

**Vermont Interagency White Paper
on
Autism Spectrum Disorders**

Report to the ACT 264 Board

March 2006

State of Vermont

**Agency of Human Services
&
Department of Education**

State of Vermont

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Executive Summary

At the request of the Act 264 Advisory Board, the State Interagency Team was charged to draft an interagency white paper to answer critical questions about autism in Vermont. In June 2005, the Department of Education and the Department of Disabilities, Aging and Independent Living hired autism specialists to address the needs of individuals with autism spectrum disorders. The State Interagency Team delegated the writing of the white paper to the two autism specialists.

The charge of the Act 264 board included questions to look at the current status of meeting the needs of this increasing population and their families. Questions address: current population, evidence-based practice, services provided by schools and social service agencies, service gaps, current and projected needs, and family supports. The autism specialists conducted a statewide assessment of supports in homes, schools, and communities.

Results are summarized below, organized by questions posed by the Act 264 Board.

1. What are the characteristics of our current population of children diagnosed with autism?

- Autism is a neurologically based developmental disorder that can have profound life-long effects in social interaction, ability to communicate, imagination and establishment of relationships.
- Autism is identified as a pervasive developmental disorder in the Diagnostic and Statistical Manual. Pervasive developmental disorders include autistic disorder, Rett's disorder, childhood disintegrative disorder, Asperger's disorder, and pervasive developmental disorder, not otherwise specified. These disorders are often referred to as autism spectrum disorders (ASD).
- Children are diagnosed by psychologists, developmental pediatricians, psychiatrists, and neurologists.
- Children and adolescents with ASD live all over the state.
- In 1992, thirteen children with ASD, receiving special education services, were identified by the Vermont Department of Education. 540 children, three to twenty-two, were identified with ASD on December 1, 2005. An additional 9 children were receiving Family, Infant and Toddler Program (FITP) services on December 1, 2005.
- As of June 30, 2005, the Vermont Community Mental Health and Developmental Services programs were serving a total of 527 children and adults with ASD. Services are not an entitlement and numbers served reflect only the individuals who were prioritized to receive funding.
- Nationally, the prevalence of autism has increased at a rate of 10-17% per year. In Vermont, over the past eight years, the number of children with ASD has grown an average of 20% per year.

2. What is evidence-based practice in working with these children and their families?

- No one intervention will be effective for all individuals with ASD, nor for the same individual across his/her lifespan.
- For young children (birth through eight), who may receive services through FITP, Essential Early Education (EEE) and schools, the National Research Council (2001) concluded that a substantial subset of children with ASD (up to 48% in some research) made marked progress when receiving intensive early intervention and recommended the following critical program components:
 - “Entry into intervention programs as soon as an autism spectrum diagnosis is seriously considered;
 - Active engagement in intensive instructional programming for a minimum of the equivalent of a full school day, 5 days (at least 25 hours) a week, with full year programming varied according to the child’s chronological age and developmental level;
 - Repeated, planned teaching opportunities generally organized around relatively brief periods of time for the youngest children (e.g., 15-20 minute intervals), including sufficient amounts of adult attention in one-to-one and very small group instruction to meet individualized goals;
 - Inclusion of a family component, including parent training;
 - Low student/teacher ratios (no more than two young children with ASD per adult in the classroom); and
 - Mechanisms for ongoing program evaluation and assessments of individual children’s progress, with results translated into adjustments in programming” (National Research Council, 2001, p. 219).
- A review of available research for school age children indicates core elements/components of effective programs include: 1) individualized supports and services for students and families; 2) systematic instruction; 3) comprehensible/structured learning environments; 4) specific curriculum content; 5) functional approach to problem behavior; and 6) family involvement.
- Because it is a relatively new diagnosis, there is limited research available regarding the most effective strategies to support individuals with Asperger’s syndrome. Recommendations for supports are based on professional clinical experience.
- Support for children and their families in the home and community need to be family-centered. Families need information, training, emotional support, assistance accessing resources and support around advocacy for their child.
- Intervention strategies with the most research support include interventions based on applied behavior analysis; early, intensive behavioral treatment; discrete trial training; TEACCH; structured teaching; Picture Exchange

Communication System; Pivotal Response Training; peer-mediated instruction; video modeling and Social Stories.

- As the number of children being diagnosed with ASD has increased, some schools and agencies have developed specialized programs and expertise to meet the needs of these children. However, there is considerable variability around the state in the availability of effective programs and services.

3. How are roles differentiated among and within major agencies serving these students?

- Services to children with ASD and their families are provided through the Family, Infant and Toddler Program (FITP); schools; Children's Personal Care Services; Developmental Services; and Child, Adolescent and Family Mental Health Services. Each program has regulations outlining eligibility and access to services.
- The Part B Interagency Agreement between the Department of Education (DOE) and the Agency of Human Services (AHS) outlines the provision of services to students who are eligible for special education and services provided by AHS.
- Some areas of responsibility for providing services are unclear, including who would have responsibility for providing intensive early intervention services for children birth to three as outlined by the National Research Council, services beyond a normal school day, and services for children with ASD and mental health issues.
- Gaps in the service system include a lack of:
 - Easy access to information regarding diagnosis, prognosis, options for treatment and intervention, available resources, parent support, etc.
 - Sufficient number of staff with experience and training in ASD to provide needed support, including direct support staff, case managers, behavior specialists, psychologists, psychiatrists, OTs, PTs, and SLPs.
 - Sufficient availability of training for staff through higher education, conferences and hands-on instruction.
 - Systems and processes to ensure smooth transitions when students change programs, especially transition from high school.
 - Infrastructure of trained personnel and financial resources to provide intensive early intervention as outlined by the National Research Council.
 - Availability of comprehensive services, when needed, for children with ASD in the home and community.
 - Availability of parent training.
 - Best practice guidelines to guide delivery of services in schools, home and community.
 - Systems and processes to enhance collaboration across school and home.

4. What is the current and projected need over the next five years?

- Vermont has seen an average annual increase of 20% in students with ASD over the past eight years. In five years, using a 20% increase as an estimate, 1,343 students, three to twenty- two, will be identified with ASD, up from 540 on December 1, 2005.
- It has been estimated that, in the future, 2500 professionals, 150-200 case managers, and 50-80 “expert” consultants will need training in order to support and meet the needs of individuals with ASD.
- Costs to provide special education services to children in Vermont with ASD are estimated to rise an additional \$19 million dollars by 2010, up from an estimated \$11 million dollars in 2005.
- Estimated annual cost to serve up to 22 children with ASD in FITP in 2010 would be \$1.2 million. However, providing intensive, early intervention services, beginning soon after diagnosis, is estimated to result in a savings in the range of one to two million dollars over the lifespan of an individual with ASD.
- An additional \$8.1 million may be needed in Children’s Personal Care Services to meet the needs of the increased number of children with ASD.
- Increased demand for services in Developmental Services and Mental Health systems.
- A statewide effort to fill systems gaps including:
 - Central location for accessing information,
 - Increased availability of training for families, professionals, school and agency staff,
 - Enhancement of transition process from school to adulthood,
 - Infrastructure of trained personnel and financial resources to provide intensive early intervention,
 - Increased availability of effective support services in the home and community,
 - Effective programs/interventions in schools.

5. What is the role of the family in meeting the needs of these children?

- Parents are advocates for their children as they know them better than other team members.
- Parents, schools and agency staff need to develop collaborative working relationships to maximize outcomes.
- Parents are teachers of their children at home. Parent training can support them in this endeavor.
- The provision of family support should be based on a family-centered approach reflecting the needs, desires and culture of the family members.

Introduction

Act 264 was passed by the Vermont Legislature in 1988. The purpose of this law is to develop and implement a coordinated system of care so that children and adolescents with severe emotional disturbance and their families receive appropriate services and supports. Local and State Interagency Teams, which include representatives from education, human services agencies and families, are available to assist in coordinating resources for these children. There is a Governor appointed Advisory Board that identifies yearly priorities on the system of care for submission to the Legislature. In the spring of 2005, the Vermont Board for Children and Youth with Special Mental Health Needs (Act 264 Advisory Board) identified the need for an interagency assessment of the current state of services for youth with autism in their schools, homes, and communities. This was identified due to the recognition of the rapidly growing number of youth with autism and related disorders and the lack of a clear strategic plan to address the needs of this population. While considerable efforts are being made by local schools, agencies and parents, the statewide systems of care for children and youth are struggling to meet the needs of this population. These youth often have complex needs requiring support in a variety of areas including communication, social, academic, behavioral and life skills.

In order to better address the needs of children with autism, the Act 264 Advisory Board requested that the State Interagency Team draft a white paper to answer critical questions regarding current and projected needs, evidence-based practice in working with these children and their families, current capacities and service gaps. In June 2005, the Department of Education (DOE) and the Department of Disabilities, Aging and Independent Living (DAIL) each hired autism specialists to address further developing the education and human services systems in supporting individuals with autism. The autism specialist position in DAIL was created as part of the reorganization of the Agency of Human Services in recognition of the needs of this population. The State Interagency Team delegated the writing of the white paper to the two autism specialists.

The autism specialists have conducted a statewide assessment of supports to children birth to twenty-two in their schools, homes, and communities. In order to gather information, they have visited school programs around the state; met with six parent support groups; Family, Infant and Toddler Program staff at the state and local level; Special Education Directors; Child, Adolescent and Family Mental Health Services Directors and state Division of Mental Health staff; staff from some Developmental Services and Mental Health Services agencies; and have heard from a variety of other individual stakeholders around the state. Information and input has also been gathered from the Autism Task Force, which is a group of professionals and parents interested in enhancing supports to individuals with autism spectrum disorders. Additional information has been gathered from state department databases. Information regarding evidence-based practice has been gathered from the professional literature and books on autism. This report responds to the questions posed by the Act 264 Advisory Board.

1. What are the characteristics of our current population of children diagnosed with autism?

Autism is one of a group of diagnoses identified in the Diagnostic and Statistical Manual (DSM-IV, TR, American Psychiatric Manual of Mental Disorders, 2000) as pervasive developmental disorders (PDD). Included in this group are autistic disorder, Rett's disorder (also known as Rett's syndrome), childhood disintegrative disorder, Asperger's disorder (also known as Asperger's syndrome), and pervasive developmental disorder, not otherwise specified (PDD.NOS). There are some overlapping symptoms across these disorders and they are commonly referred to in the professional literature as autism spectrum disorders (ASD). Because of the commonality of symptoms and recommended interventions, this paper will address the autism spectrum as opposed to only autism. The primary focus will be on autism, Asperger's disorder and PDD.NOS. Because they are so rare, childhood disintegrative disorder and Rett's disorder will not be addressed.

Autism is a developmental disorder of neurobiological origin that can have life-long effects in social interaction, ability to communicate ideas and feelings, imagination, and establishment of relationships. Autism spectrum disorders vary in severity of symptoms, age of onset, and association with other disorders, such as mental retardation, language disability, and epilepsy. The manifestation of autism varies across children and time. No two individuals with autism are alike, even if they have the same diagnosis. Autism affects approximately four times more boys than girls. According to the National Research Council (2001), "There is no single behavior that is always typical of autism and no behavior that would automatically exclude an individual child from a diagnosis of autism, even though there are strong and consistent commonalities, especially in social deficits" (p. 11).

Leo Kanner identified characteristics of autism in 1943. After more than 60 years, these characteristics are still current. They include: a) problems in relating to people and situations; b) speech and language problems; c) developmental delays; d) problems in relating to environmental changes; and e) stereotypic, repetitive actions and other peculiar motor movements (Simpson and Zions, 2000).

- ***How is autism differentially defined by the various agencies mandated to provide services to children and young adults with this disability?***

Public schools are mandated to provide educational services to children who qualify for special education. The Family, Infant and Toddler Program (FITP) is mandated to provide evaluation of children birth to three suspected of having disabilities and to plan and coordinate services. There are no other mandated services in the home and community for children diagnosed with autism spectrum disorders (ASD). Some children with ASD receive services funded through the Family, Infant and Toddler Program, Children's Personal Care Services, the Developmental Services system and/or the Child, Adolescent and Family Mental Health Services system.

Family, Infant and Toddler Program

Eligibility for FITP, administered within the Department for Children and Families, is described in the FITP Summary, January 2004. Families with children from birth through two years and eleven months of age, whose children experience developmental delays or have a diagnosed physical or mental condition, which has a high probability of resulting in a developmental delay, are eligible for the FITP. Eligibility is not based on a specific disability. Children diagnosed with ASD are eligible for FITP.

Schools

The Individuals with Disabilities Act (IDEA) was originally enacted in 1975 as the Education for All Handicapped Act (EHA). IDEA, which has recently been amended in 2004 (Individuals with Disabilities Education Improvement Act of 2004, IDEIA), entitles eligible children and youth with disabilities, including autism, to receive special education and related services. According to Mandlawitz in *Handbook of Autism and Pervasive Developmental Disorders*, (Volkmar, et al., 2005), “The essence of the Act is to ensure that all children with disabilities have available to them a free appropriate public education...designed to meet their unique needs and prepare them for employment and independent living” (p. 1161).

The Vermont Department of Education Special Education Regulations and Other Pertinent Regulations, written to reflect IDEA, includes Categories of Disabilities, effective 8/29/03:

“2362.1(i) Autism means a developmental disability significantly affecting verbal and non-verbal communications and social interaction, generally evident before three.

(1) Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child’s education performance is adversely affected primarily because the child has an emotional disturbance as defined in Rule 2362.1(h). (see Special Education Regulations)

(2) A child who manifests the characteristics of autism after age 3 could be diagnosed as having autism if the criteria in subsection (i)(1) are satisfied.

(3) The EPT (Evaluation and Planning Team, *sic*) shall obtain an opinion of a licensed physician as to the existence of autism and its effect on the student’s ability to function” (pp. 43-44).

The other autism spectrum disorders (Rett’s disorder, childhood disintegrative disorder, Asperger’s disorder, and PDD.NOS) are not specifically defined as disability categories

in the special education regulations. Children may be identified under other disability categories which are defined in the regulations.

Children's Personal Care Services

Children's Personal Care Services, administered within the Division of Disability and Aging Services, are an entitlement for Medicaid eligible children, under age twenty-one, who have a significant disability or health condition that substantially impacts care giving needs and/or the development of self-care skills. Significant disabilities or health conditions are not specifically defined by this program. The initial assessment asks for a list of disabilities or health conditions and measures the impact of these on basic daily living skills. The amount of service authorized is based upon assessed need rather than on a specific diagnosis. (Children's Personal Care Guidelines) Many children with ASD are eligible for Children's Personal Care Services.

Developmental Services

Developmental Services are administered within the Division of Disability and Aging Services (DDAS), Department of Disabilities, Aging and Independent Living. To be eligible for Developmental Services under a diagnosis of Pervasive Developmental Disorder, the following is required:

According to the "Regulations Implementing the Developmental Disabilities Act of 1996", pervasive developmental disorder (PDD) is defined as one of the following disorders: autistic disorder, Rett's disorder, childhood disintegrative disorder, Asperger's disorder, and pervasive developmental disorder, not otherwise specified. The diagnosis of PDD is based upon the criteria in the current edition of the Diagnostic and Statistical Manual (American Psychiatric Association, 2000). The diagnosis of a pervasive developmental disorder must be made by a psychologist, psychiatrist or other physician with training and experience in diagnosing pervasive developmental disorders.

In order to be eligible for Developmental Services, in addition to having a diagnosis of a pervasive developmental disorder, the person must also have substantial deficits in adaptive behavior, which occurred prior to age eighteen. Substantial deficits in adaptive behavior means that the person is functioning significantly below average compared to people his or her age in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, health and safety. Many children with ASD are eligible for Developmental Services.

Child, Adolescent and Family Mental Health Services

Child, Adolescent and Family Mental Health Services are administered within the Department of Health, Division of Mental Health. To receive services through the Child, Adolescent and Family Mental Health Services system, a child or youth needs to have a diagnosed mental health disorder. The diagnoses are based on definitions in the

Diagnostic and Statistical Manual (DSM, American Psychiatric Association, 2000) and must be made by appropriately trained professionals. While autism spectrum disorders are listed in the DSM, as noted previously, they are neurodevelopmental disorders rather than mental health diagnoses, therefore, generally, to receive Child, Adolescent and Family Mental Health Services, an additional diagnosis requiring mental health treatment would be needed.

- ***When are people typically diagnosed and by whom?***

Children in Vermont are being diagnosed with ASD by psychologists, developmental pediatricians, psychiatrists, and neurologists. Vermont Department of Education Special Education Regulations, 2362.1(i)(3), require that the opinion of a physician is obtained. Children are often diagnosed at the Child Development Clinic of the Vermont Department of Health or at Dartmouth Hitchcock Medical Center. Primary care physicians generally will not diagnose, but will refer a child to a clinician with expertise in making ASD diagnoses. Statistics regarding when children are diagnosed with ASD in Vermont are not currently available. Based on information from the FITP and DOE statistics, and parent reports, it appears that most children are being identified around age three or earlier for autistic disorder. Asperger's disorder is generally diagnosed when the child is older, around age eight. (Attwood, 1998) Children with milder symptoms are often not identified until they are older or, sometimes, not at all. Early diagnosis is important because research shows that intensive intervention at the earliest possible age results in more positive outcomes compared to intervention when the child is older (Handleman & Harris, 2000).

The National Research Council in *Educating Children with Autism* (2001) indicates that “with adequate time and training, the diagnosis of autism spectrum disorders can be made reliably in 2-year-olds by professionals experienced in the diagnostic assessment of young children with autistic spectrum disorders”(p. 212).

- ***Where do these children and adolescents live?***

Children and adolescents with ASD live all over the state. Most children live with their families. Nine children with ASD who are in state custody live in foster homes that are supported through developmental service agencies (DDAS record review). The Department for Children and Families supports additional children with ASD in their foster care system, but the exact number is not available at this time. Five children with ASD, funded through Child, Adolescent and Family Mental Health Services' home and community-based waiver, live outside their family's home (CAFU record review). Three children live in residential facilities or schools in or out of state (Department of Education, Residential Review Committee).

The Vermont Department of Education is required by the federal “Individuals with Disabilities Education Improvement Act of 2004” (IDEIA) to maintain a child count of children ages three through twenty-one receiving special education services served by public school districts. On a yearly basis since 1992, the Vermont Department of

Education has been compiling information pertaining to children eligible for special education services based upon disability categories. In 1992, thirteen children were identified with ASD. 540 children were identified with ASD on the most recent child count conducted on December 1, 2005. The information below has been disaggregated by six regions. The number of students reflects those identified with an autism spectrum disorder regardless of disability category. It does not include children with ASD on Section 504 Plans.

CHILD COUNT 12-1-05

REGIONS	BIRTH TO THREE FITP	STUDENTS THREE TO TWENTY-ONE
Central	1	73
Chittenden	2	126
Northeast		53
Northwest	2	77
South/Southeast	1	127
Southwest	3	84
Total	9	540

- *How do we account for the growing numbers of children identified with autism?*

In 1997 the Autism Society of America reported that ASD occurs in approximately 5 to 15 per 10,000 births, conservatively estimating that nearly 400,000 people in the U.S. had some form of ASD. Based on statistics from the Centers for Disease Control and Prevention, (CDC), the Autism Society reported in 2003 that ASD occurs 1 in 166 births with 1 to 1.5 million Americans affected with the disorder. According to the CDC, in 2003 approximately 141,022 children were served under the “Autism” classification for special education services. However, not all children with ASD receive special education services under the classification of “Autism”; therefore, the education data underestimate the actual prevalence of ASD. Some children with ASD receive special education services under other disability categories.

According to Fombonne, (1999) cited by the National Research Council (2001), “Two simple reasons explain the difference in current and historical rates: more complete diagnosis and a broader definition of autistic spectrum disorders” (p. 24). However it is not clear that this accounts for all of the increase in the prevalence of ASD.

Environmental factors such as diet or exposure to chemicals are being researched as possible reasons. During the last decade, researchers have begun the process of identifying genes susceptible to autism. Officials at the Centers for Disease Control and Prevention (CDC) do not have the answer to the increase in cases but are continuing to conduct research.

Nationally, the prevalence of autism has increased at a rate of 10-17% per year. (Autism Society of America, 2005) In Vermont, physicians have become better informed about the identification and diagnosis of children with ASD. In February 2002, Gretchen Kirby, former Vermont Department of Education Autism Consultant, created *Autism Spectrum Disorders-Early Intervention Fact Sheet* that was mailed to pediatricians, family physicians, special education coordinators, childcare providers, FITP staff and partners, Essential Early Education (EEE) or Early Education Initiative (EEI) teachers, school principals, and children or family service providers. Exposure in the media has also increased parental knowledge of the syndrome. Increase in diagnostic tools, expanded criteria (DSM-IV, TR, American Psychiatric Association, 2000), better training and understanding of the disorder also account for some of the increase.

Schools submit data to the Vermont Department of Education by December 1st of each school year, which identifies the students who are eligible for special education services as of that date. Children are coded based upon their identified special education disability. Students on the autism spectrum are coded in 5 categories. The 540 students on the December 1, 2005 child count were coded as follows: autism: 362; pervasive developmental disorder/not otherwise specified (PDD.NOS): 94; Asperger's syndrome: 77; childhood disintegrative disorder (CDD): 4 and Rett's syndrome: 3. The total of 540 may not accurately reflect the actual number of students with ASD in the state. Due to Vermont Department of Education Special Education Regulations, based upon IDEIA, some children with ASD are not found eligible for special education services. Special education regulations, (2362(a)(2), require that, if a student has a disability, the disability must result in an adverse effect on the educational performance in one or more of the basic skill areas. The basic skill areas are: oral expression, listening comprehension, written expression, basic reading skills, reading comprehension, mathematics calculation, mathematics reasoning, and motor skills. Students found to have a disability that does not result in an adverse effect may receive services under EST (Educational Support Team) or 504 plans but they would not be identified for child count purposes. The Family, Infant and Toddler Program is also required to annually count children receiving their services. On 12/1/05, FITP was serving 9 children, ages birth to three, who had an autism spectrum disorder. An additional 24 children with ASD were served within the 12 month period prior to 12/1/05 (FITP Child Count data). These 24 children transitioned from FITP into EEE services during the year and are counted in the DOE data. The child count data from FITP and DOE, totaling 549 children and youth, is the best estimate of the number of individuals with ASD under 22 in Vermont.

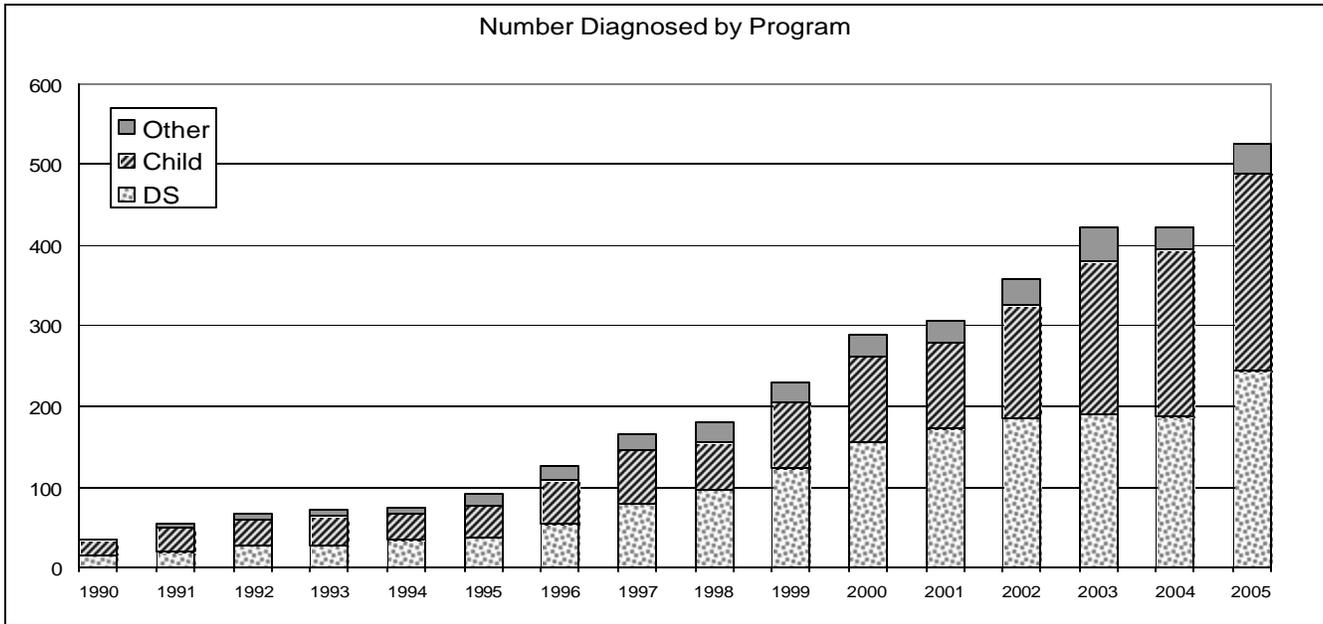
Many of the 549 children and youth with ASD identified by DOE and FITP also receive services from the Vermont Community Mental Health and Developmental Services programs. These programs were serving a total of 527 individuals with ASD as of June 30, 2005. This includes 243 adults and children receiving Developmental Services, 245 children under age twenty-two in Child, Adolescent and Family Mental Health Services and 39 adults in Adult Mental Health Services. (This information comes from data reported to the Agency of Human Services by the community Developmental Services and Mental Health agencies. It includes any person with an autism spectrum diagnosis who received any service in a given fiscal year.) The graphs on pages 13, 14 and 15

show the growth in the number of individuals with ASD served in these programs since 1990. The total number of people who received services in the Community Mental Health and Developmental Services systems who had a diagnosis of ASD has increased significantly over the past 15 years. The number of people with ASD served represents an average annual growth rate of 21% over the past 15 years. The services provided by these programs are not entitlements and therefore the numbers served reflect those who were prioritized to receive funding. There are individuals with ASD diagnoses who do not receive services through community mental health or developmental services.

Some of the increase in the numbers served in Community Mental Health and Developmental Services can be explained by a change in eligibility criteria within Developmental Services in 1996. Eligibility for DS expanded in 1996 from serving individuals with mental retardation to include those with pervasive developmental disorders. In addition, the diagnosis of Asperger's disorder was added to the DSM as a specific diagnosis in 1994. As the number of people eligible to receive services expanded, the developmental and mental health services systems have developed additional services to meet the needs. These changes likely account for some, but not all, of the increase in the number of individuals with ASD served through Community Mental Health and Developmental Services.

Between 1994 and 2003 the number of children in the United States being classified as having autism increased from 22,664 to 141,022. It is apparent that the number of individuals diagnosed with ASD is increasing throughout the country and in Vermont. Regardless of the reasons for the increase, the reality is that schools and agencies need to find ways to increase capacity and provide programs/interventions that will meet and support the needs in the school, home, and community for individuals with autism spectrum disorders and their families.

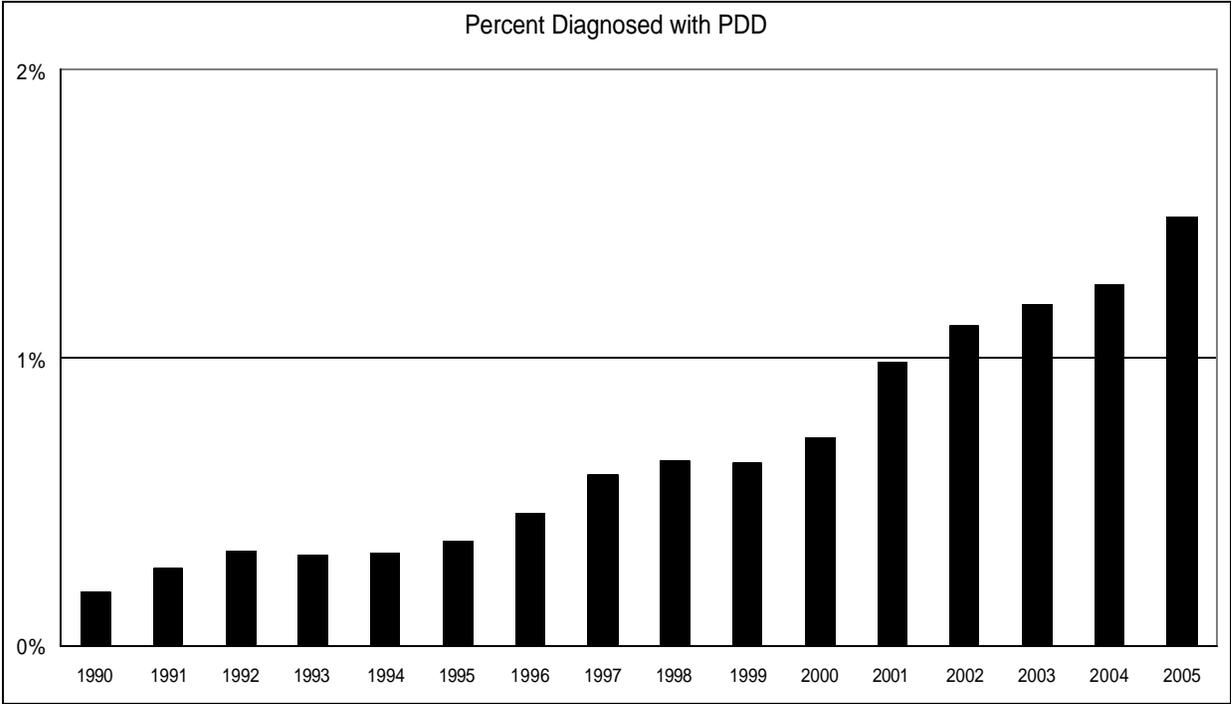
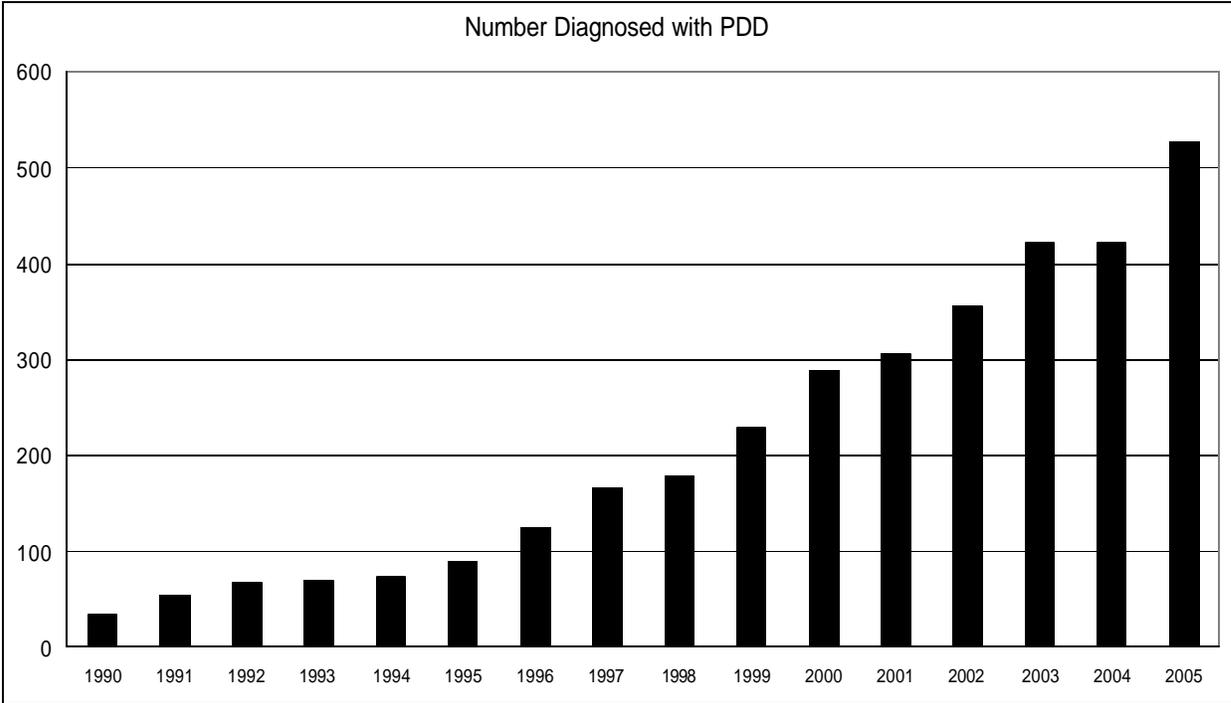
**Pervasive Developmental Disorders
In VT Community Mental Health & Developmental Services Programs: 1990- 2005**



Other= Adult Mental Health, Child= Children's Mental Health, DS= Developmental Services (adults & children)

<u>Program</u>	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
DS	15	19	27	27	33	36	53	79	96	123	156	172	185	190	186	243
Child	18	30	32	35	34	40	54	66	59	82	106	107	139	189	207	245
Other	2	5	9	8	7	14	18	21	24	24	26	27	32	43	29	39

**Pervasive Developmental Disorder
in VT Community Mental Health & Developmental Services Programs: 1990-2005**

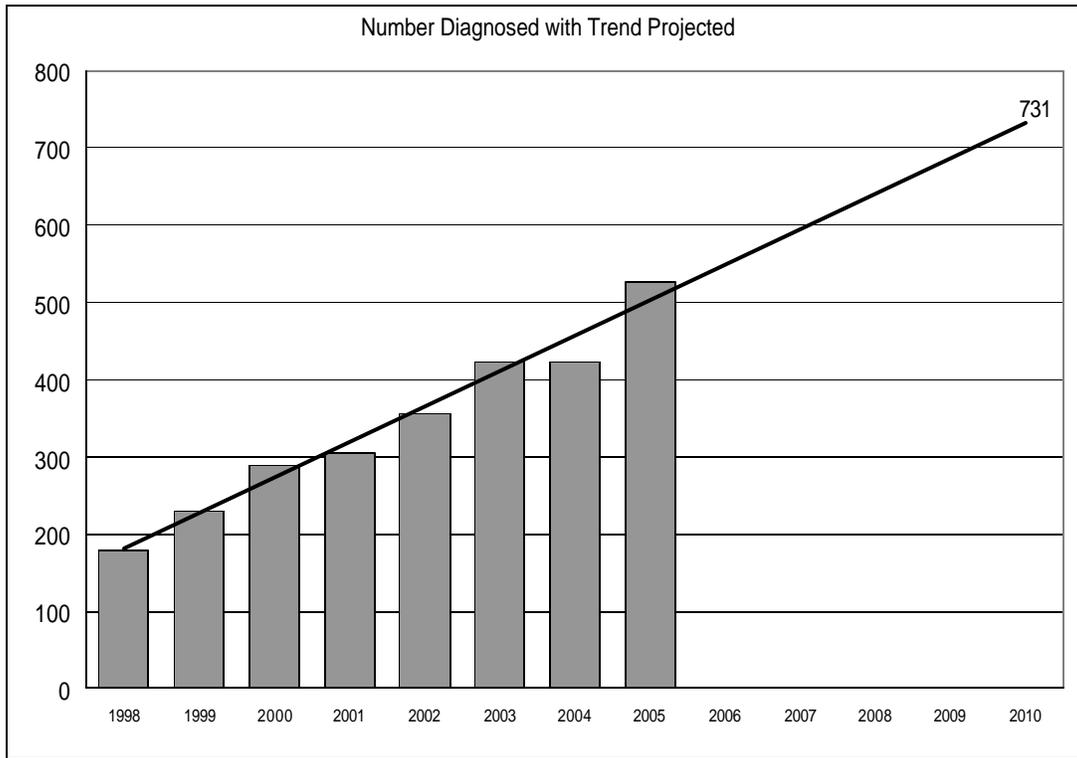


Diagnosed

	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
#	35	54	68	70	74	90	125	166	179	229	288	306	356	422	422	527
%	0.2%	0.3%	0.3%	0.3%	0.3%	0.4%	0.5%	0.6%	0.6%	0.6%	0.7%	1.0%	1.1%	1.2%	1.3%	1.5%

This report is based on analysis of Monthly Service Report data provided to DMH by designated community agencies. These data files include up to four diagnoses for each person. For this analysis a diagnosis of PDD (299.00 or 299.80) in any of the four diagnosis fields was considered to be evidence of the identification of this disorder by CMHC staff.

Pervasive Developmental Disorder
in VT Community Mental Health and Developmental Services Programs



Diagnosed		1998	1999	2000	2001	2002	2003	2004	2005
	#		179	229	288	306	356	422	422
%		0.6%	0.6%	0.7%	1.0%	1.1%	1.2%	1.3%	1.5%

This report is based on analysis of Monthly Service Report data provided to DMH by designated community agencies. These data files include up to four diagnoses for each person. For this analysis a diagnosis of PDD (299.00 or 299.80) in any of the four diagnosis fields was considered to be evidence of the identification of this disorder by CMHC staff.

2. *What is evidence based practice in working with these children and their families?*

The best way to help individuals with autism involves a team effort with parents playing an integral role as respected partners. “No one individual or group of individuals has unlocked all of the complex variables involved in autism....a coordinated effort by all involved can greatly enhance the functioning level of the child with autism and concomitantly reduce the tremendous familial stress associated with having a child with a disability” (Koegel, 1995, p. ix - x). Parents need to be seen as collaborators in their child’s treatment programs beginning at the time of diagnosis. As a child ages, he/she should also be increasingly involved in decision making in all aspects of his/her life. For many individuals, there will need to be an interdisciplinary team that functions as a unit throughout the lifespan of individuals with ASD. “Given the intensity and unique pattern of stressors faced by families of children with autism, the need for parent-professional

collaboration in autism intervention is paramount.” (Volkmar, et al., 2005, pp. 1059-1060).

The *Handbook of Autism and Pervasive Developmental Disorders*, (Volkmar, et al., 2005) cites eight research-based general approaches that are “most relevant to working with families of children with autism” (p. 1061). These are defined as:

- “Provide family members with information from the professional literature in an organized and accessible format.
 - Train parents to implement instruction techniques or behavior management strategies.
 - Help family members apply principles of learning to education and management.
 - Work with family members to increase the positive valence and decrease the negative aspects of parent-child relationships.
 - Train family members in cognitive techniques in order to modify emotional and behavioral responses.
 - Provide family member with empathy, a listening ear, and basic problem solving either through individual sessions or group work.
 - Assist family member in obtaining access to resources, services, and basic necessities.
 - Assist family member in advocating for the identified child’s needs across the lifetime” (pp. 1062-1063).
- ***How do schools, community providers and parents work together to maximize services?***

Individuals with ASD learn best through routine and consistent approaches. Therefore the most effective services are well coordinated across the home, school and community. There does not appear to be a consistent means across the state for coordinating and maximizing the effectiveness of services across school, home, and community providers. Intervention services, provided through FITP and daycare, are family-centered. A primary focus of FITP is to coordinate services needed by the child and his/her family. The focus, once students transition from FITP to EEE and enter the school system changes from family-centered services to child-centered educational services. Best practices include family as key players in the development and implementation of educational programs for children with ASD. Even with FITP and EEE services available to families, some parents feel that they are left on their own to find information, resources, and services for their children. Educational services are generally provided in school or alternative school settings, while family support services are provided separately in the home. Some teams share common goals, interventions and resources, and staff are cross-trained. However, this is not common. While parents and community providers generally participate in educational planning, goals and interventions are not often shared across settings. Schools are often not aware of the goals being addressed at home and in the community. It is recognized that some issues being addressed at home are private and should not be shared with the school team. Shared goals and strategies

would be particularly helpful in areas such as communication, social skills and addressing challenging behavior. A common approach would enhance learning for the child.

Few school age children with ASD have coordinated services plans as outlined in Act 264 as these plans were initially developed for children with severe emotional disturbance, not ASD. The new Part B interagency agreement between the Department of Education (DOE) and the Agency of Human Services (AHS) now broadens the availability of coordinated services plans for all children receiving special education and human services, as needed. This process could be used to maximize outcomes for children with ASD. However, any service provided in the home needs to be provided in a family-centered manner that respects family privacy and choices.

- ***What is the continuum of services that exists to serve the range of young people on the autism diagnostic continuum?***

Family, Infant and Toddler Program

Part C of IDEIA provides intervention services for children birth to three years of age and their families. The DOE and AHS share the responsibility for implementation of Part C. The coordination of service delivery is the responsibility of the Family, Infant and Toddler Program (FITP). As required by federal law, school districts must conduct annual child find activities, which include evaluating and determining eligibility, and be involved with transition planning of children from FITP to Essential Early Education (EEE) six months prior to the child's third birthday.

The Family Infant and Toddler Program is a family-centered coordinated system of intervention services for infants, toddlers and their families. The services address developmental delays, health conditions, and prepare the children to be ready to learn from school and the community. Supports and services are developed to meet each child's unique needs and the needs of their families in their home and community.

FITP services, based upon the assessed needs of the child and family, are identified in an Individualized Family Service Plan (IFSP). Intervention resources and supports may include help with obtaining and coordinating community services and supports, such as assistive technology; trained home visitor/child development specialist; health services to help a child benefit from other intervention services; nursing; physical and/or occupational therapy; counseling/psychological and social work services; specialized instruction; transportation assistance; medical diagnosis for evaluation and eligibility; hearing and vision services; nutrition; and communication.

Services and supports are provided in the most convenient and natural places for the family and their child. These can include the family's home, child care setting, community playgroup, etc. The daily routine, lifestyle, culture, community, chronological age and developmental level must all be taken into account when planning and providing intervention services for children under the age of three.

Schools

Part B of IDEIA includes special education requirements beginning on a child's third birthday and continuing through age twenty-two, when appropriate. Vermont Special Education Rules are designed to ensure that eligible Vermont students with disabilities receive a free and appropriate public education (FAPE) in accordance with state and federal laws and regulations and in a cost-effective manner. A FAPE includes services and placement based upon individual needs. Rule 2360.2(a) states: "An eligible child shall be entitled to a free appropriate public education beginning no later than the child's third birthday and continuing, unless otherwise provided herein, through 21 years of age. An individualized education program (IEP), rather than an individualized family service plan (IFSP), shall be in effect for an eligible child by his or her third birthday. If a child's third birthday occurs during the summer, the child's IEP team shall determine the date when services under the IEP will begin."(p. 7). Some students will graduate prior to the age of twenty-one if all graduation requirements have been met.

Children between their third birthday through five years and eleven months of age are eligible for early childhood special education services through the Essential Early Education (EEE) program. Vermont Special Education Regulation 2360.5.7 states:

“(b) Eligibility for EEE services

(1) A child who received special instruction, developmental therapy services or speech services through an IFSP shall be eligible for EEE without the need for additional evaluation.

(2) A child who did not receive special instruction, developmental therapy or speech services through an IFSP, may be eligible for EEE services if the Evaluation and Planning Team determines that the child has a medical condition which may result in significant delays by the time of the child's sixth birthday.”
(p. 31)

Services provided are outlined in an IEP that addresses the student's present developmental level. For preschoolers, the IEP may also address how the disability affects participation in developmentally appropriate play activities.

If a child, age six through age twenty-one, is eligible for special education services as outlined in the regulations, the IEP team writes a plan to address the child's specific needs. The IEP must include: (a) a description of all special education services, related services, and supplementary aids and services that the child will need to be able to derive benefit from the educational program; (b) a description of the special education program, including present levels of academic achievement and functional performance; and (c) accommodations and/or modifications necessary for the child to progress in the general education curriculum.

The Special Education Rules of the Vermont Department of Education contain specific guidelines about the education of students with disabilities. The rule, 2364.1, regarding Least Restrictive Environment (LRE) states:

“Each school district shall ensure that a student eligible for special education services shall be educated with his or her non-disabled chronological age peers, to the maximum extent appropriate in the school he or she would attend if he or she did not have a disability.

(a) Barriers to the participation of students with disabilities in the regular education environment shall be addressed whenever possible by the provision of accommodations, modifications, and supplementary aids and services rather than by placement in separate programs.

- (1) A child with a disability shall not be removed from education in age-appropriate regular classrooms solely because of needed modifications in the general curriculum;
- (2) Special classes, separate schooling or other removal of children with disabilities from the regular educational environment shall occur only if the nature or severity of the child’s disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily; or
- (3) In selecting the LRE, consideration shall be given to any potential harmful effect on the student or on the quality of services he or she needs” (pp. 70-71).

The continuum of least restricted environment includes:

1. regular classes
 - a. classroom accommodations
 - b. small group specialized instruction
 - c. individualized instruction
2. special classes
3. alternative placements
 - a. special schools
 - b. independent schools
 - c. home/hospital instruction
 - d. residential facilities.

Home and Community Services

For children with ASD under age three, FITP (described above) is the entity responsible for coordinating services in the home and community. Currently for children over age three, home and community supports specifically for children with ASD in Vermont are not the responsibility of any one entity. Children and their families can access a variety of disability related services outside of the school setting. They may receive services

from Children's Personal Care Services, Developmental Services, or Child, Adolescent and Family Mental Health Services.

Children's Personal Care Services

Children's Personal Care Services (CPCS) offers 1:1 assistance with activities of daily living such as bathing, dressing, eating, etc. in a person's home or community. Based upon an assessment of need, an allotment of hours per six month period of time is authorized. Families can use these hours flexibly when they are needed. Families can have services provided by an agency or they can manage these services themselves. Some, but not all, home health, developmental services and children's mental health agencies are currently providing CPCS. Many agencies have stated that they are unwilling to provide this service because they feel the state Medicaid reimbursement rate is too low to cover their costs. Family management involves parents hiring, training and supervising the personal care workers. This service is an entitlement under Medicaid EPSDT (Early, Periodic Screening, Diagnosis and Treatment) and is available to all eligible children (see eligibility criteria on page 8).

As of January 2005, 1,166 children were enrolled in CPCS with the average number of hours authorized being 25 hours per week. The percentage of these children who have an autism spectrum diagnosis is not accessible through the current database. However, according to the CPCS administrator, a significant proportion of children with ASD do qualify for and are receiving this service. A survey of satisfaction with this program was completed and results reported in June 2005 (Vermont Children's Personal Care Services, Program Status Report). According to this report, 80% of these services were family managed and only 20% provided by an agency. Some families could only family-manage their services as there were no provider agencies providing CPCS in their areas. Families reported a number of positive aspects of this program. In addition to providing assistance with activities of daily living, families saw additional benefits to the services including giving them and their child a break, providing social and community activities, supervision of the child, and skill training for their child.

Some of the difficulties with this service include difficulty hiring, training and retaining personal care workers. In fact, only 64% of the allocated hours were utilized during 2004-2005. For some families of children with ASD, CPCS meets their needs. For others, especially for children with very intense needs and families who want their child to receive intensive services from professionally trained and supervised staff, CPCS are not adequate. The program only pays for a personal care worker. It does not include any clinical services, case management, or supervisory staff. These are generally needed when providing an intensive treatment or intervention. Some families have been able to collaborate with the school team to get their personal care assistants (PCA) trained to implement more intensive services. However, this is more the exception than the rule. Some children also have developmental services waiver funding which can be combined with the CPCS to create an intensive package of support. An additional issue is that some families do not want the responsibility for hiring and supervising workers; yet, in some areas of the state there are no provider agencies available to provide the service.

Developmental Services

Some children with ASD receive funding through the Developmental Services (DS) system. Developmental Services are administered through the Vermont Department of Disabilities, Aging and Independent Living (DAIL), Division of Disability and Aging Services (DDAS). DAIL contracts with 15 developmental service agencies across the state to provide these services. A survey of these agencies conducted in 2004 shows that agencies were serving 218 children, under age eighteen, with ASD. This includes children receiving all types of DS funding including Flexible Family Funding, Targeted Case Management and Home and Community-based Waiver. In all funding categories, it is likely that this number is an underestimate as a number of children may be reported as having a diagnosis of mental retardation when they also have an unreported diagnosis of an ASD.

The Vermont State System of Care for Developmental Services describes the availability of resources for individuals with developmental disabilities. One of the resources available is Flexible Family Funding. Families with children with developmental disabilities, including ASD, living with them at home may be eligible for this funding. This is money that can be used at the family's discretion towards services and supports that are in the child's or the family's best interest. The amount is based upon a sliding scale, which takes into consideration family size and income. The maximum amount available per year is \$1,122.

Some DS agencies may be able to offer Targeted Case Management support to some families. The child must be Medicaid eligible to receive this service. Case management can be used to assist families in planning, developing and accessing other services; advocacy; and monitoring the well being of the child and family. This might be offered when case management would be helpful and the agency has the funds available. DS agencies have limited Targeted Case Management funds available.

Children with developmental disabilities can also access state-funded respite homes. These homes are designed to give families a temporary break from their care giving responsibilities. These are not crisis beds. A person with a developmental disability can stay at a state respite home for up to 14 days per year. Medicaid eligibility is not required. The four homes are located in Salisbury, Morrisville, Rutland and St. Albans. Each home can accommodate one person at a time.

Crisis services are available through the DS designated agencies for any child with a developmental disability experiencing a crisis.

Some children receive DS Home and Community-based Waiver services, known as "waiver". Funding through the waiver is not an entitlement, but is allocated based upon priorities outlined in the Vermont State System of Care Plan for Developmental Services. In December 2001, the funding priorities changed for the DS waiver for children under

eighteen due to limitations in funding. Since then, access to this funding for children who are newly applying for services is limited to those at risk of admission to a nursing home or a psychiatric hospital. Children who were already funded prior to December 2001 have continued to receive services. Increases in the amount of funding for children who are already receiving waiver services can be made if funds are available within their agency, but otherwise these children cannot receive an increased funding unless they meet one of the current funding priorities. Because of the current criteria for receiving waiver funding, most children under eighteen with ASD would not have access to this funding. For those children who do have DS waiver funding, they receive services such as respite, case management, clinical supports, home supports and assistive technology. The funding priorities are broader for young adults, age eighteen to twenty-two. Service options under the DS waiver for these and all adults include residential supports; work supports; community supports; clinical interventions; service coordination; crisis support; respite care; and transportation.

As of September 2005, 193 children with developmental disabilities under age eighteen were receiving DS waiver funded supports (DDAS waiver database). 86 (or 45%) of these children are on the autism spectrum (DDAS waiver records). An additional 52 individuals with ASD, aged eighteen to twenty-two were receiving waiver supports. This is a total of 138 children and young adults with ASD who receive waiver services. Of the 138 individuals, 66 had a diagnosis of autistic disorder, 58 had PDD.NOS, 11 had Asperger's syndrome and 3 had Rett's syndrome. All but a few of the individuals with ASD, under age 21, who receive DS waiver funding also receive Children's Personal Care Services (CPCS). Some families and agencies have been able to combine the resources from the waiver and CPCS to create an intensive package of supports. DDAS is currently working with the Office of Vermont Health Access to develop a process of transferring funding from CPCS to the waiver to create a unified service plan, when needed, that better meets an individual's needs.

Developmental services are often provided in collaboration with other agencies and schools. The level of collaboration varies considerably depending on the needs of the individual and the organizations involved.

The Division of Disability and Aging Services, which administers the DS waiver, and Department for Children and Families (DCF) have an agreement, which allows children with developmental disabilities in DCF custody to live in foster homes that are developed and supported by developmental service agencies. This allows for these children to receive support from an agency with the additional expertise in developmental disabilities when this is needed. The services for these children are funded through the DS waiver with DCF paying the state match portion of the funding. Developmental service agencies are currently supporting 32 children with developmental disabilities in DCF custody through waiver funding. Nine of these children are on the autism spectrum.

Almost all of the children who receive developmental services are also eligible for special education through their local school district. The most common collaboration

between schools and developmental service agencies is participation in each other's educational and treatment team meetings. Collaboration at this level might consist of information sharing, agreeing to work on similar goals, and/or cross-hiring or cross-training staff to increase consistency of approaches across settings.

In some other cases, schools may request that an agency provide some portion of a student's educational program, such as an extension of the school day, vocational services or the hiring and supervision of an individual aide. In some rare circumstances, developmental services agencies are providing an alternative educational program outside the school. In these circumstances, there is no financial collaboration with Medicaid funds. Schools contract with agencies for the full cost of these services. Providing educational services has been outside the primary scope and mission of developmental services and therefore, this option has remained the exception rather than the rule. Only some of the developmental service agencies have the capacity to offer an individualized, alternative, education program.

There are strengths and challenges within the DS system in supporting children and youth with ASD and their families. One strength of serving children through the developmental services system is overall knowledge and expertise in supporting individuals with developmental disabilities. However, there is much variability around the state in the level of expertise in addressing the unique needs of individuals with ASD. An additional positive aspect of the DS system is that supports continue into adulthood and there is not a need to transition to another system when a child becomes an adult. Another strength is the flexibility in the DS waiver in funding a package of supports tailored to a person's individual needs. However, as noted previously, the availability of this funding for children is currently quite limited. Some individuals with ASD have cognitive abilities in the average or above average range. This is sometimes a challenge for developmental services agencies who have less experience supporting individuals with higher cognitive skills. A general challenge within the system is the frequent staff turnover that interrupts continuity of services.

Child, Adolescent and Family Mental Health Services

As of June 2005, 245 children and youth, under age twenty-two, with ASD and co-occurring mental health disorders were receiving services from the Child, Adolescent and Family Mental Health Services system. The mission of this system is to assure timely delivery of effective prevention, early intervention, and behavioral health treatment and supports through a family-centered system of care for all children and families in Vermont. Services are designed to treat mental health needs and are provided by local community mental health centers, in collaboration with other community providers. The system provides for core capacities in each of twelve regions of the state, including immediate crisis response, clinic-based treatment, outreach treatment, family support, prevention, screening, referral and community consultation. Also, available on a statewide basis for those children with acute mental health needs are emergency or hospital diversion placements, intensive residential services and inpatient hospital services. Some of the specific services available within these categories include

assessment; group, individual or family therapy; intensive in-home or out-of-home community support; medication services; service coordination; skills training and social support; respite; family education; training; and consultation. These resources are limited and those children with the highest level of clinical mental health needs are prioritized. People apply for services at the Designated Community Mental Health Center in their area. Intake coordinators will help determine what treatment programs and clinical services will be most appropriate to address the individual's mental health needs. Not all programs have the same eligibility criteria. The intake assessment is used to determine clinical needs and eligibility for specific treatment programs.

Some children's mental health services are provided in collaboration with schools. These include home-school coordinators, counseling services, day treatment programs, and behavior interventionists. Three mental health agencies provide specialized autism programs in schools, described in the next section. Services focus on specific mental health needs and are designed to treat the child and family in partnership with home and school.

There are some strengths and challenges in providing services to children and youth with ASD through Children, Adolescents and Family Mental Health Services system. A strength is the variety of available services which can be tailored to the individual needs of a child and family. Another strength of this system is the formalized collaborative relationships with schools and other community providers. One of the challenges is the common problem of staff turnover at all levels of service provision that affects the ability to consistently deliver the services. Mental health agencies triage services to those most in need; therefore, the people with the highest needs receive services first. However, the community mental health centers have a variety of services and supports that can be offered to those who are not triaged as high needs. Some individuals may receive some of the services that they need while waiting for additional services. Also, the level of expertise in ASD of staff providing services is variable around the state. The Directors of Children's Mental Health Services indicated that they have limited numbers of staff with sufficient training to provide needed services to people with ASD. Even in the three agencies with specialized autism programs, their clinical staff have limited time to consult outside their programs. Most staff of community mental health centers are more familiar with supporting children and youth with clinical mental health issues. Autism spectrum disorders are developmental disabilities. Many people with ASD also have cognitive impairments, which must be accommodated when providing any treatment or support. Staff of these programs are less familiar with supporting people with cognitive limitations. Also, there are some issues regarding the "fit" between the types of services being provided by behavior interventionists and in the specialized autism programs and the funding mechanism. Some of the interventions that are recommended for individuals with ASD do not fit within mental health's Medicaid guidelines for billable services. This limits what can be provided through existing funding mechanisms within the children's mental health system.

There are also a number of children in the state who have diagnoses on the autism spectrum and additional serious mental health problems. These children present unique

challenges to the State's service systems. It is unclear who is in the best position to serve these children. The mental health system is accustomed to serving children and youth with clinical mental health issues and has less experience with addressing the needs of individuals with developmental disabilities. The developmental services system is more accustomed to addressing the needs of individuals with developmental disabilities. While the developmental services system does address the psychiatric needs of the individuals it serves, it does struggle with meeting the needs of those with very serious mental illness, such as psychosis and bi-polar disorder. Both systems have crisis services available, but mental health has a broader range of options available. These include short-term assessment beds and longer term residential services for children who need more extensive treatment and stabilization. Developmental services has two short-term crisis beds statewide and one three-bed home for children with developmental disabilities and mental health or extreme behavioral issues. In rare circumstances, developmental services will place a child outside his/her family home in a developmental home in order to receive needed support. With these children with complex needs, it is often difficult to sort out which aspects of a child's difficulties are related to ASD and which are related to mental health diagnoses, how they may be interrelated and how to develop a plan of treatment/intervention to address all the child's challenges. There are further difficulties deciding who has the expertise to serve the child and who should be responsible for paying. Situations like these have presented themselves repeatedly to Local Interagency Teams (LIT) and the State Interagency Team (SIT) for resolution. A role of these teams is to ensure that children receive coordinated services when multiple agencies are involved and to facilitate access to resources needed to implement a plan of coordinated services. The current reorganization of the Agency of Human Services presents a good opportunity to resolve some of these issues and further develop the system in an integrated fashion to meet the unique needs of children with ASD and other mental health diagnoses.

- ***Are there communities/regions that are particularly effective in serving these young people in their school, community and home?***

As will be discussed in the next section, the definition of what constitutes the most effective supports and interventions for children with ASD is still evolving. A framework for evaluating services in schools, home and community for children with ASD is not currently available in Vermont. Best practice guidelines are needed to help schools and agencies in designing effective programs. The authors of this white paper have visited programs or spoken to special educators, teachers, parents and community providers about available programs. Without a framework for assessing effectiveness, definitive statements regarding the effectiveness of specific programs would be premature. Below is a description of some of the school programs visited. The descriptions provided are informational only and should not be construed as recommendations. None of the programs have outcome data to demonstrate their effectiveness, but they do have individual student data that shows what works for a specific child and a general sense of what works for children in their programs. Services to children and families in the home and community are individualized and are not part of a "program", per se. Information about community services was gathered from

community providers and families. Through this survey of available programs in the state, some common themes emerged regarding key ingredients for effective programs. These are discussed as well.

Currently, there are three specialized autism programs, provided by mental health centers, in local schools. These are provided by Washington County Mental Health, (WCMH), Baird Center of Howard Center for Human Services in Chittenden County and Counseling Services of Addison County, (CSAC). The programs were developed in response to the needs of local school districts for specialized expertise in supporting children and youth with ASD in their schools. Schools are responsible for providing academic instruction and related services, such as occupational therapy, physical therapy, and language services, while the mental health programs provide individualized support to the child to access the educational curriculum. These programs provide intensive, specialized instructional and behavioral treatment support services year-round to individuals with Autism Spectrum Disorder ages two through twenty-one. Services are provided in home, school, and community settings, and target the teaching and shaping of essential communication, social, adaptive behavior, daily living, and functional learning skills. The program staff possess broad ASD knowledge and expertise and implement programming utilizing multiple treatment methodologies under the principles of Applied Behavior Analysis (ABA) (described on page 31.) Each child has an intensively trained and supported individual interventionist. The programs at WCMH and Baird are directed by doctoral level clinicians with expertise in ASD. The CSAC program is just starting its second school year. They have been advertising since February 2004, to hire a director for the program with the appropriate level of expertise. It is difficult to find appropriately trained individuals who are willing to accept the pay that is offered in Vermont. Each child also has a clinical case manager who supervises the interventionists for 3-4 children. Trained substitute staff are also available to ensure continuity of services. These are intensive programs richly staffed with specifically trained staff. They are funded with Medicaid through the Success-Beyond-Six funding mechanism with the school paying the state portion of the Medicaid funds.

Presently, the Baird program has reached their capacity with 17 students in the school-based program. Four students are on a waiting list for inclusion in the program. WCMH has also reached their capacity with 15 students in the school-based program. CSAC has 9 students and 3 referrals. At the present time, this program is limiting the number of students to 9 due to the lack of qualified and trained personnel available to provide the services. Both Baird and WCMH also provide consultation services through contractual agreements with schools. WCMH is providing weekly support to the Lyndon Town School through a contractual agreement for a number of students on the autism spectrum. Baird provides district-wide consultation for one day a week in Essex Town and two days a week in the Burlington School District.

There are also a number of supervisory unions that have developed specialized programs to serve students with ASD. The Stepping Stones Program, an alternative day program, in Newport City, through Orleans-Essex Supervisory Union, has been in operation since August 2003. There are 11 elementary through high school students, 7 identified with

autism spectrum disorder, presently in the program. Each student receives individualized instruction including ABA, occupational therapy, physical therapy, assistive technology and communication/language skills. The program is designed upon TEACCH (Treatment and Education for Autistic and Related Communication Handicapped Children), which is the statewide program model in North Carolina for supporting children with ASD. Group interaction includes snack/lunch, food preparation, and game time to increase social and adaptive behavior skills. There is a half-time program director, two special educators, 11 instructional assistants who work/interact with all students, one-day a week occupational therapist; one-day a week physical therapist; and one-day a week speech and language pathologist. The school district also contracts with an occupational therapist and special educator who have extensive experience with children on the autism spectrum. These two individuals are available to consult to the Stepping Stones Program.

The Hartford Autism Regional Program, HARP, is one of three collaborative programs in the Hartford School District. The programs under the Hartford Area Regional Collaborative serve students in the region from seven supervisory unions in Vermont and three in New Hampshire. The Autism Regional Program is located in Wilder, Vermont and opened in August 2005 after three years of planning. HARP currently serves middle school aged students with autism who cannot be integrated into the regular classroom setting because of their behavior and communication challenges. Presently the program has enrolled six students from four different supervisory unions in Vermont and New Hampshire. Staff includes three special educators, one of whom is ABA certified, and a part time speech language pathologist and occupational therapist as well as personal care tutors. High school students with autism can be served in the Regional Resource Center (RRC) at Hartford High School. The RRC is also one of the Hartford Area Regional Collaborative programs. The high school program has been operational for close to 20 years and provides services to students with intensive needs, including several with an ASD diagnosis. Elementary and preschool students within the Hartford Area Regional Collaborative catchment area are increasing in numbers. To date these students are generally served within their home school programs in preschool and child care programs or individualized elementary programs. A close professional relationship with the parent directed organization, Autism Resources for Community and Home (ARCH), in the region exists and HARP is actively exploring ways to collaborate in serving preschool and elementary aged students with ASD.

The Bennington School District located in the Southwest Vermont Supervisory Union has developed the ACORNS (Autistic Children with Opportunities for Reaching New Success) program. The program has been operational for four years. It was begun with the assistance of a grant from the Vermont Department of Education and the expertise of the Vermont Autism Society. Presently, there are 4 students (3 with ASD), Kindergarten through 4th grade in ACORNS. Next school year, two more kindergarten students will be entering the program. The program is staffed by one certified special education teacher with specialized training in autism and three paraprofessionals. Each student receives individualized one-on-one instruction based upon his or her specific needs. Group activities, such as morning meeting, also occur on a daily basis. Some students are

integrated into the regular education environment for some part of the day while other students remain in the ACORNS classroom all day. Services are also provided by an occupational therapist (one hour a week), adaptive physical education teacher (one time a week plus swimming once a week), speech and language pathologist (one time a week with 2 students and consultation with 2 students), and a physical therapist (one time a week with 1 student).

This year, the Bennington school district has also addressed the needs of the students with ASD at the preschool level. A preschool classroom has been created to meet the needs of these students. The class has a total of 15 students, 7 with ASD. There are two certified teachers, one with specialized training in autism, and three paraprofessionals in the classroom. Each certified teacher provides one-on-one instruction, based upon ABA principles, to the students with ASD. The amount of instruction is dependent upon individual needs. Students attend school three hours a day, five days a week.

Windham Southeast Supervisory Union has an Intensive District Program that supports approximately 19 students. However, not all of these students are on the autism spectrum. This program is designed to assist students in increasing functional life skills to attain as much independence as possible.

Brattleboro Union High School in the Windham Southeast Supervisory Union has a specialized program, The Farm, for students on the autism spectrum. This program was developed to address the individual needs of high school students. Presently, in its first year of operation, there are 11 students who receive all or part of their education in this alternative program. The program includes individual and group instruction under the direction of a lead teacher and one-on-one assistants.

The Rutland Northeast Supervisory Union has developed The Blue House, a specialized program for preschool and elementary-age students with ASD. Most students spend only part of their day at this alternative program, receiving one-on-one instruction, including discrete trial learning and Floortime, based upon individual needs. The staff includes a special education teacher with expertise in autism spectrum disorders and individual assistants for every student. There are, presently, six students in the program.

Once students have aged-out of the Blue House program, they enter Otter Valley Union High School where there are four alternative placements that serve all students with intensive needs, including students with ASD. These are: a) working farm; b) experiential learning program c) apartment; and d) individual tutoring. Programming is individualized for each student. It is the philosophy of this high school that it is more beneficial to the students and programs to hire certified special educators rather than individual assistants. The school has found that it is beneficial to replace two assistants with one certified special educator.

Some students with ASD are mainstreamed into the regular education environments throughout schools in Vermont. These students receive support ranging from one-on-one individual assistants who help them remain in the classroom to sporadic check-ins from

the teacher. There are also independent schools licensed in the state to provide services for students on the spectrum. There are other private entities that provide services to school districts through contractual arrangements.

Based upon this survey of school programs, some common themes began to emerge regarding the ingredients of effective programs including, but not limited to:

- Professionals with knowledge and understanding of autism;
- Skilled staff;
- On-going training for staff and parents;
- Low (e.g. 1:1 or 2:1) student/teacher ratio;
- Every staff person, within a program, is familiar with every child's IEP and behavior plan;
- Administrative support;
- Manageable caseload for case manager that allows sufficient planning time to supervise and train personnel, and work with the students;
- Available resources, including consultants;
- Classroom space that allows for individual work places that provides maximum privacy and limited distractions; space that allows for reduction in noise level;
- Team planning and regular team meetings;
- Programs that are individualized to address strengths and weaknesses, address the core deficits of autism; eclectic in use of approaches (discrete trials, incidental teaching, structured teaching, "floor time", etc.); include activities that motivate the child; provide structure, routine, and consistency;
- Planned teaching opportunities including one-on-one and small group instruction;
- Teachable moments wherever the student goes (cafeteria, bathroom, playground, classroom, hallway, etc.);
- Visual supports, such as daily schedules and choice boards;
- Use of social stories to facilitate social engagement;
- Inclusion in regular education environment when possible;
- On-going monitoring of progress;
- Individual behavior plans with reward systems based on a child's interests; and
- Daily communication with parents and/or caregivers.

The ability to provide effective supports in the home and community varies around the state. A full assessment of the effectiveness of community programs has not yet been completed. However, based upon initial visits to schools, parent support groups and community providers, some general statements can be made. The ability to provide effective services depends upon the availability of funding for services; the skills and knowledge of community providers regarding supporting individuals with ASD; levels of teaming across school, home and community providers; and the availability of

consultants or specialists with knowledge of ASD in the area. In areas where there are significant numbers of children with ASD, some agencies have been able to develop resources targeted at meeting the needs of individuals with ASD.

- ***What is the research basis for services to children with autism in the home, school, and community?***

This is a very broad question. Children with ASD are a very heterogeneous group (ranging from toddlers who are non-verbal with significant developmental delays to young adults with above average cognitive abilities, but significant social and relating challenges) living and being educated in diverse circumstances. Therefore, it is unlikely that any one approach will work for all children with ASD in all circumstances. The complexity of ASD affects research efforts and the treatments being researched. There are different bodies of research that address different aspects of service delivery to children with ASD and their families. There are bodies of research that address different age groups; school vs. home and community support; different diagnoses within the autism spectrum; specific treatment, intervention or educational strategies; and comprehensive program models. Also, different approaches are recommended for children and adolescents with Asperger's disorder. Recently there has been considerable research regarding effectiveness of early intervention for young children with ASD. These bodies of research answer different questions regarding effectiveness (National Research Council, 2001). A comprehensive review of existing research is beyond the scope of this paper; however, some of the most important research is summarized. A review of the research around early intervention for young children will be discussed first, followed by school age children, Asperger's disorder and then a discussion of the limitations of this research.

There is much controversy in the field regarding appropriate treatment, support and intervention for ASD. Many people have strongly held opinions regarding what is appropriate and most effective. Because the causes of ASD are unknown, the field has been particularly vulnerable to purported "cures" that do not stand up to scientific scrutiny. Different systems (developmental disabilities, children's mental health, FITP, schools, etc.) each have their own traditions and guiding philosophies regarding supporting children with disabilities. Some of the interventions reviewed may conflict with people's beliefs and philosophies. The following is a review of the current research. Readers are advised to maintain an open mind. Families and providers are faced with many choices when selecting supports and interventions. The current available research offers a basis of scientific support for selecting interventions that have a stronger likelihood of being effective.

There has been a recent push in both education and the social sciences to utilize evidence-based practices in order to maximize outcomes and cost-effectiveness. The Federal *No Child Left Behind Act*, promotes the use of scientifically based research to improve accountability and educational outcomes. Professional organizations, such as the American Psychological Association, are developing clinical practice guidelines, which promote the use of evidence-based treatments. Evidence-based practices are those

that are supported as being effective by high quality, peer-reviewed research. There is not a uniform standard in the education or social sciences for assessing the quality and quantity of research needed to determine that a given practice is evidence-based. A variety of standards has been proposed by the professional and scientific communities. A full discussion of the relative merits of these standards and research design is beyond the scope of this paper. The interventions discussed below have been reviewed using the framework for examining interventions (Chorpita, 2003) selected by the Vermont Autism Task Force. This framework is in Appendix I.

Research on early intervention for young children

There is still considerable debate in the field regarding the most effective interventions for young children with ASD. There are a variety of models and intervention strategies being promoted as effective interventions for young children (age birth to eight), although the supporting research focused primarily on children ages three to eight. The interventions range from applied behavior analysis to relationship-based models, specific skill-based intervention to physiologically-oriented interventions (Heflin and Simpson, 1998). This is not a complete list of all interventions used, but some of the most frequently cited. The following is a brief discussion of some of the interventions and the research regarding their effectiveness.

Behavioral Approaches:

Applied Behavior Analysis (ABA): ABA is a systematic approach for increasing desired behaviors and decreasing undesired behaviors, which is grounded upon the principles of learning theory. It is based upon the premise that behavior is influenced by environmental events. This understanding leads to structured interventions focused on measurable units of behavior. Data is gathered regularly for the purposes of assessment, monitoring of progress and guiding adjustments in intervention. ABA has a significant research base, which supports its effectiveness in addressing a wide range of behaviors and skills for individuals with disabilities, including ASD. There are a range of intervention strategies that fall under the ABA approach, including discrete trial training; verbal behavior training; pivotal response training; structured teaching; visual schedules; incidental teaching; peer-mediated instruction; video modeling; and Picture Exchange Communication System (PECS). A variety of national model programs for children with ASD are based on an ABA framework. Research supports the positive gains from these approaches and models in various areas such as social skills, communication and measured IQ. Because of differences in approaches and model programs based on ABA, however, general statements cannot be made about the effectiveness of ABA as a treatment for ASD. The research does support specific gains for specific interventions. In addition, while many children have made significant progress with interventions and model programs based upon ABA, not all children have benefited to the same degree and not in the same areas of functioning. The research cannot tell us at this point which interventions will work for which children. Despite these limitations in the current research, ABA has strong research supporting its effectiveness for addressing a wide

range of areas affected by autism spectrum disorders (National Research Council, 2001; Herbert, et al., 2002; Simpson, 2005).

Discrete Trial Training: Discrete trial training is one method, within the ABA framework, of teaching new skills. Each trial includes the presentation of a stimulus or teacher's instruction, the child's response, and the consequence. The consequence is based upon whether the child's response was correct or not. A correct response is reinforced with praise or a tangible reinforcer, while incorrect responses result in correction such as verbal feedback or physical guidance. The discrete trial format generally includes multiple trials teaching a specific behavior. Discrete trial training has been effective in initial teaching of a variety of skills. However, skills need to be quickly expanded to more natural environments to promote generalization. This is a teacher directed approach where the adult initiates the activity, determines the expected response and provides the reinforcement (Prizant and Wetherby, 1998). Support for discrete trial training comes from the Young Autism Program at UCLA. This program was initiated by O. Ivar Lovaas in 1970. Discrete trial training is a major component of the Young Autism Program. It is implemented by parents and trained therapists in a child's home during the first year, progressing to community and school settings. The focus is on developing language and early cognitive skills and addressing behavior issues. During the second year, more advanced skills are taught. The program involves at least 40 hours a week of intensive instruction. Research for this approach includes a study of 19 children who received this program for two years. There were two control groups, one with 19 children who received 10 hours a week or less of the ABA program and another in which 21 children received unspecified community interventions, but no ABA. Lovaas (1987) reports that 47% of the 40 hour per week ABA group were found to have IQ scores in the normal range and were reported to be functioning in typical grade classrooms without support. Only one child from either of the control groups demonstrated similar gains. Follow-up of these children at age thirteen, showed that 8 of the 9 high outcome students continued to have high IQs and were functioning unsupported in the classroom. A recent replication of the UCLA early intensive behavioral treatment program resulted in 48% of the children showing rapid learning, achieving average scores on measures of cognitive, language, adaptive and social skills and succeeding in regular education classrooms (Sallows and Graupner, 2005). This was a very well designed study, which adds support for effectiveness of early intensive behavioral treatment, of which discrete trial training is a major component. Other replication studies have showed positive, but more modest outcomes (Anderson et al., 1987; Birnbrauer and Leach, 1993; Smith et al., 2000); however, the treatment in these studies was less intense than that provided to children in the Lovaas study. The research by Dr. Lovaas is the basis for much of the desire for discrete trial training and intensive behavioral treatment for young children with autism. Discrete trial training is a well established intervention for teaching a variety of skills to children with ASD.

Picture Exchange Communication System (PECS): PECS is a structured program that involves a child exchanging a symbol, such as a picture, for a desired item. It can be expanded to using multiple words for labeling and commenting. Some children using PECS later develop speech. A number of studies show increased communication skills

after two years of PECS usage (Bondy & Frost, 1994; Ganz & Simpson, 2004; Schwartz, 1998; Charlop-Christy, et al., 2002). This intervention is based on behavioral teaching methods with an emphasis on encouraging the child to communicate spontaneously. PECS is a promising practice for enhancing communication.

Peer-mediated intervention: In peer-mediated intervention, peers are taught to initiate play with children with ASD through sharing, offering assistance, suggesting play ideas, and showing affection. Teachers remind peers to use their initiation strategies to facilitate play with their peers with ASD. Research indicates interactions increase, stereotypic behaviors decrease, time engaged with peers increase and initiations and responses to initiations by children with ASD increase (Lee & Odom, 1996; Strain et al., 1996; Royers, 1996). Peer-mediated intervention is a promising practice increasing social and communication skills.

Pivotal Response Training (PRT): PRT involves teaching pivotal behaviors or those central to a child's day to day functioning (e.g., motivation, responsivity to multiple cues, self-initiation, empathy, self-regulation, social interaction) with the ultimate goal of facilitating generalized improvements across contexts. The premise is that teaching pivotal behaviors should result in widespread positive effects on many other behaviors. PRT includes providing opportunities for a child to respond spontaneously to a clear question or instruction, interspersing maintenance tasks (those the child can do) with novel tasks (those the child will be learning), shared control or giving the child choice in selecting a learning task and structuring the environment so that the child can respond to multiple cues. It also involves use of natural consequences and reinforcers. This approach uses a behavioral approach to teaching in natural contexts, building on the interests and motivations of the child with ASD. Koegel, et al. (1999) explored whether teaching self initiations of interaction with others would result in positive outcomes for children with autism. Four children received a comprehensive program which included a modified discrete trial format, with the PRT described above, and parent education. Parent education was provided in the home, while the other interventions were provided in regular preschool programs. Five to seven years after the early intervention, all four children were functioning very similar to their age peers. They were in regular education classrooms achieving average to above average grades, involved in social activities with friends and involved in extra curricular activities. Their adaptive behavior, as measured by standardized assessment, was very similar to or above their chronological age peers. A comprehensive review of the research on PRT (Humphries, 2003) concluded that "the evidence supports claims that PRT is effective in improving the social-emotional and communicative behavior of young children with ASD. Therefore PRT is recommended as an evidence-based intervention for this purpose" (p. 5). PRT is a promising practice for increasing skills in a variety of areas affected by ASD.

Relationship-based models:

DIR (Floortime): Another frequently promoted approach is DIR (Developmental, Individual Differences, Relationship-based therapy or Floortime) developed by Stanley Greenspan and Serena Weider. DIR is a developmentally-based intervention that is

based upon the premise that early learning grows out of the intimate relationships with caregivers. The strategy involves starting where the child is at developmentally and building up skills by promoting and elaborating on communication interactions between the child and caregiver. The caregiver follows the lead of the child in a play situation and gradually encourages longer and more complex interactions. Support for this model of intervention is based on testimonials and a chart review of 200 children completed retrospectively by Greenspan and Weider (1997). They found that 58% of the children were deemed to have “very good outcomes” including purposeful organized problem solving interactions; increased trust and intimate connections with parents; displaying more pleasurable affect; and heightened capacity for abstract thinking. The research for DIR is not based upon experimental design, but was a retrospective chart review published in a non-peer-reviewed journal founded by the authors. A recent study on the use of a developmental, social-pragmatic language intervention, which incorporated many of the components of DIR, showed an increase in spontaneous language for 2 of 3 young children with ASD (Ingersoll, 2005). This was a well designed study which provides some preliminary support for this intervention to increase language. Additional research is needed to verify the effectiveness of this approach. DIR is a possibly efficacious intervention.

Relationship Development Intervention (RDI): RDI is a parent-based program developed to target deficits in “experience-sharing” in a systematic manner, resembling stages of typical development. After an initial evaluation of the child’s functioning, parents receive several days training from an RDI consultant. Training focuses on building motivation; modification of communication style; enhancing memory formation; development of user-friendly practice environments; and generalizing motivation and skills into everyday life. Through the use of videotapes of home sessions and live consultation, parents receive feedback and ongoing training. Later, the strategies are used with an individual peer and small groups. A preliminary evaluation of the effectiveness of RDI was conducted by Gutstein, developer of this intervention. It compared 17 children receiving RDI with 14 children receiving a variety of other interventions. The RDI group demonstrated significantly greater improvement in their scores on the Autism Diagnostic Observation Schedule (a diagnostic tool), diagnostic classification and classroom placement (Gutstein, 2005). This was based upon a retrospective study with methodological limitations. Additional research is needed to support the effectiveness of the intervention. Until further research is conducted, RDI should be considered an untested intervention.

Social Communication, Emotional Regulation, and Transactional Support (SCERTS): The SCERTS model is a comprehensive framework designed to enhance the communication and socio-emotional abilities of young children with ASD. The model was developed through collaboration of Barry Prizant, PhD., Amy Wetherby, PhD., Emily Rubin, MS, CCC-SLP, Pat Rydell, PhD., and Amy Laurent, OTR/L. The model has a developmental focus with the child’s functional needs and family priorities being considered while guided by research on child development. SCERTS focuses on building a child’s capacity to communicate and develop emotional regulation. It is an integrated approach that recognizes that the most meaningful learning experiences in

childhood occur in everyday activities across settings with a variety of partners. It is designed to encourage professionals to collaborate with each other and with families (Prizant, B, et al., 2003). This program's effectiveness has not yet been researched or reviewed by peers. Additional research is needed to support the effectiveness of the intervention. Until further research is conducted, SCERTS should be considered an untested intervention.

Skills-based interventions:

Social Stories: Social stories are short stories that describe a social situation and provide information about relevant social cues (e.g., what they mean and why they occur) to help an individual reflect on appropriate responses (Gray, 1995). They have been reported as effective for preschoolers through adults and particularly for those who have an interest in written or literacy-based material (Swaggart et al., 1995). They are used to teach social skills and appropriate behavior for particular situations. Research indicates fewer inappropriate social behaviors for children with ASD in the home and school setting following the use of social stories (Cullain, 2000; Kuoch & Mirenda, 2004; Kuttler et al., 1998; Norris & Dattilo, 1999; Smith, 2001; Swaggart, et al., 1995). Social stories are a promising practice.

Video Modeling: Video modeling is a visual strategy used to help a person understand the roles and responsibilities people take on in particular situations or how to perform a specific skill. A person with ASD watches a short video of an adult, peer or themselves performing an identified skill or task. Then the person is provided opportunities to practice that skill in his/her daily life. It has been used to teach skills such as greeting; naming or labeling; independent play; cooperative and social play; self-help skills; (Charlop-Christy et al., 2000), responding to questions and asking questions; and participating in a back and forth conversational exchange around a specified topic (Charlop & Milstein, 1989). It has also been applied to teach daily-living skills such as pet care, table setting and making orange juice (Shipley-Benamou et al., 2002). It has also been effective in teaching children to take the perspective of another person (Charlop-Christy & Daneshvar, 2003; LeBlanc et al., 2003). A review of the research on video modeling for children with ASD (Ayers & Langone, 2005) found 15 studies on this topic, with all but one showing positive results. Their conclusion was that video modeling is a promising tool for teaching social and functional life skills.

Facilitated Communication: Facilitated Communication (FC) is a method of supporting individuals with severe communication problems while they type messages. It involves providing physical and emotional support to the person typing. Considerable controversy surrounded this intervention as the authorship of the communication was questioned, given the level of physical support provided to the communicator. The use of FC has been rejected by much, but not all, of the scientific and professional community (Perry & Condillac, 2003, Hebert, et al., 2002, Simpson, 2005, American Academy of Pediatrics, 1998). "There are over 50 research studies of FC with 143 communicators. The American Speech-Language-Hearing Association (1994) has stated that there is a lack of scientific evidence validating FC skills and a preponderance of evidence of facilitator

influence on messages attributed to communicators”(ASHA Technical report, 1994, in National Research Council, 2001, p. 62). Additional problems also arose when parents or caregivers were accused of abuse by people using FC. “While the research studies do not support the validity of this intervention, there have been some qualitative studies indicating that some children with autism have learned independent communication skills through FC” (Beukelman and Mirenda, 1998, cited in National Research Council, 2001, p. 62). They further suggest that the lack of validation of FC should not dissuade teams from considering training in the use of augmentative and alternative communication systems including the use of keyboards. However, the goal must be independent use of the system without physical support and that communication prior to independence be viewed with skepticism and need for validation. There is a significant amount of research indicating that FC is not a valid method of communication. There are some studies that have shown a few individuals have learned independent communication through FC (Weiss, et al., 1996). While a limited number of organizations support the use of FC, most professional organizations do not.

Physiologically-based interventions:

Sensory Integration: There is a consensus in the research that individuals with ASD often process sensory information differently than those without ASD. Some of these differences include either seeking of/or aversion to sounds, touch, movements, oral sensations, pressure and sight. Sensory integration therapy involves providing sensory experiences that are designed to help the nervous system modulate, organize, and integrate information from the environment. This is supposed to allow for more adaptive responses to the environment. Reviews of existing research on the efficacy of sensory integration indicate that there is limited research with small samples and uncontrolled designs. Due to these limitations in the research, definitive conclusions cannot be drawn at this point. Additional research is needed. (National Research Council, 2001; Herbert, et al., 2003; Perry & Condillac, 2003; Baranek, 2002; Dawson & Watling, 2000). It is recommended that in designing supports, individuals with ASD be supported with strategies to cope with unusual sensory responses and/or that environments be modified to accommodate their sensitivities. In the absence of clear support for sensory integration, teams should identify expected outcomes from the intervention and use data to measure whether it is achieving the desired results. Sensory integration is currently an unsupported intervention.

Biological interventions: There has been considerable use of complementary and alternative medicine for children with ASD. Some of the interventions being used include chelation therapy; craniosacral therapy; vitamin therapy; casein free and gluten free diets; secretin therapy; immunotherapy; antifungal medicines; and others. To date the underlying physiological causes of ASD are unknown. There is not sufficient evidence to suggest that any of these alternative medicine approaches are effective and some can have negative side effects. (Perry & Condillac, 2003; Herbert, et al., 2003). These interventions are either untested or unsupported.

Medication: Some psychotropic medications have been prescribed for children with autism. They are not a cure for ASD, but may help diminish some of the symptoms of autism such as anxiety and aggression. There is evidence that some of these medications, such as risperidone, are helpful (McDougle et al., 2000 in Volkmar, 2005). Because of the potential side-effects, psychotropic medications should be used with caution and only as an adjunct to other educational and therapeutic approaches (Volkmar, et al., 2005; Herbert, et al., 2003).

The above research refers mostly to children with ASD age three to eight, although some interventions have been used with older children. There has not been significant research on interventions for very young children (birth to three), particularly since until recently, children were not often diagnosed until three or older. There is not enough research to conclude which interventions will be most effective with children birth to three. For very young children, their developmental level should be taken into consideration implementing interventions. One program, the Walden program, has used incidental teaching in an integrated toddler classroom for children, ranging from eighteen to thirty-six months. The children with ASD showed increases in verbal communication and playing near peers (McGee, et al., 1999).

Research on interventions for school aged children and adults :

There is fierce debate over which intervention options are the most promising for individuals with autism. Research has shown that no single method for teaching students with autism is successful for all students as every student with autism is a unique individual with a very different presenting profile. Over time, students' needs change and require changes, modifications and adaptations to interventions being used. "The list of intervention options for children and youth with autism is ever increasing, and this serves only to exacerbate the problem of professionals' and parents' abilities to choose the most efficient and effective treatment methods" (Heflin & Simpson, 1998, p. 194).

In its April 2002 *Congressional Appropriations Committee Report on the State of Autism Research*, the National Institutes of Health (NIH) stated: "Most research this far has been focused on young children and specifically on improving developmental functioning in the areas of language, basic cognitive skills, social functioning and daily living skills. Research is now needed on strategies to improve "real-world" functioning of individuals with autism, throughout their school-age years and beyond" (p. 19).

There has been little attempt to integrate findings for young children into a curricular foundation for school-aged children with autism. In Vermont, there is inconsistency of intervention practices and service delivery in school districts and in individual schools within the same district or supervisory union. Iovannone, et al. (2003) have reviewed reports that identified effective practices for individuals with ASD. Based upon these reports, the researchers have integrated and identified core components that should be included in comprehensive educational programs for students with autism spectrum disorder. They state: "Although the majority of the previous reviews focused on programs targeting young children (eight years of age and younger), we believe that the areas identified are consistent with effective practices for children of any age with ASD.

Although less information is available regarding the application of these practices with school-age children, there is no reason to believe that these broad core components would not apply to an older child” (Iovannone, et al., 2004, p. 153). The core elements/components include: 1) individualized supports and services for students and families; 2) systematic instruction; 3) comprehensible/structured learning environments; 4) specific curriculum content; 5) functional approach to problem behavior; and 6) family involvement.

1) Individualized supports and services for students and families

Students with autism spectrum disorder and their families are all unique and require individualized instructional supports to address their learning styles, interests, and culture. The IEP is the framework for developing the proper level of supports and services for each student. Services in school can range from full integration in the general education curriculum with minimal or moderate modification to a more functional lifeskills approach. No one program or instructional strategy will meet the needs of all students with autism. Services should be developed based upon individualized, comprehensive assessments of strengths and challenges. Therefore, schools and teachers must be flexible in designing programs that reflect the individual student and family.

2) Systematic instruction

Students with ASD need carefully planned instruction that identifies the educational goals, the procedures, the effectiveness of the teaching, and data collection.

3) Comprehensible/structured learning environments:

Students with ASD need clearly defined activities, schedules and environments. “A comprehensible environment allows a student with ASD (and others) to (a) predict what is currently happening within the learning process and what will happen next, (b) anticipate requirements of specific settings, and (c) learn and generalize a variety of skills” (Iovannone, et al., 2003, p. 158).

4) Specific curriculum content

The core deficits, in individuals with ASD, of communication and social interaction must be addressed in any program. The focus on curriculum content should be on the skills that are: 1) useful in the student’s life; 2) increase the student’s independence; 3) improve the student’s quality of life; and 4) increase the student’s competence.

5) Functional approach to problem behavior

Interventions for problem behavior should focus on assessing the function a behavior serves for an individual and replacing the behaviors with more appropriate alternative behaviors. According to the National Research Council (2001), in order for educational

interventions addressing problem behaviors to be successful, interventions should focus on replacing problem behaviors with an appropriate replacement or alternative that will serve the same purpose for the child. This functional behavioral assessment is the basis for developing behavior support plans according to a positive behavior support framework. Plans would include multiple positive interventions that prevent problem behavior from occurring, teach appropriate replacement behaviors, especially communication skills, change the way others respond to behavior, alter environmental triggers, provide positive environments and choice, etc.

6) Family involvement

Family members are usually the most stable people in the student's life. Schools need to develop collaborative relationships with families so that skills taught in the school environment can be generalized to the home and community with the help of the family. (Iovannone, et al., 2003)

Examples of School-based Programs:

Two program models have demonstrated effectiveness within school districts. The TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) model was founded in 1972 by Eric Schopler at the University of North Carolina Department of Psychiatry. It is a statewide program, preschool to adulthood, mandated by state law to provide a variety of services to individuals with autism and their families. TEACCH has regional centers throughout North Carolina. These centers set up and consult in specialized classrooms. There are hundreds of public school classrooms based on TEACCH principles. The classrooms are usually self-contained classrooms, set up in public schools, for students with autism. Strategies used in TEACCH can be adapted to regular classrooms.

The primary principles of TEACCH are:

- 1) understanding and respecting the characteristics of autism;
- 2) a reliance on the parent-professional collaboration, and
- 3) lifelong community-based services.

The educational approach is the use of structured teaching. The goals of structured teaching are to improve the level of skills, relying on specific interests and modifying the environment to address the deficits. Communication is also a main focus of the model. Communication instruction emphasizes generalization, functionality, incidental teaching, and alternative communication techniques.

No studies examining the effectiveness of structured teaching in the classroom have been found. However, the efficacy of structured teaching of preschool children in home-based programs has been researched. Ozonoff and Cathcart (1998, in Volkmar, et al., 2005) "found that students who received home-based structured teaching significantly improved on developmental and cognitive tasks in the areas of imitation, fine-motor skills, gross-motor skills, and nonverbal cognitive skills compared to students who did not receive this

type of intervention at home. In addition, the experimental group exceeded the control group on other developmental measures by two to three times and gained 9.6 months after 4 months of treatment” (p. 1050). Short (1984, in Volkmar, et al., 2005) “compared behaviors of children during the waiting period for treatment and then after their parents had received training in structured teaching and implemented these methods at home. These children showed significant increases in appropriate play, work, communication, and social interactions compared to their behavior during the waiting period” (p. 1050). According to Harris, et al. in *Handbook of Autism and Pervasive Developmental Disorders* (Volkmar, et al., 2005), “Although both of these studies evaluated the use of the methodology at home, they also lend support to the effectiveness of structured teaching as an educational approach to children with autism.” (p. 1050).

The Denver Model at the University of Colorado Health Sciences Center was started by Sally Rogers in 1981. The model is based on the main deficits of autism as outlined by Rogers and Pennington (1991 in Volkmar, 2005). These deficits include skills such as imitation, emotion sharing, theory of mind, and social perception. The Denver Model provides educational consultants to public schools that educate children with autism in an inclusive setting. The Denver Model has demonstrated efficacy in educating children with autism. Rogers and Lewis (1989, in Volkmar, 2005) found that “children with both autism and pervasive developmental disorder showed significant developmental changes in cognitive, social-emotional, perceptual-motor, motor activities, symbolic play, and social relatedness beyond what would be expected for the passage of time after about 7 months of treatment. The treatment gains were maintained after 12 months” (pp. 1050-1051).

There is not much research available on effective programs for educating transition age youth. As children approach adulthood, the focus of instruction should shift to preparing for adult roles in work, college, community living and recreation. Adolescent issues regarding relationships and sexuality should also be addressed. As youth move towards adulthood, models of support should move towards supporting people to be as independent as possible and having as much control and self-determination as possible. Careful planning for transition to adult life is needed. Transition planning is mandated as part of IDEIA, which requires a focus on preparing the student for successful adult living.

As noted previously, individuals with ASD are a very diverse group. The current available research for school aged children cannot identify which interventions work best for which subgroups of children or an individual child with a specific profile. All interventions need to be tailored to the specific strengths and needs of individual children.

Services for Individuals with Asperger’s Syndrome

Asperger’s syndrome, AS, (called Asperger’s Disorder in the DSM-IV) was first identified in 1944 by Hans Asperger; however, it received little attention as a clinical diagnosis until 1981 when Lorna Wing from the United Kingdom coined the term Asperger’s syndrome. It was not recognized as a distinct clinical disorder in the United States until 1994 when it was classified in the DSM-IV. Because of its relatively recent

classification, there is currently little research regarding effective interventions for Asperger's syndrome (Safran, et al., 2003). However, there are a variety of clinical treatment interventions recommended in the professional literature. While there is overlap with interventions recommended for children with other pervasive developmental disorders, there are some differences in approaches related to the relatively preserved cognitive and language abilities of individuals with Asperger's. Individuals with Asperger's share the difficulties with social interaction and restricted repetitive behavior or interests that those with autism have, but they do not have cognitive or language delays. However, their difficulties do cause significant impairments in social, occupational or other important areas of functioning (DSM-IV, TR, American Psychiatric Association, 2000).

As with supporting any individual with special needs, the first step in the process includes a thorough assessment of the person's strengths and challenges. Then an individualized intervention approach can be developed based on the person's assessed needs. As with other autism spectrum disorders, no single intervention approach is going to be successful for all individuals with Asperger's. Ongoing monitoring of effectiveness of a chosen approach should be an integral part of the program. Below are some of the interventions recommended in the professional literature.

The most significant feature of Asperger's syndrome is difficulty understanding and following social rules for interacting. While typically developing children acquire this understanding relatively easily through ongoing social interaction, children with AS must be specifically taught how to interact with others in the socially accepted manner. There are a number of strategies designed to teach these skills. One of them is Social Stories developed by Carol Gray. These were discussed previously (page 35) as a technique for intervention for children with ASD. They are particularly useful for children with AS who are generally good readers. Other ways of teaching social skills include social skills groups, role playing, video modeling, peer-mediated instruction, pivotal response training, and computer programs that help with recognizing emotions or subtle non-verbal cues. The Relationship Development Intervention (RDI) and the SCERTS models, discussed previously, are additional models that can be used for addressing social skills. There are also a variety of social skills curricula available commercially. Regardless of the strategy used, the child will need ample opportunities to practice their newly acquired skills in everyday settings. These opportunities can be promoted by having an aide available in school to act as a coach or by educating teachers, peers and family members regarding skills being addressed so they can be encouraged in real situations. Social skills are not an end in themselves, but must lead to meaningful outcomes such as being effective and successful in relationships, school, work, leisure and independent living. Interventions should be evaluated in terms of approaching these outcomes (Volkmar, et al., 2005).

A child with AS may need some accommodations to achieve academic success. Some children have difficulty with motor coordination and may need to use a computer to complete written assignments. Some children with AS have sensory sensitivities that need to be accommodated. They may need quieter, less distracting environments. They

also should be taught how to cope with their sensory sensitivities. They may need graphic organizers, written schedules or instructions. They may also need visual schedules that support understanding their routines and also preparing them for any changes in it. Teachers may need to alter their communication style to accommodate the unique way of understanding by the child with AS. Also, careful planning of transition from school to college or work and adult living will be needed. (Safran, 2003)

Children and youth with AS are particularly prone to additional mental health difficulties, most commonly anxiety and depression, which research indicates at rates as high as 65% (Volkmar, et al., 2005). Anxiety results from not understanding how to navigate the social world, repeated failure in social situations and fear of additional failures. When a child reaches adolescence and peer relationships become very important, the child can experience depression related to low self-esteem, struggles to “fit in” and lack of friends. Frustration and anxiety can also lead to rage behavior involving tantrums or aggression. There are a number of recommended interventions to address or prevent these issues. (Volkmar, et al., 2005)

The primary prevention strategy is the teaching of social skills to help the child gain what he needs to be successful in social situations. Additionally, medication may be indicated to help address symptoms of anxiety or depression. These should be used together with other strategies to address the underlying causes. Cognitive Behavioral Therapy is one possible intervention. The focus of this therapy would be on learning to regulate one’s emotions, learning alternative coping strategies, social skills, perspective taking, conflict resolution and/or friendship skills. Skills then have to be applied in real life situations (Attwood, 1999). Some additional strategies include setting clear expectations and limits; teaching self-monitoring of anxiety and allowing planned breaks when anxiety builds up; scheduled breaks in the day; teaching relaxation techniques; and other emotional self-regulation strategies. Children with AS often have difficulty during unstructured times of day such as lunch and recess. Specific plans for these times are needed. Plans might include eating lunch with a selected Circle of Friends or spending part of the free time in the library pursuing personal interests. Having an adult mentor or ally in the school to help the child resolve problems and conflicts can be helpful as well. Educating teachers, peers, family and community members in understanding the diagnosis, its impact on the child and teaching others how to accommodate the child’s issues can go a long way in promoting acceptance and inclusion. This can also help prevent teasing and bullying of which children and adolescents with AS are too often the target. Schools also need to enact and enforce strong anti-bullying policies (Safran, 2003; Volkmar, et al., 2005). (See Vermont Education Law Title 16 §11(a)(32).

Individuals with Asperger’s syndrome are often very intelligent and creative people with special talents on which they can capitalize. With proper support and encouragement, individuals with AS can lead fulfilling, independent and productive lives. Without proper support, a person may end up un- or underemployed, socially isolated and dependent or develop serious secondary mental health problems.

The interventions discussed above are based mostly on clinical experience rather than research. Due to the limited research currently available on effective interventions for Asperger's syndrome, it is recommended that the team continually evaluate selected interventions for effectiveness with individual children.

Discussion and summary of the research

Considerable research has focused recently on answering the question of the most effective methods of early intervention services for young children (birth to eight) with ASD in their homes, school and community. There continues to be much debate in the field about which approaches are most effective. There are a variety of issues that should be discussed regarding the current state of available research. Both Prizant and Wetherby (1999) and the National Research Council (2001) have discussed the limitations in the current available research regarding effective intervention for young children. The following is a discussion of these limitations.

- Research has supported the effectiveness of a range of approaches that differ considerably in philosophy and practice.
- Research comparing one treatment to another using matched samples of comparison groups randomly assigned to different treatments do not exist. Therefore, statements of relative efficacy cannot be made.
- No one approach is equally effective for all children. Even in studies reporting very good outcomes, not all children achieved the same results (e.g. 47% in Lovaas (1987) and 58% in the Greenspan (1997) achieved high outcomes.)
- The characteristics of the children in studies described in the literature are quite limited, making generalization of the results difficult.
- There are methodological shortcomings in the available research, such as lack of appropriate experimental design, lack of matched control group, lack of use of standard assessment tools for measuring pre and post level of functioning, etc.
- There are numerous measures of outcomes presented in the literature, with a lack of consensus regarding appropriate, meaningful outcomes. The definition of "intensity of treatment" is variably defined and current research cannot conclusively state how much of what treatment is an appropriate level of intensity.
- There is much overlap in approaches, making it difficult to identify the critical elements which result in the best outcomes.
- Fidelity of treatment has not been typically measured in the research. Fidelity of treatment refers to whether the treatment procedures described in the study are in fact what was actually being provided to the children.
- Studies have not documented or accounted for other variables outside of the treatment package, such as what is happening outside of the school day; family variables; medical interventions; alternative treatments; etc.

These shortcomings in the available body of research make it difficult to make definitive statements regarding the most effective interventions for young children.

Despite the limitations of current available research, a summary of the findings for early intervention will be provided. The National Research Council (2001) commissioned a review of the available research regarding educating young (birth to eight) children with ASD. The committee included national leaders in autism research and intervention. The National Research Council (2001) concluded that research strongly suggests that a substantial subset of children with ASD made marked progress when receiving intensive early intervention. Some model programs report a portion of children progressing to near normal functioning. “However, the research to date is not at a level of experimental sophistication that permits unequivocal statements on the efficacy of a given approach, nor do data support claims of ‘recovery’ as a function of early intervention” (National Research Council, 2001, p. 166). Nor are there research studies showing that one method or intervention is superior to another.

The National Research Council (2001) indicates in a review of national model preschool programs that there is strong consensus that the following features of a program are critical:

- “Entry into intervention programs as soon as an autism spectrum diagnosis is seriously considered;
- Active engagement in intensive instructional programming for a minimum of the equivalent of a full school day, 5 days (at least 25 hours) a week, with full year programming varied according to the child’s chronological age and developmental level;
- Repeated, planned teaching opportunities generally organized around relatively brief periods of time for the youngest children (e.g., 15-20 minute intervals), including sufficient amounts of adult attention in one-to-one and very small group instruction to meet individualized goals;
- Inclusion of a family component, including parent training;
- Low student/teacher ratios (no more than two young children with ASD per adult in the classroom); and
- Mechanisms for ongoing program evaluation and assessments of individual children’s progress, with results translated into adjustments in programming” (National Research Council, 2001, p. 219).

Programs should focus on the core deficits of autism, specifically communication and social skills and learning to attend to and engage with the environment to promote learning.

In conclusion, there is strong support for intensive early intervention for preschool age children with ASD. While there are still questions regarding the most appropriate interventions, the strongest scientific support is for programs based upon ABA. Other interventions such as DIR and RDI show some promise, but do not yet have sufficient evidence to support their efficacy. Research also shows more modest gains when

interventions are started after preschool (Handleman & Harris, 2000). If intensive early intervention results in half the children functioning at a near typical level, in addition to the obvious benefits for the children and their families, the savings to the state in special education and human services costs over the lifespan would be substantial.

There has been less research regarding the most effective practices in supporting school age students with ASD and children with Asperger's syndrome. Additional research is needed before conclusive statements regarding evidence-based practice for supporting school age students and children with Asperger's syndrome can be made.

In considering appropriate services for children with ASD and their families, it is important to keep in mind that evidenced-based practice, while extremely important, is not the only consideration for deciding appropriate intervention and support, either from an individual standpoint or policy level. Additional best practice parameters should also be considered. These include whether the interventions are easily taught, replicable and adaptable to community environments; whether they are consistent with the values of choice and control, self-determination and community living; whether the methods are respectful for the child/youth and family's dignity, priorities, culture and involvement; and whether they are cost effective. (UCEDD checklist, 2005) They should also be individualized, based on an assessment of a child's current strengths and needs. Interventions should also be based on knowledge of typical child development (Prizant & Rubin, 1999). Once an intervention is selected, the effectiveness of the intervention for an individual should be evaluated on an ongoing basis, with adjustments made accordingly.

- ***What are the current service designs and capacity levels in Vermont?***

There were 540 children ages three through twenty-one identified with ASD on 12/1/05 receiving special education services. Many of these children also receive some type of support in the home through the Agency of Human Services. An additional 9 children from birth through three were receiving Family, Infant and Toddler Program services. Services in schools vary depending on individual student needs and available resources in the school. Due to the rising population of students on the autism spectrum, some schools have developed their capacities to meet the needs of these students by developing specialized programs or bringing in additional resources. Human services agencies supporting children and their families in their homes are also working on developing their capacities to serve this population. However, adequate services are not universally available throughout the state. Expertise is available in some programs and not in others. When specific expertise is not available in a program, sometimes the program can contract with a consultant, such as an OT, SLP, behavior specialist, etc. However, outside consultants are not readily available in all areas of the state. There are not currently enough educators, SLPs, OTs, psychologists, doctors, psychiatrists, case managers, paraprofessionals, vocational specialists, etc. with expertise in educating and supporting people with ASD. Children are sometimes offered what is available rather than what may meet their needs.

Children with ASD need individually designed interventions and supports. In a small rural state, it can be a challenge to develop a range of options to meet those individual needs within a school or community program. Schools and other human services agencies would benefit from increased availability of consultants and clinicians to help design and support their programs. Also, additional training of in-house professionals would also be beneficial.

- ***Which model approaches should Vermont highlight?***

No one approach is appropriate for all individuals on the autism spectrum or even for the same individual across his/her lifespan. For young (birth to eight) children with ASD, the strongest research supports intensive early intervention, using strategies based on applied behavioral analysis. Programs should be based on the recommendations of the National Research Council (2001) noted on page 44 of this document. Intensive early intervention, as soon after diagnosis as possible, needs to be available to all children with ASD throughout Vermont.

For older school age children, there is not sufficient research to support one type of intervention over another. A range of options is needed to support students in the least restrictive environment. A summary of available research on services to school age children identifies some of the core components of effective services. The core elements/components include: 1) individualized supports and services for students and families; 2) systematic instruction; 3) comprehensible/structured learning environments; 4) specific curriculum content; 5) functional approach to problem behavior; and 6) family involvement (Iovannone, et al., 2003). These are discussed in more detail on pages 38-39 of this document. Additional ingredients of effective programs are noted on page 29.

Highlighting model approaches would involve providing accurate information regarding effectiveness, promoting their use through training, and facilitating systems changes to increase access to these approaches. Vermont should highlight some of the intervention strategies with the most research support, including interventions based on ABA, early, intensive behavioral treatment, discrete trial training, TEACCH, structured teaching, Picture Exchange Communication System, Pivotal Response Training, peer-mediated instruction, Social Stories and video modeling. These are practices supported by research as being effective, which may be appropriate depending on a child's age and specific needs.

There are other interventions that have less evidence of their effectiveness but may be appropriate for some individuals. These include, SCERTS (Social Communication, Emotional Regulation, and Transactional Support), RDI (Relationship Development Intervention), and DIR/Floortime (Developmental, Individual Differences, Relationship-based). When using approaches with less scientific research support, teams should gather data and reassess the effectiveness for individual children on an on-going basis.

While some strategies are appropriately used across settings, supporting children with ASD and their families in their homes and communities generally requires a different

approach to service delivery than school services. Services provided in a home setting must be family-centered. Families may need a variety of supports such as information about the diagnosis and treatment options, parent training, emotional support, assistance with accessing resources and services, and training and support around advocating for their child. These are discussed in more detail on pages 60-63. Also, to maximize the effectiveness of interventions, services in the school and home should be well coordinated. Research shows better outcomes for children whose parents have received training in interventions. Parent training should be available.

3. How are roles differentiated among and within the major agencies serving these students?

- ***What services are provided by schools?***

See second bullet under question 2 on pages 18-19.

- ***What services are provided by community mental health agencies through mental health or developmental services programs?***

See second bullet under question 2 on pages 19-25.

- ***What services are provided by other agencies including private nonprofits?***

There are few private nonprofits in Vermont that provide services and/or interventions that are specifically for students with ASD and their families. The Philo Center, founded as a non-profit in 1999, is located in Shelburne, Vermont. The center provides occupational therapy and speech-language therapy to children and young adults with disabilities including autism.

The following non-profits provide family support:

- ARC– provides support and information to families of individuals with special needs;
- ARCH (Autism Resources for Community and Home) of the Upper Valley – support group that provides information to families of children with autism;
- Autism Society of Vermont – provides information and support for Vermonters with ASD and their families, service providers and other interested citizens;
- Parent To Parent of Vermont – families are matched with trained parent volunteers who provide information, resources, and emotional support;
- Vermont Achievement Center – provides child care information including referrals and subsidies for child care; Early Education and Care Program for children from six weeks through twelve years of age; and Kid Konnections, a before and after school program in Rutland area schools;

- Vermont Parent Information Center – statewide network of support for families of children with disabilities.

- ***What are the major service gaps?***

A questionnaire was distributed at the annual Vermont Summer Institute on Autism Spectrum Disorders (2005). This is the largest annual gathering of professionals and family members involved with individuals with ASD in Vermont. A total of 154 people responded to the questionnaire. The following are areas in which at least 40% of the respondents felt there was a significant gap in service.

General:

- Availability of information regarding where to locate resources to provide services
- Information/assistance with transition from school to adult life
- Coordination of home and school services

In schools:

- Availability of paraprofessionals in school with sufficient training and background in ASD
- Availability of consultants to design specialized services

In the home and community:

- Availability of funding for services/supports outside of school
- Availability of direct support staff (respite, personal care workers, community support workers, employment workers, in-home support workers) with sufficient training and background in ASD
- Availability of behavior specialists, other clinicians and consultants to design specialized services
- Availability of people to provide training to teams
- Support groups for individuals with ASD
- Crisis support

Additional information on gaps in the system was gathered through meetings with Family, Infant and Toddler state and local agency staff; Child, Adolescent and Family Mental Health Services Directors and State Division staff; parent support groups around the state; visiting school programs; discussions with some developmental service agency staff; and input from the Autism Task Force. Some of these gaps have been identified in previous sections.

When a child is first diagnosed with ASD, families need both information and emotional support. Families and service providers need easy access to information regarding the diagnosis, prognosis, options for treatment and intervention, available resources and parent support groups, etc. There is a lot of information regarding autism spectrum disorders available, but sorting through it all can be daunting. Also, locating resources for support and intervention often takes much searching. There is not currently a place in Vermont where people can go to get the most up to date information, all in one place.

Parents have expressed frustration with this, especially at a time when they are dealing with emotional aspects of discovering that their child has a significant disability.

There are some gaps in services that are common to all schools and community programs. Major gaps include not having sufficient number of trained staff at all levels to provide the needed supports. This includes direct support staff, case managers, behavior specialists, psychologists, psychiatrists, occupational therapists, physical therapists, speech-language pathologists and specialists who can provide training and support to direct support staff and families. There are some training opportunities and higher education courses available for these professionals, but time and costs are sometimes barriers to accessing them. Teams need assistance in selecting interventions that match the needs of individuals with ASD and training in how to implement these interventions. The programs generally require a specialist who can design, monitor and troubleshoot strategies so that they are effective. The time, personnel and financial resources needed are often greater than is typically available within the existing systems of support.

As the number of students diagnosed with ASD has increased, schools throughout Vermont have begun to develop educational services to meet the unique needs of these students. Some school programs have developed effective programs to meet the needs of students with ASD. However, a number of schools continue to struggle to provide appropriate programs/services for these students. This is particularly challenging for smaller school districts that only have a few students on the spectrum. In some schools, there is a lack of trained personnel who have an understanding of autism. Many school personnel feel that they “reinvent the wheel” for every student on the spectrum. Vermont does not currently have best practice guidelines to assist schools in designing educational services for children on the spectrum. Schools often rely on individual aides to provide instruction to students with ASD; sometimes, without providing them adequate supervision, support, or training. Services vary from school to school, depending upon the availability of trained consultants. There are few alternative programs for students on the spectrum. Many schools lack the space needed to provide a safe environment away from distractions, for individualized instruction, occupational and physical therapy, and speech language services.

Intensive services for ASD can be quite costly, creating pressure on school budgets. The law requires that a “free and appropriate public education” or FAPE must be provided by schools, regardless of cost. However, interpretation of the *Rowley* case (1982 in Volkmar, et al., 2005) indicates that the “optimal” level of services does not need to be provided. Special education law does not require that school districts provide every possible service nor does it specify which services to provide. School districts may opt to provide services that will adequately meet the individual needs of a student with ASD. This decision, between two equally effective educational programs, may be based upon costs if the student is benefiting educationally from the less costly of the two programs. Thus there may be a gap between the level of services desired by the family and what schools are legally obligated to provide.

Another area that is challenging for individuals with ASD and their families is transition. This includes transitions from FITP to EEE to elementary to middle to high school to adulthood. Individuals with ASD often have difficulty with changes in people, places and routines. Therefore, they need carefully planned transitions. There may be a need to provide more intensive supports for a time, even after things have gone well for a relatively long time. This includes planning as the individual with autism moves from one grade to another. Teachers need to be actively involved prior to the child entering their classrooms. The school administration and new team members need to have sufficient time available to commit to this process. When youth are exiting school, they and their families need information regarding options for support in higher education, work and living arrangements. There needs to be a more coordinated effort among all agencies, parents, and caregivers to ensure that participants have a clear understanding of the child and programs as the student transitions into the new environment and program. Families have indicated that there are gaps in ensuring smooth transitions. This varies from school to school and from region to region of the state. Some areas have systems in place to ensure smooth transitions and others do not.

The National Research Council (2001) in *Educating Children with Autism* recommends at least 25 hours a week of intensive early intervention as soon as a child is diagnosed. If diagnosis occurs prior to age three, the Family, Infant and Toddler Program is responsible for coordinating services for the child and his/her family. However, 25 hours a week of active engagement in intensive instructional programming is considerably more service than children in FITP generally receive in Vermont and the personnel and financial resources to provide this amount of service are not readily available through either FITP or other sources. When a child turns three, schools become responsible for providing a free and appropriate public education (FAPE) to children with disabilities. Essential Early Education programs typically provide 3-5 half days a week of a preschool program and some additional home visiting for parent education or support. The preschool program may or may not be an intensive program and is frequently less than the recommended minimum of 25 hours a week. Many children with ASD have access to Children's Personal Care Services, however, issues related to hiring, training, retaining, and supervising these workers limits the usefulness of this service for providing an intensive early intervention. Additional resources through the Agency of Human Services to add to FITP or EEE services are also not readily available. Access to intensive early intervention as recommended by the National Research Council for children with ASD, ages birth through eight, is not widely available in Vermont. To date, the state systems of care for children have not identified this issue as a gap in the system. There is not yet a consensus that this issue should be addressed, nor a commitment to develop the infrastructure needed to provide these services.

There are some gaps that are specific to the community services providers. In the Family, Infant and Toddler Program, a number of issues have been identified. FITP historically has been a program that provides information, training and support to caregivers, at home or in childcare settings, in fostering the development of young children with disabilities. The recommendation to provide intensive early intervention services is in contrast to the type and intensity of services generally provided within

FITP. The program has been attempting to fill the gaps, but there is not currently a readily available system of supports that can be provided soon after a child is diagnosed. The program will authorize funding for 1:1 staff when a plan of treatment has been developed which requires that level of staffing to implement. However, there are some difficulties with determining who will actually hire the staff person. The program has secured additional funding for developmental educators to provide two hours a day of specialized instruction for children who need this. FITP has an ASD consultant available to teams around the state, but the programs vary in the availability of staff and access to related service providers with sufficient knowledge and training around ASD and time to implement intensive programs. There is also a significant issue with transition to school services at age three. If a child is diagnosed at age two and a half, it can be difficult for an FITP agency to set up a comprehensive program that is only to be in place for a few months. A specialized program that is working for the child might not be continued when the child transitions to an early education program within the school system. While schools are required to participate in the transition process, they are not obligated to continue the child's services as set up in FITP. This transition can be very disruptive to the child's progress.

Another gap in service is providing support for children and their families in the home and community. Depending on individual and family needs, there may be a need for case management; respite; support for participation in the community; skills instruction; clinical support; crisis support; parent training; etc. As noted previously, some of these services may be available to some individuals and their families. There are financial limitations in all community programs. Developmental services and children's mental health programs operate within capped budgets with specific priorities regarding who receives services. Children, newly applying for developmental services, can receive only minimal services. Comprehensive services are only available if a child is at risk of institutionalization in a psychiatric hospital or nursing home or is in DCF custody. Services in children's mental health are prioritized to those with the most acute mental health needs. Even when a child can receive comprehensive services through mental health or developmental services, there are challenges for supporting children who have ASD and additional mental health diagnoses. These challenges are related to deciding which program has the best expertise to support the child and who has the financial obligation to pay for supports. Personal care services are available to most children with ASD, but they only fund a worker with no benefits, training, supervision or clinical support. The majority of personal care assistants are hired, trained and supervised by families. For some families this is an additional responsibility, which they may not want. Within all the community service programs, locating, training and retaining skilled providers is challenging. In summary, while there are a variety of sources for support within home and community, no one entity has been designated to address the needs of individuals with ASD. A funding source that matches the specific needs of individuals with ASD is not always available.

Parent education has been identified as an important component of successful programs. Outcomes are enhanced when families can integrate the interventions into the home and community. Opportunities for parent training are limited within community programs.

FITP is oriented to providing direct training and support to families and has staff specifically hired for this purpose. Essential Early Education (EEE) programs also provide a limited amount of home visiting for support and instruction. Some school districts will offer training to families to carry-over interventions being used in school. Parent-to-Parent of Vermont and the Vermont Developmental Disabilities Council also provides funds for parents to attend training. While informative, one time training at a conference is generally not sufficient for families to implement strategies in the home. Hands-on instruction, practice, monitoring, and feedback are also often needed as well. This is not readily available due to a lack of available professionals and sources of funding.

Another gap in the statewide service system is collaboration between school and home. The level of collaboration varies around the state and from situation to situation. In some situations, there is no collaboration at all. In other situations, community agency staff may attend school meetings and each team is aware of the support, treatment and educational goals of the other, but there is no attempt to align goals, use similar interventions or ensure consistency across environments. In a few situations, teams share goals, interventions and consultants to ensure a consistent program across the child's day. Sometimes, there are philosophical differences regarding appropriate approaches between the school and home services that can get in the way of coordinated, consistent services.

- *What are the areas of shared or overlapping responsibility?*

The Vermont Department of Education (DOE) and Vermont Agency of Human Services (AHS) signed an Interagency Agreement pursuant to Part B of the Individuals with Disabilities Education Act (IDEIA) in June 2005. The following is stated as part of the agreement: "The interagency agreement outlines the provision of services to students who are eligible for both special education and services provided by AHS and its member departments and offices including Department of Health (VDH), Department for Children and Families (DCF), Department of Disabilities, Aging and Independent Living (DAIL), Department of Corrections (DOC), and Office of Vermont Health Access (OVHA).

The DOE, the local education agencies (LEA) and AHS work together to assure that children and youth with disabilities, ages 3-22, receive services for which they are eligible in a timely and coordinated manner. Ultimate responsibility to ensure a free and appropriate public education (FAPE) to students with disabilities lies with DOE and responsibility to provide a FAPE lies with the LEA. AHS is responsible for supporting students and their families toward successful outcomes in their broader functioning consistent with federal law including 34CFR §300.142 as well as state law. These agencies will work together to assure the needs of eligible students with disabilities are met, services are coordinated and integrated, funds are efficiently used, and a dispute resolution process is in place to resolve interagency policy and funding disputes when a conflict arises.

In recognition of the importance of providing a smooth transition from education to adult life, transition services for eligible students will be community-driven, involve a comprehensive system including AHS, DOE, employers, the workforce system and youth and their families. These services will be provided with the intent to increase the number of youth with disabilities entering employment, further education, and independent or supported living.” (p. 2) The DOE and AHS are in the process of establishing systems to implement this agreement.

At the present time, the DOE and AHS are rewriting the Interagency Agreement pursuant to Part C of IDEIA. Part C, which is implemented through the Family Infant and Toddler Program (FITP), provides for early intervention services for infants and toddlers with disabilities and their families. AHS and DOE share the responsibility for implementation.

AHS contracts with 12 Regional Host Agencies to carry out most of the Federal and State requirements to assure that Vermont meets or exceeds the rules associated with Part C of IDEIA. Each host agency has a regional planning team that advises and assists in setting goals and priorities; assuring services are early; effective for the child and family; collaborative across agencies or systems; and of high quality. The host agencies provide and coordinate the majority of the services. The responsibilities of the local school districts to children from birth to age three and their families are: (1) “child find” and (2) participation in transition planning for children from FITP to EEE services. The LEA must also ensure that the child transitioning from FITP to EEE has an Individualized Education Program (IEP) in place by his/her third birthday in order to meet Part B compliance.

There are some areas where it is less clear where responsibility lies. For example, the National Research Council (2001) recommends at least 25 hours a week of intensive early intervention as soon as a child is diagnosed with an ASD. As noted previously, this level of service is not readily available in most areas of the state. For children under age three, the Family, Infant and Toddler Program is responsible for providing services to the child and his/her family. When a child turns three, schools become responsible for providing educational services. Most human services agencies are not currently structured to provide intensive early intervention. Are schools responsible for providing this level of service or should the additional services be the responsibility of an agency within the Agency of Human Services? While educational services are an entitlement, there are not currently any services which children over three are universally entitled to within the Agency of Human Services that would provide an intensive early intervention. If state policy makers agree that this type of service should be available, decisions need to be made regarding responsibility for developing and funding this service.

For older children who are in school full time, schools are responsible for providing a FAPE. The United States Supreme Court interpreted the provision of FAPE in its ruling on the *Rowley* case in 1982. According to the court’s ruling, judges and hearing officers must determine if the school’s program is “reasonably calculated to provide some educational benefit.” According to Mandlawitz in *Handbook of Autism and Pervasive Developmental Disorders* (Volkmar, et al., 2005), the courts have ruled that schools need

to provide services that are more than the minimum; however, schools do not need to provide “optimal” services. The court rulings provide some general guidelines to school districts. However, the decisions still leave considerable gray area regarding the definition of “appropriate” services. In some cases, the school day may be insufficient to ensure the child’s learning. In some of these situations, schools are being asked to provide extended day or extended year programming. Mandlawitz states (in Volkmar, et al., 2005), “Provision of FAPE may not be confined to the bounds of a normal school day or school year. The decision to provide extended day or year services is made by a team of professionals and the parents and is based on considerations such as possible regression during periods away from school or assessment of the rate of educational progress.” (p. 1164) However, it remains unclear exactly when schools would have a responsibility to provide additional hours of service beyond the regular school day. Special education regulations do require the provision of summer services if the child will regress over the summer. Additional services in the home or community may or may not be available through programs funded through the Agency of Human Services as these are not entitled services. It can be challenging to decipher when a need beyond the school day is an educational one versus when there is a need for family support in the home.

There is also some potential overlapping of responsibility between developmental services and children’s mental health for children with ASD. A child with ASD who has additional mental health issues could potentially be eligible to receive services from either developmental services or children’s mental health. A consistent procedure for sorting out the responsibility for these children has not been established at the local or state level.

4. What is the current and projected need over the next five years?

Current Department of Education data indicates that there are 540 children and youth (three to twenty-one) who are identified with Autism Spectrum Disorders in Vermont. Vermont has seen an average annual increase of 20% in students identified as being on the Autism Spectrum over the past 8 years, even while the total student population has decreased. It is presumed that this trend will continue. Using a 20% increase as an estimate over the next five years, reveals that more than 1,343 children and youth will be identified as being on the Autism Spectrum by 2010.

In March 2005, the Vermont Higher Education Collaborative Board, estimated that over the next five years, 2,500 professionals will need training to meet the demands of individuals on the autism spectrum. An additional 150-200 ASD case managers and 50-80 “expert” consultants will be needed.

The Government Accountability Office released *Special Education Children with Autism* on February 14, 2005. According to the Special Education Expenditure Project, SEEP, the estimated expenditure per child, ages six through twenty-one, with autism was \$18,790 in the 1999-2000 school year. For the same school year, the per student expenditure for the typical regular education student was \$6,556. Included in the \$18,790

were expenses associated with: instruction: regular and special education; administration and support: school and district levels and special education programs; regular and special education transportation services; and school facilities. The estimated expenditures of educating a child with autism were generally greater than those of educating a child with other disabilities in public school settings. The estimated cost (rounded to the nearest hundred) for other disabilities were: average special education student: \$12,500; emotional disturbance: \$14,100; mental retardation: \$15,000; and multiple disabilities: \$20,100.

The average cost for educating a child with an autism spectrum disorder in Vermont is not currently available. However, the average cost per student for special education was \$14,604 for 2005, approximately \$2,000 more than the national average in the 1999-2000 school year. It is likely that the costs of educating students with autism have grown as well. Using a conservative estimate of an additional \$2,000, the current cost of educating a student with ASD might be \$20,790 in Vermont. Child count for 12/1/05 was 540 children with ASD. So, a conservative estimate of Vermont's cost of educating children with ASD might be over \$11 million for 2005. If average costs rise by \$2,000 per student over the next five years and the growth rate of 20% in the number of students per year continues, 1,343 students on the autism spectrum will be receiving special education services at an additional cost of \$19 million by 2010. The DOE collects information on students whose educational day programs cost over \$50,000 per year. There are currently 92 students statewide with programs that exceed this cost, 39 of whom have an autism spectrum diagnosis. The average cost of the 39 reported programs is \$75,873 per student.

If intensive early intervention services were to be provided to young children with ASD, annual costs for these services could be anticipated to be high for several years, but then diminish over the child's lifespan. This is based upon research from model programs around the country that report that a substantial number of children make significant gains from these services. The state of Wisconsin has been providing these services through Medicaid for several years at an annual cost of approximately \$40-55,000 per child. In Vermont, the costs of this type of service in two specialized autism programs in Chittenden and Washington Counties cost close to \$80,000 per child annually. These programs are funded through Medicaid with schools paying the state match. Information regarding the costs to other schools that offer this level of service has not been gathered yet. Jacobson, et al. (1998) estimates that the savings for children who receive intensive early intervention could be in the range of \$1 million to \$2 million per individual over the lifespan. These estimates take into consideration the costs of special education and human services and future employment. It also takes into consideration varying degrees of benefit from the service. These are rough estimates. Actual financial analysis of the impact of providing this service on future costs has not been done to date.

It is more difficult to project the costs for services in the home, which would be funded through the Agency of Human Services. Most of these services are not entitlements and programs operate within capped budgets. Therefore, there is a difference between identified needs and services that may be provided. If the growth rate of 20% in the number of children being diagnosed with ASD continues over the next five years, there

could be as many as 22 children identified in the Family, Infant and Toddler Program. If intensive early intervention services were provided to all these children at an estimated cost of \$55,000 per year, the cost would be \$1.2 million in 2010. Most children who have an autism spectrum diagnosis qualify for Children's Personal Care Services. Again, using the 20% growth rate in children diagnosed with ASD, there may be as many as 1,343 children with ASD by 2010, 803 more than there were as of 12/1/05. The current average annual cost for this service is \$10,129 per year. The increase in the number of children could result in an additional annual cost of \$8.1 million by 2010. This estimate presumes that there are no changes to method of allocating of services or the rate of reimbursement. There are currently 86 children with ASD under 18 receiving developmental services waiver funding at a total annual cost just over \$2 million. For the 77 who are living at home with their families, the average annual cost is \$18,587. For those children with ASD who are in foster care and funded through the DS waiver, the average annual cost is \$63,652. According to the Developmental Services (DS) System of Care Plan, children under 18 can only access DS Medicaid waiver funding if they are at risk of admission to a psychiatric hospital or nursing home. Prior to December 2001, access to waiver funding for children was broader. Children who were funded in the past have continued to receive services. Unless, there is a change in the funding priorities for children under eighteen in developmental services, it is likely that costs to the DS system for children will decrease over time as few children will be entering developmental services. However, there will be a greater number of young adults with ASD needing developmental services. The number of children with ASD receiving children's mental health services is also projected to grow. Based on the growth trend over the past 8 years, the Division of Mental Health's statistics unit estimates that there will be 731 individuals with ASD receiving developmental or mental health services in the next five years. Cost estimates for these services are not currently available.

All of the above figures are rough estimates. There are many factors affecting these estimates that are not known, including potential changes in policies of all funding sources and whether projected growth rates in the population continue. However, based on the past growth rates, it is likely that there will be increased numbers of individuals with ASD in need of services. All systems will need to have increased capacity to meet these needs. This will require additional financial resources and increased availability of trained personnel to deliver needed supports.

If an investment in intensive early intervention is made in Vermont, it would be important for the state to monitor the impact of these services on future utilization of special education and human services.

- ***What services currently exist to support and train families?***

There are some resources that support and train families in Vermont. Parent support groups in various areas of the state offer trainings, workshops, and monthly meetings to support the families in their areas.

The Baird Autism Program in Burlington and Autism Collaborative of Washington County Mental Health in Montpelier offer support/trainings to families in and around their areas of the State. The trainings range from introductory classes on autism to specialized treatment information. Howard Community Services is planning on providing some training to parents in the Burlington area.

As noted previously, the Family, Infant and Toddler Program is oriented to providing parent support and training. Essential Early Education programs also often include some home visiting to provide training and support. Families who receive support through developmental services or children's mental health receive family support, and to a lesser extent, training as part of their individualized services.

The Autism Society of Vermont, in collaboration with the Department of Communication Sciences at the University of Vermont, plans a yearly Summer Institute on Autism that provides the opportunity for families to learn more about interventions, assessment, and other pertinent information about the disorder. The society also offers free *Make and Take* workshops on teaching basic skills to support families of children with autism spectrum disorders. Vermont Parent Information Center (VPIC), and Parent-to-Parent are organizations that support and inform families of children with special needs. Parents can access scholarship money through Parent-to-Parent and the Vermont Developmental Disabilities Council to attend workshops and conferences that would be a financial impossibility. The Disability Law Project has five offices in Vermont that provide legal support regarding special education and disability issues. Some schools, though not many, invite parents and/or caregivers to trainings that are offered to school staff.

Services to support and train families are not universally available in the state and what is available is not always adequate.

- ***What services exist to serve these youth in early childhood and school age?***

See Question 2 of this white paper.

- ***What services exist to support and train staff who serve these youth in their home, school, and community?***

There are relatively few training programs that meet the needs of staff and educators to provide for the needs of individuals on the autism spectrum in Vermont. Trainings need to be provided regionally and statewide to increase the number of staff trained to work with students with ASD. An immediate need is workshops that will provide basic information about the spectrum, brief overview of interventions, and behavior management. In addition to coursework and conferences, staff often need hands-on instruction in implementing interventions, ongoing supervision and feedback to become proficient. Individuals, who will become in-state trainers, need to be recruited and trained in specific interventions. These trainers will, in turn, provide on-going training to professionals and paraprofessionals who provide instruction to students on the spectrum.

The University of Vermont offers a three credit graduate course entitled, *Seminar in Autism Spectrum Disorders: Issues in Assessment and Intervention* on campus and via distance learning to sites across the state. UVM, in cooperation with the Autism Society of Vermont, offers a yearly summer institute on autism for parents, caregivers, and professionals. The program provides up-to-date information on research, assessment, interventions, etc. Professionals can receive three graduate credits for attending this conference and completing additional work when enrolled in the UVM course.

Johnson State College offers two concentrations in Applied Behavior Analysis off-campus for employees of human service organizations. Successful completion of coursework and internships in either *Developmental Disabilities and ABA* or *Children's Mental Health and ABA* will prepare students to sit for the Certification Examination of the National Behavior Analyst Certification Board.

The Higher Education Collaborative for Education Workforce Development (VT HEC), a partnership between the Vermont Department of Education, the Vermont State Colleges, and the University of Vermont, offers an Autism Program through Vermont Interactive Television, (VIT). The program is a 24 credit sequence being offered for Johnson State College credit and can lead to a M.Ed/CAGS with a focus on preparing autism case managers. Presently, the three courses offered through VT HEC are the same courses that are offered at the University of Vermont (*Seminar in Autism Spectrum Disorders*) and Johnson State College (*Applied Behavior Analysis I & II*). The remaining courses will include: Teaming; Social & Adaptive Skills; Academic Curriculum; and Academic Instruction. This degree program has just become available in the past year.

The annual Summer Autism Institute sponsored by the Autism Society of Vermont and the University of Vermont (mentioned above) offers day-long presentations on topics related to autism. The institute is attended by individuals who provide services to individuals on the spectrum. There are autism conferences presented throughout New England. A basic autism course (Autism I) was sponsored by the Vermont DOE during Spring and Fall 2003 and presented through the Lamoille Area Professional Development Academy (LAPDA). Autism II was presented during Spring 2004. The courses were presented over the Interactive Learning Network (ILN) that allowed many individuals from all areas of Vermont to take part. More than 200 participants attended Autism I and approximately 100 participants attended Autism II. During 2003 and 2004, the DOE presented TEACCH Classroom Training I for professionals who work with students with autism. During 2003, the training was in Bennington and in Essex Junction during 2004. The 5-day training provided hands-on experience with students with autism, supervised experience in a demonstration classroom setting, and presentations and demonstrations by Division TEACCH staff from the University of North Carolina. Participation at both trainings was limited to thirty.

School districts and community agencies also rely on in-house professionals and outside consultants to provide in-house training and ongoing supervision and support to staff.

There are not enough professionals with sufficient training in ASD to meet all the need statewide.

- ***What is the continuum of services that needs to be in place to serve these children, young adults and adults?***

A continuum of services from birth to death is needed for individuals on the autism spectrum. The overall goal for individuals with autistic spectrum disorders is the same as for other individuals: personal independence and social responsibility (National Research Council, 2001).

According to Koegel in *Teaching Children with Autism* (1995), instructional focus changes as the student matures. Communication, social interaction and adaptive behavior need to be addressed in the preschool years. Academic instruction becomes the focus during elementary school years in addition to language and social skills. Secondary school programs should focus on transitioning the student into the community.

A need that must be addressed prior to implementation of the continuum is to increase the number of well-prepared professionals and paraprofessionals to work with children and families. Three stages of training are essential. The first stage is “initial training, which occurs pre-service or in the first few weeks of school and assumes that the trainees have minimal knowledge or experience working with children with autistic spectrum disorders and their families”. The second stage “consists of ongoing training and mentorship, usually in the first year of teaching” and the final stage “includes the major effort to provide technical assistance to existing programs through numerous state and federal agencies” (*National Research Council, 2001, p. 189-190*).

“A special emphasis should be placed on training of trainers. There is a short supply of expertise and experience in the field of education for children with autism spectrum disorders, and special attention should be paid to rapidly increase the capabilities of the trainers, who may have experience in special education or related fields, but not in the special skills and practices for children with autistic spectrum disorders” (National Research Council, 2001, p. 226). Trainers/consultants are needed in the areas of speech therapy, occupational therapy, physical therapy, applied behavior analysis, verbal and nonverbal communication, social development, and adaptive behavior.

Outside of school, additional services are needed. First, there needs to be effective screening procedures to ensure the earliest identification of children on the autism spectrum. In addition to screening for developmental delays, screening for specific indicators of possible ASD would be needed. All providers who come into contact with young children should have knowledge of the indicators and know where to refer families for evaluations.

Families need quick access to professionals who can provide a diagnosis. Families sometimes have to wait several months to get an appointment with a specialist who can

provide a diagnosis or travel out-of-state to special diagnostic centers. Additional in-state professionals would be helpful.

Families, schools and service providers need access to information about autism spectrum diagnosis; options for treatment, intervention and education; where to get services; funding resources; professional resources; support groups; etc. A centralized location to gather this information is needed.

An infrastructure of financial and personnel resources to provide intensive, early intervention services is needed from time of initial diagnosis to entry into full-time school services. Schools and the AHS would need to embrace the recommendations of the National Research Council (2001) as noted above on page 44 in order to support this infrastructure. This would also require the availability of knowledgeable consultants or in-house program staff to design and monitor the delivery of these services in the home, school and community. Ongoing training for direct support staff and families will be needed.

Some families will need ongoing training and support at home in strategies to assist their child in learning life skills and to help address challenging behavior. Currently, parent training is available on a very limited basis to some families. Funding and training of personnel to deliver this type of support would be needed. Additional funding and personnel are also needed to provide support to children in their homes.

Statewide enhancement of the transition process from school to adulthood is also needed. This would require a coordinated effort on the part of schools and community providers.

After students with ASD graduate from school, there needs to be a range of options available from continued education, to vocational support and a range of living options. There has not been much focus to date on supporting young adults in college. This is an area that would need further development. Work, community and home supports are available to some individuals with ASD within the developmental services system. The providers of this system would benefit from additional training in the understanding of autism spectrum diagnoses and providing appropriate supports.

5. *What is the role of the family in meeting the needs of these children?*

- ***How do we support and train parents in ways that are useful, and respect the family's values and culture?***

Having a child with ASD can be extremely stressful for families. Comparison studies have typically shown that parent stress is significantly greater for mothers of children with autism than for mothers of children with mental retardation or physical disabilities (Bouma & Schweitzer, 1990; Holroyd & McArthur, 1976 in Koegel, 1995). The types of stress encountered by families generally changes over the child's lifespan. Initially, parents must deal with the emotional aspects of discovering that their child has a significant developmental disability. There is the need to locate information about the

diagnosis and the options for treatment and education. There is stress involved in trying to locate and access appropriate programs and funding for services. Parents must also learn to navigate and advocate in school and human services systems. As recommended treatment for ASD is often expensive, there is often conflict between parents advocating for these programs and schools attempting to manage within a budget. As children get older, parental concern shifts to their child's future independence and acceptance in the community.

Additional stressors include the impact of attending to the child's needs on the family as a whole. Family life can end up revolving around the needs of the child with autism. There are concerns about taking the child into the community due to behavior challenges. This can be particularly challenging as the child appears "normal" physically, but may be exhibiting extreme behavior problems that are not understood by community members. There is the need for constant vigilance for children who have no understanding of danger. As the child grows bigger and stronger, some families struggle with addressing behavior challenges such as aggression. The time spent attending to the needs of the child with ASD can impact the parents' relationship; time available for other children; relationships with friends and family; and ability to work outside the home. Some families may experience additional stressors unrelated to the child with ASD, including poverty, marital problems, single parenthood, substance abuse or other mental health or health problems that further complicate caring for a child with ASD.

Many families cope with the stress very well on their own. Others benefit from a variety of formal and informal support systems. Some informal supports include relying on the family's social support network, such as friends, family, church, etc. Many families benefit from participation in parent support groups. These groups vary, but may provide emotional support, information regarding resources and interventions, empowerment, a sense of community and affiliation (Perry & Condillac, 2003). Support from formal systems can include parent education regarding treatment options; referrals to resources such as support groups, programs and funding sources; referrals to medical services, respite care, summer camps and recreation activities; assistance and information regarding transition planning (from FITP to EEE to school to adult services); and parent training. Families are unique and have diverse needs. The provision of family support should be based upon a family-centered approach reflecting the needs, desires, and culture of the family members.

Sometimes crisis situations develop in families when care giving and behavioral challenges become too great for the family to manage. All parents have a role as teachers of their children, helping them to learn important life skills and socially appropriate behavior. Parents of children with ASD may require additional training and support in this role due to the unique needs of their children. In addition to staff support to the child, which gives parents a break, services should also help parents learn skills to effectively manage challenging behavior and teach useful life skills. This effort can help reduce family stress and problems in the long run. While this type of parent/ professional partnership can improve long term outcomes, it should be offered when needed and

desired by the family, respecting that it may not be feasible given the many demands on parents time and energy.

Most of the research regarding support for families of children with autism pertains to parent training. Parent training involves teaching parents the specific skills needed to teach their children new skills and to manage challenging behavior. Most of the national model programs for young children with ASD include parent training as a critical component. Some of the intervention models rely on parents as a major teacher of their children (DIR, RDI). Parent training is important for a number of reasons. One reason is that children with autism often have difficulty transferring a skill learned in one environment to another. Therefore, having the parents encouraging their child to practice newly learned skills at home enhances the child's learning. This difficulty with generalization is more problematic for children with ASD than children with other disabilities. Also, more learning opportunities result in faster learning. Parent training can also help increase parents feelings of competence in parenting their child with ASD. Studies show that parents can learn techniques for teaching new skills and managing behavior. One study compared parents trained to facilitate social interaction and communication with a control group of parents who did not receive this training. The parents who received the training used the facilitative strategies more frequently and their children had larger vocabularies 7 months after training started (McConachie, et al., 2005). In another study, fathers were taught to imitate their children's initiation of a vocal or motor behavior in an animated, exaggerated manner. Fathers were able to learn this strategy and their children's rate of initiating interactions increased significantly (Elder, et al., 2005). Parent education has resulted in short term gains for children, but there were inconsistencies regarding long-term effects (Koegel, 1995). Difficulties were related to acquiring the skills and/or problems implementing skills to a broad range of child behaviors or environments. Better results were obtained when general behavioral principles were taught rather than teaching interventions for particular problem behaviors. Also, natural teaching methods, which can be incorporated into daily routines, worked better and were used longer than highly structured formal teaching (Koegel, 1995). Better results were also found when ongoing consultation and support was available as opposed to initial training only (Harris, 1986, in National Research Council, 2001). Any attempts at providing parent training must take into consideration the parent's availability to commit the time and energy required. This is impacted by many variables including parents other commitments such as other children; work; caring for extended family; household management; personal issues such as mental or physical health; etc. As noted earlier, family supports must be provided in a family-centered manner, which respects the individual needs, capacities and desires of families.

Families also have a role as advocates for their children. Families will work with an ever-changing series of professionals, teams and systems over the life of their child. The one constant in their lives will be the parents who will need to take on the role as advocate for their child. In their role as advocate, parents need to learn regulations related to education and human service support systems and their rights within these systems. They will also need to learn how to effectively collaborate with those systems to ensure that their child receives appropriate services.

Family Support America (2005), a national family support organization, outlines principles for providing respectful family support as follows:

- Staff and families work together in relationships based on equality and respect.
- Staff enhance families' capacity to support the growth and development of all family members--adults, youth, and children.
- Families are resources to their own members, to other families, to programs, and to communities.
- Programs affirm and strengthen families' cultural, racial, and linguistic identities and enhance their ability to function in a multicultural society.
- Programs are embedded in their communities and contribute to the community-building process.
- Programs advocate with families for services and systems that are fair, responsive, and accountable to the families served.
- Practitioners work with families to mobilize formal and informal resources to support family development.
- Programs are flexible and continually responsive to emerging family and community issues.
- Principles of family support are modeled in all program activities, including planning, governance, and administration.

Family support provided within this framework would be respectful of families' values and culture.

- *How can parents of these children function best as a resource?*

Parents know their children better than anyone else. They can bring this knowledge to the team in planning for educational and home services. Many parents have also spent time educating themselves regarding their child's diagnosis. Teams can draw on this knowledge as well. As noted previously, parents will need to be their child's advocate in order to obtain needed services and supports. And, of course, parents have to balance their role as advocate and team member with their usual role as parent in providing a loving, safe, stable and nurturing home for their child.

Summary and Recommendations

The number of Vermont children diagnosed with autism spectrum disorders has been growing at an average annual rate of 20% over the past eight years. Because of their complex needs, supporting children with ASD presents significant challenges to families, schools and human service agencies. The growing population is increasing costs for special education; Family, Infant and Toddler Services; and services funded through Medicaid including Children's Personal Care Services; Child, Adolescent and Family Mental Health Services; and Developmental Services. Schools and human services agencies are struggling to put in place appropriate programs and services to meet the

needs of these children and their families. These children often require specialized educational and treatment approaches. While needs are being met in some places, there are not enough sufficiently trained personnel and/or financial resources available to meet the needs of all the children with ASD.

Because of the diverse needs of people on the autism spectrum, no one approach is appropriate for all people with ASD. A range of approaches needs to be available. Research supports the effectiveness of intensive early intervention for children birth to eight. Research shows that up to almost half of children receiving intensive early intervention have made marked progress. Intensive early intervention is not widely available in the state. In order to make this more widely available, there needs to be a consensus that it should be provided, and an infrastructure of trained personnel and financial resources available. It is not clear who would be responsible for paying for, developing and providing these services. Provision of intensive early intervention could lead to significant improvement in functioning of children as well as reduce family stress and costs for schools and human services agencies.

Schools and human services agencies would benefit from additional training in supporting children with ASD using interventions that are evidence-based. Training needs to occur on many levels including general overview of ASD, conferences and workshops, college course work and hands-on training and supervision. Parent training has been found to increase outcomes for children with ASD. Parent training needs to be made more readily available.

Recommendations:

- Develop a central location for accessing information regarding diagnosis, prognosis, options of treatment and intervention, available resources, parent support, etc.
- Start a dialogue with FITP, early childhood educational and service providers regarding the need to provide intensive early intervention for young children with ASD in accordance with the recommendations of the National Research Council. When agreement is reached, develop an infrastructure of trained personnel and financial resources to provide this service.
- Expand the availability of training to schools, agencies, specialists, consultants and families in evidence-based practices. Develop a cadre of trainers to provide the training.
- Enhance the ability of schools and agencies to meet the needs of children with ASD through development of best practice guidelines, technical assistance and training.
- Enhance coordination of services across home and school and the transition process from school to adult living.
- Increase the availability of comprehensive services, when needed, at home and in the community. The Agency of Human Services needs to clearly delineate who has the responsibility for developing and paying for a system of services to meet the needs of children with ASD.

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Appendix I: Evidence-based Practice

Evidence based practice refers to those interventions, treatments, and methodologies that are considered effective by the current autism research base and are therefore more likely to result in positive outcomes for students.

“Thus far, there is no one universally accepted and recommended treatment for autism. That is not to say that all treatments are equally effective. Deciding which treatment is appropriate for your child (student) can be an exceedingly difficult and stressful choice. The first question that must be answered before making this choice is: ‘What standard should we use when evaluating treatments for autism?’ A treatment can only be deemed effective if it is based on sound, scientifically validated principles and supported by empirical data. In simple terms, this means that treatments for autism must be backed by the same quality of research that we demand from other fields of science, such as medicine, chemistry and engineering.” (Irwin, 2005)

Data on effectiveness and appropriateness for each individual must be considered when selecting, designing and implementing programs. Every program must include an evaluation component, which not only enables the team to make data-based decisions, but establishes a process for periodic review of the impact on the individual’s life.

There are levels of research and evidence of the various approaches and methodology upon which decisions can be made. Chorpita and colleagues (2002) have proposed a framework for examining interventions. This framework has been used to rate the effectiveness of interventions described in this paper.

Framework for Examining Interventions

(adapted from Chorpita et al, 2002)

Level I: Well established interventions meeting four criteria:

1. Two or more examples exist in the literature where groups of individuals who received one treatment performed better than either those who did not receive the treatment or those who received treatment with a different intervention; and/or where the experimenter has statistically demonstrated that the intervention in question can produce the same level of effects or improvement as a more established intervention (group design)
OR
A large series of case studies have been done with strong experimental designs comparing one intervention with another.
2. Treatment manuals exist for the experimental procedures.
3. Participant samples are clearly defined.
4. Two or more researchers have reported significant effects.

Level II: Probably efficacious (promising) treatments meeting one of the following three criteria:

1. Intervention is found to be superior to a control group in at least two studies reported in the literature.
2. Evidence of one example in the literature where groups of individuals who received one treatment performed better than either those who did not receive the treatment or those who received treatment with a different intervention; and/or where the experimenter has statistically demonstrated that the intervention in question can produce the same level of effects or improvement as a more established intervention (group design)
3. A small series of case studies with clear participant description, strong experimental designs, and use of procedural manuals compared to a group that did not receive treatment or received another intervention.

Level III: Possibly efficacious treatments requiring only one of the following criteria:

1. Evidence of one example in the literature where groups of individuals who received one treatment performed better than either those who did not receive the treatment or those who received treatment with a different intervention; and/or where the experimenter has statistically demonstrated that the intervention in question can produce the same level of effects or improvement as a more established intervention (group design)
- OR
2. A small series of case studies with clear participant and treatment description, strong experimental designs with two or more researchers reporting similar effects and comparison to a group that did not receive treatment or received another intervention.

Level IV: Untested and unsupported treatments

Level V: Possibly harmful treatments

