentioned the lack of information on the study subjects' severity of autism symptoms as a limitation to their findings. Without consistency on this information, it is difficult to delineate subgroups of subjects with ASD who may respond differently (either positively or negatively) to various treatments.

Due to the desire to tailor services toward individual needs, eclectic treatment models are the most frequently used intervention with children with ASD (Schreck & Mazur, 2008). These eclectic models use various treatment components based on child and family needs, which makes describing and measuring results for specific components of treatment difficult for researchers. Moreover, when differing types of interventions are compared, there needs to be some measure of model fidelity. In fact, measures of model fidelity were noted as missing from several of the studies included in the meta-analyses, with some control groups not differing substantially from the treatment groups in terms of services attained.

As much attention continues to be placed on the early identification of autism, the primary focus of the literature of ASD treatments is on children. Only one meta-analysis made mention of the presence of adult subjects in the research studies examined (which accounted for only 11% of all studies); the other meta-analyses made no mention of adult subjects. Further, the National Standards project only discusses treatments as they relate to children. They have identified that assessing treatments for ASD adults is a critical next step in their research. This is clearly an area that clinicians and researchers both need to explore.

Summary and Conclusions

The literature review of the treatment of ASD focused on the examination of eight (8) recent meta-analyses of treatments for ASD. Meta-analysis is a statistical technique that is most often used to assess the clinical effectiveness of healthcare interventions. The technique provides an estimate of treatment effect by combining the findings from several independent studies giving due weight to the size of the different studies included. The results of several of the meta-analyses reviewed were guarded with respect to the effectiveness of treatments for autism. Most recommended the need for further, more rigorous studies before the treatment under consideration could be categorized as an evidence-based practice.

One of two recognized organizations that assess research studies on new treatments that are attempting to gain the designation of an “evidence-based treatment” (National Professional Development Center (NPDC), identified 24 “evidence-based” treatments for autism. The other organization, the National Autism Center (NAC) classified eleven (11) treatments for autism as “established treatments”.

Through this review of the literature on autism treatments, it is clear that there are several promising treatments for ASD that have evidence supporting their effectiveness. Applied Behavior Analysis (ABA) is the most well-known and best-researched intervention for children with ASD. ABA is considered to be both an established treatment and even an “evidence-based practice” by a national organization. Meta-analyses indicated medium to large effect sizes for changes in IQ, language, communication, and behavior using ABA techniques.

One of the issues surrounding ABA is the payment obligation for the treatment which has been variously assumed by educational, behavioral health, and insurance entities or private payment. The treatment, typically administered daily for several hours in the home by both certified and non-licensed personnel, can continue over long periods of time, sometimes years. This treatment is also effectively administered in school-based programs with sufficient staffing and environmental accommodations.

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APPENDIX D

Family Focus Group Summary

FAMILY FOCUS GROUP SUMMARY

ASD Feasibility Study
Family Focus Group
May 10, 2012

On May 10, 2012, a group of family members of youth and adults with Autism Spectrum Disorder, drawn from the CT Behavioral Health Advisory Council, met as a Focus Group to provide input regarding their service needs. Eleven family members and one young adult member with ASD participated in the focus group.

The following issues were raised during the hour-long discussion.

1. Need for individualized treatment

- “staff need to understand that one child is different than another”
- “symptoms change”
- “need to consider the needs of the entire family”
- “discharge planning (from the hospital) is not individualized”

2. Time-limited treatment is problematic

- “just as he improved, the treatment was stopped”
- This is not an acute illness; treatment geared towards acute illnesses don't work here
- Treatment was crisis stabilization; end of treatment was not based on success in the environment

3. School related issues

- “Teachers need training on autism”
- “IQ should not be the basis for whether he receives services”; “there are a lot of autistic kids with an IQ of 71 in this state”

4. Programs that have been helpful

- Social Club/Club Houses with skills trainings, opportunities to socialize with peers, therapeutic services not necessary
- Have been unable to get funding for these programs
- Look at program called “Focus” for a template
- Summer camps with counselors trained to work with this population; look at program called “Synergy” for template; also Brian Armstrong, ABA therapist does specialized programming
- Summer school

5. Language barriers

- Lack of Spanish speaking services for this population

6. Transportation issues

- Need transportation to get to services in Hartford and New Haven area
- Drivers need coaching in dealing with this population (e.g., blasting radio is over-stimulating)
- Parents cannot always accompany their family member (other children in family, etc); need support services to accompany member to services

7. Issues associated with adult ASD population

- Need therapists who specialize in this population
- Once school ends, there is no source for structure in the lives of this population; need job training programs

8. Other services needed: "Wish List"

- Respite services
- Support groups for parents of this population
- Recreational services geared for this population
- Specialized in-home services for this population (IICAPs not effective)
- Training for EMPS workers for how to deal with ASD population
- Specialized crisis stabilization services
- Arts schools
- Fix form used for request for DCF Voluntary Services (have to sign a form that implies youth is neglected or that DCF has custody)
- Services for military families (currently requests for services results in stigma and lack of advancement for military-involved family member)

APPENDIX E: NATIONAL PROFESSIONAL DEVELOPMENT CENTER'S EVIDENCE-BASED TREATMENTS FOR AUTISM

- Antecedent-Based Intervention (ABI)
- Computer-Aided Instruction (CAI)
- Differential Reinforcement
- Discrete Trial Training (including the Lovaas method)
- Extinction
- Functional Communication Training (FCT)
- Naturalistic Intervention
- Parent Implemented Intervention
- Peer-Mediated Instruction and Intervention (PMII)
- Picture Exchange Communication System (PECS)
- Pivotal Response Training (PRT)
- Prompting
- Reinforcement
- Response Interruption/Redirection
- Self-Management
- Social Narratives
- Social Skills Groups
- Speech Generating Devices (SGD)
- Structured Work Systems
- Task Analysis
- Time Delay
- Visual Supports

APPENDIX E: NATIONAL AUTISM CENTER'S FINAL CLASSIFICATION OF AUTISM TREATMENTS

Established Treatments

According to the National Autism Center's National Standards Project, the eleven (11) Established Treatments are:

- Antecedent Package
- Behavioral Package
- Comprehensive Behavioral Treatment for Young Children
- Joint Attention Intervention
- Modeling
- Naturalistic Teaching Strategies
- Peer Training Package
- Pivotal Response Treatment
- Schedules
- Self-management
- Story-based Intervention Package

Emerging Treatments (Those with emerging levels of evidence):

- Augmentative and Alternative Communication Device
- Cognitive Behavioral Intervention Package
- Developmental Relationship-based Treatment
- Exercise
- Exposure Package
- Imitation-based Interaction
- Initiation Training
- Language Training (Production)
- Language Training (Production & Understanding)
- Massage/Touch Therapy
- Multi-component Package
- Music Therapy
- Peer-mediated Instructional Arrangement
- Picture Exchange Communication System
- Reductive Package
- Scripting
- Sign Instruction
- Social Communication Intervention
- Social Skills Package
- Structured Teaching
- Technology-based Treatment
- Theory of Mind Training

Un-established Treatments (Those with poor supportive evidence):

- Academic Interventions
- Auditory Integration Training
- Facilitated Communication
- Gluten- and Casein-Free Diet
- Sensory Integrative Package